

# **LONG-TERM CARE – A CHALLENGE AND AN OPPORTUNITY FOR A BETTER TOMORROW**

*Evaluation of pilot projects  
in the field of long-term care*

Ljubljana, March 2022



REPUBLIC OF SLOVENIA  
MINISTRY OF HEALTH



EUROPEAN UNION  
EUROPEAN SOCIAL FUND



Evencija pilitnih projekat  
v področju dolgotrajne oskrbe

# ACKNOWLEDGEMENTS

*In addition to the authors, many people contributed to the creation of the text in front of you. The authors of the text are therefore extremely grateful to each of them for their valuable assistance in the implementation of the evaluation of the pilot projects of long-term care.*

*We thank the employees of the pilot projects, especially the managers, coordinators and assessors, for their cooperation in providing a considerable amount of information, establishing contact with various stakeholders, connecting with users and informal carers, conducting surveys and, finally, for letting us into your work process believing that your experience will help create better system solutions.*

*Special thanks go to users and informal carers. Without the insight into your personal experience, evaluation in this form would not be possible. Thank you for your openness, willingness and trust.*

*We thank the representatives of municipalities from the project environments for sharing experiences, views and vision, the developer of the information system Aleja Soft, d. o. o., and providers of supportive technologies A.L.P. Peca, d. o. o., MKS Electronic Systems, d. o. o., and Telekom Slovenije, d. d., for your participation in the preparation of data and for numerous explanations regarding your work in the project and beyond. We also*



## FOREWORD BY THE MINISTER OF HEALTH

*Long-term care comprises a set of measures, services and activities intended for persons who, due to illness, weakness arising from old age, injuries, disability, lack or loss of intellectual abilities, are for a long period or permanently dependent on the assistance of other people to perform activities of daily living and instrumental activities of daily living.*

*All modern and responsible societies face the challenges of regulating long-term care systems. Systems that will respond flexibly to the needs of users and at the same time be stable in the long term, financially sustainable and will strengthen the development of community forms of care.*

*Slovenia is one of the fastest ageing societies. As the population ages, the need for long-term care services increases. The development of new technologies, new methods of treatment, a better living environment and the awareness of the population about taking care of our health enable us to live better and longer. The ageing of the population is thus a reflection of the development of society, and the search for answers regarding appropriate assistance in periods when, due to illness, injury, old age or disability, we can no longer fully take care of ourselves is a reflection of social responsibility to every citizen.*

*In 2017, the Ministry of Health took over the task of preparing a proposal for the Long-Term Care Act and implementing pilot projects in the field of long-term care. We took full advantage of the opportunity we received in Slovenia with the possibility of implementing a pilot project in the field of long-term care, which was co-financed by the European Social Fund. On one hand, we were able to test the mechanisms and procedures proposed for the future unified systemic regulation of long-term care and upgrade them so that they are as user-friendly and administratively non-burdensome as possible within the solutions provided by the Long-Term Care Act. On the other hand, as part of the activities involved in the "Implementation of pilot projects that will support the transition to the implementation of the systemic long-term care act", we were able to provide beneficiaries with services they cannot access at home under the current regulation and verify whether these meet their needs and enable them to maintain the highest possible degree of independence. Activities involved in the implementation of pilot projects enable*

*beneficiaries to play an active role in the entire process, from planning to the provision of services. At the same time, the project activities confirmed the importance of investing in knowledge and strengthening the competencies of employees in the field of long-term care, not only because of the higher quality and safety of services provided to users but also because of knowledge and skills for protecting employee health. Finally, the project activities also confirmed the exceptional role of informal carers in the field of long-term care, as they represent an important complement to the services to be provided within the future uniform system of long-term care within formal services, so that beneficiaries with comparable needs under the same conditions will receive comparable services regardless of the environment in which they reside.*

*The pilot project in the field of long-term care, coordinated by the Ministry of Health, has been completed. The results of the evaluation of the pilot project in the field of long-term care show that in Slovenia we need new solutions and answers to the needs of citizens in periods of life when they are no longer able to take care of themselves. The challenge of adopting a systemic law in the field of long-term care is behind us. This, however, is only the beginning of a huge amount of work that will enable the law to come to life in practice, and in all environments provide those in need with services that are high quality, safe and tailored to individual needs.*

*The solutions proposed in the Long-Term Care Act (adopted 2021) have been verified within project activities coordinated by the Ministry of Health and provide the beneficiaries with the option to choose where and what services they want. They enable the active role of beneficiaries, strengthen support for informal care providers, strengthen the conditions to link health, social care and long-term care systems with the aim of continuous and integrated care. The solutions bring new services, including services to strengthen and maintain independence, enable citizens with comparable needs to access comparable rights and meet the wishes of the majority, to remain at home and in the circle of their social network woven over many years, despite various disabilities, even during the period of life when they are no longer able to take care of themselves completely, with diverse, high-quality and safe long-term care services provided within the public network.*

Janez Poklukar,  
Minister of Health

## **FOREWORD BY THE DIRECTOR OF THE SOCIAL PROTECTION INSTITUTE OF THE REPUBLIC OF SLOVENIA**

*In developed western societies, the population is ageing, due to which the proportion of the older adults in the total population is increasing. Slovenia is no exception in this respect. In these societies, the concept of the welfare state has been formed, in accordance with which the state plays an important role in the economic and social protection of citizens. Due to the ageing of the population, the problem of caring for the older adults is becoming more and more acute. This framework also includes long-term care for that segment of the older adults who, for various reasons (illness, disability, mental health problems, etc.), need assistance and support in everyday life. Of course, it would be wrong to limit long-term care only to the medical aspect (how many days we will add to the life of a person), as the social aspect (how good those days will be) is also extremely important.*

*There are many problems in establishing long-term care, from the lack of systemic regulation of the field today to ensuring the sustainability of the financial system tomorrow. Therefore, research in this area is essential. It is important for decision-makers to be aware of this, as only thus will they have the knowledge to establish a fair and sustainable long-term care system. The goal we have committed ourselves to is the realisation of Principle 18 of the European Pillar of Social Rights, which states: "Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services."*

*The text in front of you is the result of monitoring the implementation of pilot projects by various contractors in the period from 2018 to 2020 in Celje, Dravograd and Krško. It was a demanding and large-scale innovation, in the framework of which tools and procedures for assessing eligibility for long-term care, the whole process and new long-term care services for people living at home in their home environment were tested in*

*pilot environments. The evaluation, in which researchers from the Social Protection Institute of the Republic of Slovenia, the Faculty of Social Sciences of the University of Ljubljana and the Institute for Economic Research participated, was equally demanding.*

*Monitoring and evaluating the implementation of these projects has yielded numerous results that can be used as a tool in controlling the solutions for long-term care system regulation. Through the pilot project, we obtained a credible and appropriate evaluation tool in Slovenia, which, following the German model, was developed within the framework of the project "Preparation of bases for the implementation of pilot projects that will support the transition to the implementation of the systemic long-term care act" at the Social Protection Institute of the Republic of Slovenia in 2016-2017. The tool has been tested on almost 2,000 people in pilot projects. In the pilot environments, interest in e-care was very high. We believe that it needs to be developed systemically, a position which was actually reinforced by the Covid-19 epidemic. Despite the fact that the effects of social concepts such as the quality of life usually show up in the long term, we find that pilot activities have had a positive effect on users, especially in terms of improved health and well-being. New services have also reduced the workload of informal carers.*

*Cooperation and networking is important both in the provision of services and research in the field of long-term care, as well as in the preparation of legal solutions. Legislation that systematically regulates long-term care is currently being drafted, but I believe that we will have to prepare at least one more study for the financial assessment of long-term care in Slovenia. Once this information is available, it will be up to the politicians to come together and adopt comprehensive, professionally sound and financially sustainable legislation in the field of long-term care and long-term care insurance.*

Mag. Barbara Kobal Tomc,  
Director of the Social Protection Institute  
of the Republic of Slovenia

## REVIEWS

Assistant Professor Nikolaj Lipič, doc. dr.  
Alma Mater Europaea ECM

*Long-term care is the central research axis of the present scientific monograph with the goal of presenting and updating the scientific and research findings gathered during the evaluation of pilot projects during the “Implementation of pilot projects supporting the transition to the implementation of a systemic law on long-term care” project, which ran between 2018 and 2020, and is designed to support the transition to the implementation of a systemic law on long-term care. Project activities were implemented in three closed pilot environments, namely in Celje, Dravograd and Krško.*

*This monograph portrays long-term care as a multidimensional model with some integral components, which are discussed individually and which form a coherent whole to model systemic solutions at the micro (local), meso (regional) and macro (state) levels. They are the foundation for the formation and implementation of a socially acceptable and economically sustainable long-term care system in Slovenia, while the complexity of demographic, social and political, technological, and social and economic changes in the last three decades have also been taken into consideration as they represent a paradigm shift in long-term care in Slovenia. The monograph also takes into account a set of key milestones of societal development to date, the specificities and capabilities of the Slovenian health and social care system, and the characteristics of the socio-cultural environment in which long-term care is provided. The authors want to emphasise that we should not only observe the global development trends in the field of long-term care, but become key players in outlining future long-term care policies.*

*The monograph presents a project development and innovation study in the field of long-term care in Slovenia. From a methodological point of view, it is worth emphasising that the study has a systematic and rigorous methodological framework, i.e. research approach based on both quantitative and qualitative research paradigms. The research phases follow a logical sequence. A concurrent triangulation design and a concurrent nested design are also used, which ensure a balanced contribution of both quantitative and qualitative research findings. A range of different relevant and up-to-date research methods ensures that the study as a whole is organised in a transparent and structured way. Primary and secondary data were used in the study, which creates a unique and extensive database in the field of long-term care in Slovenia that can be used to carry out a number of analyses that would meaningfully complement the collection of research results and insights in this research area. The data were collected using a variety of research methods, which are described in detail in the monograph both in terms of their*



*purpose and the scope of the data covered, i.e. the size of the individual samples included in the study at each stage. The advantage of the study lies in its strict adherence to the key principles of scientific research – generalisability, objectivity, verifiability, validity and reliability. The researchers were guided by rigorous professional and ethics research standards in the field of health and social care. Epistemologically, the study describes the interplay between scientific theory, scientific methods and experience.*

*The monograph uses the correct scientific terminology and language usage. The research findings are presented in a way that is comprehensible to scientific and professional communities as well as to the general public. It is suitable for everyone involved in the field of long-term care: decision-makers at all levels of decision-making (local, regional and national), experts and researchers, and coordinators, providers, users and relatives of long-term care services users. This is all the more important as it is the first comprehensive study in the field of long-term care in the Slovenian scientific setting. The comparison between the results of the study and the findings of a number of authors in the domestic and foreign professional and scientific literature deepens the understanding of the field and allows for international comparability.*

*The monograph contributes to the understanding of the needs of the long-term care system in Slovenia and, in doing so, it is based on efficiency. Research innovation is reflected in the efficient implementation of methods, procedures and services. At the level of efficiency of methods, it focuses on the approaches of assess eligibility, on personal planning and the coordination of services, and taking into account the dynamics of teamwork in long-term care. The effectiveness of procedures is checked on the basis of the forms used, the procedures followed to claim the right to long-term care, the procedures for assessing eligibility, for personal planning, coordination and the provision of services, the integration of e-care and e-health, the drawing up of waiting lists and complaints procedures. The effectiveness of services is checked at the level of inclusive care services and services to maintain independence and the integration of support services.*

*The key development objectives for the establishment of the long-term care system are focused on at least two goals at societal level. The first objective is to ensure the quality of life of all groups involved in the long-term care system, such as users, informal carers and employees in the long-term care system, thereby contributing to a more humane society and to social well-being. In this way, health inequalities can be overcome and the social*

*inclusion of different target groups can be strengthened, including long-term care services users. The second objective targets the transition to community forms of long-term care, which have to have a clear organisational structure, information and communication system, a local project council and a project team, as well as set cooperation protocols for the provision of inclusive care in the community.*

*The monograph emphasises the user-centeredness of long-term care, which must become the goal of long-term care services. All these challenges and changes, according to the authors, can only be achieved by adapting policies and implementing reforms in the field of long-term care.*

*The scientific monograph is an original scientific contribution to the field of long-term care research in Slovenia, as it deals with the research area in an interdisciplinary manner and undoubtedly contributes to the creation of optimal societal solutions in the field of the systemic implementation of long-term care at the national, regional and local levels through concrete research results and findings. It supports deinstitutionalisation and creates opportunities for the development of the concept of active ageing at individual, community and societal levels. The monograph's integrated approach to long-term care also provides a challenge and an opportunity for closer cooperation between health and social care professionals.*

Mircha Poldrugovac, dr. med.  
Amsterdam UMC location University of Amsterdam,  
Department of Public and Occupational Health, Amsterdam,  
the Netherlands; Amsterdam Public Health research institute,  
Amsterdam, the Netherlands

*The monograph is the result of a detailed, professional and in-depth evaluation of pilot projects in the field of long-term care that took place between 2018 and 2020. The role of the pilot projects was to support the transition to the implementation of the systemic law in the field of long-term care. The complexity of regulation of this field is also reflected in the complexity of projects. Extensive evaluation is thus necessary so that the experience of pilot projects can be best used to introduce the changes brought by the envisaged law on long-term care.*

*A key element of evaluation is the use of qualitative and quantitative methods. In addition to recognising the success of implementation of individual solutions, such an approach also enables understanding of the elements that were key to the success or failure of solutions and the reasons thereof. It is also exceptionally important to take into account a broad range of perspectives: service users, their informal carers, a broader range of stakeholders and providers of pilot projects, which are numerous, and which play different roles. Additionally, the value of the evaluation also comes from a comparison of data and experience that stem from three very different pilot environments.*

*The results presented in the monograph reflect the methodology in that they are presented in an elaborate and nuanced way. For example, the reader finds that the initial concept of the evaluation and the project itself makes it impossible to evaluate the staffing requirements that changes to how long-term care is provided would bring. At the same time, the reader obtains a considerable amount of valuable information about the workload of pilot project providers and the suitability of the set time frames for the provision of services. The information is further expanded by analyses of interviews with providers that describe the challenges they faced in providing services as part of the pilot project. When reviewing the effectiveness of procedures, it is possible to determine which parts of the established procedures have proven to be useful and to what degree. In addition, we also find out how the procedures in the pilot environments were adapted in practice, which is a valuable starting point for improvements.*

*Perhaps the most important issue from the societal aspect concerns the success of pilot projects in improving the long-term care of users. Readers find the results very encouraging: there is a noticeable improvement in the quality of life of users, as measured by the EQ-5D tool one year after the services piloted by the project started to be used. Satisfaction as expressed in interviews and surveys was also very high. In addition to*

*these findings, the authors also identified several challenges and the desire of many users for the intensity of services to be increased. This is valuable information for those who use and organise the long-term care system.*

*Also exceptionally interesting are the findings regarding the experience of informal carers. A description of the situation itself is important for planners of the long-term care system: who are the informal carers, how often people in need of long-term care can rely on them, how much time informal carers dedicate to the person they care for, what tasks they perform, etc. However, through the project, the authors also offer us an insight into how long-term care services in a pilot can affect informal carers. An interesting finding is that many factors indicate the objective relief of informal carers through the project, which however did not reflect on the subjective burden of these persons. Such a finding represents a recommendation for long-term care planners to pay extra attention to the role of informal carers.*

*The authors of the monograph also clearly present the limitations of the evaluation and its findings. For example, there are clearly identified cases in which the small sample size limits the possibilities or prevents statistical processing of data, for example in relation to the use of certain support technologies. It is also pointed out that the initial measurements, which are expected to refer to the situation before the start of the project, were actually performed after the very beginning of the project. Regardless of the reasons, which are of an administrative-organisational nature, it is important that the reader is aware of these restrictions.*

*The authors did not limit themselves to a narrow view of the methodological limitations of the research process, but also asked themselves about the broader purpose of the pilot project and its evaluation. In this respect, two types of goals in particular were identified,*

*which were not envisaged in the evaluation: financial impact assessments and short-term and long-term consequences on total expenditure. The possibility of performing such calculations is largely conditioned by a comprehensive overview of services related to the long-term care received by users. The authors point out that the concept of the project did not envisage monitoring the implementation of existing services that were not part of the pilot, although they will be part of the regulation of long-term care in the future. It is valuable to recognise such shortcomings because this acquaints planners with the existing unknowns and can direct future activities.*

*I would recommend anyone who thinks they can influence the long-term care system in Slovenia to read this monograph. The Ministry of Health commissioned the evaluation and used it to draft the new law. However, this does not mean that it is the only institution for which the results are important and interesting. Any stakeholder who wants to make a constructive contribution to creating solutions for the modernisation of the long-term care system and participate in its organisation and, in particular, its implementation, will find useful messages in this monograph. The monograph is also intended for all experts and, especially, researchers in the field of long-term care, who can better understand the starting points and plans for modernising the long-term care system in Slovenia. Experts are the providers of further research that will make it possible to make decisions that are supported by scientific evidence. In this sense, researchers are also stakeholders who make an important contribution to creating the long-term care system.*

*At a time when opinion polls show that the trust of the general public in science is at a low level, a monograph that elaborately shows the possibilities and limitations of science-based evaluation is an important contribution to a high level of public debate in the field of long-term care.*

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## LONG-TERM CARE – A CHALLENGE AND AN OPPORTUNITY FOR A BETTER TOMORROW

A monograph, “Long-term care: A challenge and an opportunity for a better tomorrow,” was drafted as part of the “Evaluation of pilot projects in the field of long-term care,” which was carried out by the Social Protection Institute of the Republic of Slovenia, the Faculty of Social Sciences of the University of Ljubljana and the Institute for Economic Research in the 2019–2020 period. Within the European cohesion project, i.e. the Community-based long-term care model, the evaluation was commissioned by the Long-Term Care Directorate of the Ministry of Health in order to prepare a general assessment of pilot projects with which the pilot environments could test new methods, procedures, mechanisms and services in the field of long-term care, while the key general objective is for the findings of the evaluation to help create better solutions regarding long-term care and possible projections of the future long-term care system.

The monograph was prepared in cooperation between the evaluator and the contracting authority of the evaluation, each with their roles and perspectives. During the writing, the authors again agreed that a dictionary of terms relating to long-term care is needed in Slovenia, as was suggested by a number of initiatives coming from various sides. In expert circles, we frequently encounter various uses, ascription of meaning and understanding of individual terms which, to a great extent, are the results of long-term care fragmentation and its interdisciplinarity. After a recent adoption of the Long-Term Care Act, the urgency and opportunity to unify and consider a uniform and current long-term care terminology is even more evident. Such a terminology would be clear, inclusive and, above all, enable unambiguous communication of all stakeholders and more efficient functioning of the complex and broad field of long-term care.

When writing, the authors usually used the so-called set terms or concepts, while knowing that their suitability would have to be considered in the future. We tried to use Slovenian terms and avoid foreign ones as much as possible. For the most part, we succeeded. Certain terms, such as evaluation, activities and coordination, were kept either due to the established use within the projects (evaluation, activities) or because no suitable synonyms existed in Slovenian (e.g. coordination, integrated care). Some terms were used only in places where original texts were cited. For example, the term “pokretnost” (mobility) was only used when referring to the statements from the validated questionnaire; in other cases, the term “pomičnost” (mobility) was used. If it was assessed that incorrect understanding may occur, the term or concept was further explained (e.g. assistive technologies).

We also observed the differences between the terms applicant, beneficiary and user. The term “applicant” refers to the person completing an application to participate in the project, the “beneficiary” is a person who was assessed and is eligible for long-term care services within pilot projects as per the assessment, and the “user” is a person who actually participates in the service implementation within the pilot projects. Nevertheless, we sometimes found ourselves in a dilemma about which term was more suitable.

For a number of years now, discussions have been taking place in national and international expert circles about how to address people above the age of 65, so as not to discriminate and stigmatise. The authors of the monograph decided to use the phrases “older people” or “older adults,” which we believe neutrally address the relevant population and do not create a distinction on the basis of chronological age. Nevertheless, when reading the text, a reader will also come across

terms such as “an old person” and “the elderly,” particularly in sections where other authors’ works were cited. Although, we wished to maintain a neutral position, we certainly did not fully succeed throughout the entire text.

We tried to capture as many themes as possible that were addressed by the evaluation of pilot projects regarding long-term care. It was impossible to fully utilise and contextualise all themes or aspects and data in this monograph, but they remain a rich source of information for further analyses and research. The themes selected were assessed as being the most relevant for the first publication of results and the monograph was thus divided into twelve main chapters. As the monograph was written before the Long-Term Care Act was adopted, we accordingly refer to different variants of the proposed act in individual chapters, most frequently to the act proposed in 2021.

In the first chapter, *Contribution of pilot projects in the field of long-term care when planning system solutions in the Republic of Slovenia*, the authors present the challenges of several decades of attempts to provide a uniform system regulation in long-term care in the Republic of Slovenia and the fragmentation of the current arrangement of rights or services relating to long-term care and its vision. They also discuss the concept and the model of pilot projects in the field of long-term care, which were the subject of evaluation and their contribution to the planning of system solutions, as anticipated in the Long-Term Care Act<sup>1</sup>. The presentation of evaluation design and its implementation with the help of mixed research methods is provided in the chapter, *Evaluation of pilot projects and methodology*. All measuring instruments and research methods used during the evaluation are discussed in this chapter and all types of data collected, including that which was not described in further detail and used in other chapters of the monograph. This is a comprehensive methodology review of the evaluation to which the reader returns time and again when reading other chapters, as the details in the methodological

description of individual chapters are usually cited in this chapter.

The third chapter, *Transition to integrated long-term care by establishing a single entry point, integrated care team and connecting stakeholders*, addresses the process of establishing single entry points in pilot projects as one of the starting points of the integrated approach and describes the course and characteristics of employing key personnel in pilot projects, especially the long-term care coordinator and the integrated care team. Because the cooperation of various stakeholders at the local level is important for integrated implementation of long-term care, this chapter discusses the forms of organisational cooperation and integration established in the pilot projects. In the fourth chapter, *From application to service: Experience of procedures in pilot projects*, the procedure is presented as it was developed and tested in pilot projects. All the main steps in the procedure are described, from completing the application for the assessment of eligibility to long-term care to the inclusion in long-term care and the receipt of services. Special emphasis is placed on waiting lists and complaints channels.

Subsequent chapters refer to work methods and techniques in long-term care. In the fifth chapter, *Assessment of eligibility for long-term care*, we first present the characteristics of assessing eligibility, which was tested for the first time in the field of long-term care in Slovenia. The experience of assessors with the eligibility assessment is discussed, as a new professional profile of the assessor was tested in the pilot projects. The chapter ends with the assessment of suitability of classifying applicants in the category of eligibility for long-term care. Personal planning and the coordination of services are the topics of the next chapter, *Personal planning and coordination in long-term care: Identifying needs and planning care together with the user*. The profile of the long-term care coordinator is introduced and their central role in the project from the aspect of coordinating care and personal planning. A special emphasis is

1 Zakon o dolgotrajni oskrbi (Uradni list RS, št. 196/21). Retrieved from: <http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO7621>

placed on the personal plan, as the key document for implementing and receiving long-term care. The elements of a personal plan are compared to the concepts of the method according to which training for the employees in pilot projects took place. In the chapter, *Teamwork and integration of stakeholders as the foundations for ensuring integrated long-term care*, we describe the dynamics of teams established in the pilot environments. Furthermore, we present the organisational climate, employee satisfaction and cooperation between the employees in the sense of providing mutual social support, which is also linked to the quality of working life. At the end of this chapter, we focus on the cooperation of the employees with other important stakeholders in the local environment which, in addition to cooperation within and between the teams, also represents one of the foundations of integrated long-term care.

The next two chapters deal with the services provided at the users' homes by means of the pilot projects. In the chapter, *Implementing and strengthening long-term home care services*, all services are presented, with the emphasis on new services in the home environment provided by the pilot environments within the pilot projects. The new services were also examined through the lens of user satisfaction, usefulness and the recognised effects of receiving them. As part of the evaluation, we also monitored the introduction of assistive technologies, e-care and e-health in the pilot projects. The results of monitoring are presented in the ninth chapter, *Perception of the use of assistive technologies*. We particularly highlighted the effects of user inclusion in e-care, in which significantly more users were participating than in e-health.

In addition to the employees and the quality of their working lives mentioned in the seventh

chapter, the two target groups monitored within the evaluation, i.e. the users and their informal carers, were also important. It was expected that the pilot activities would have the greatest impact on these two groups because the services or care were intended for them. In the tenth chapter, *How pilot projects contributed to the quality of life and the state of health of users*, the service users are first discussed, followed by a presentation about how their quality of life has changed after the pilot activities. Similarly, in the chapter, *Care for those who care: Studying the quality of life of informal carers*, we discuss who are the informal carers, how they care and what is their burden. Special emphasis is placed on the assessment of how the pilot activities impacted the lives of informal carers.

The monograph ends with the chapter, *Electronic management of procedures and services and information system suitability*, in which is presented and assessed the information system developed and used by the pilot environments together with the information system developer for the needs of the pilot project implementation.

The monograph illustrates the complexity of pilot projects regarding long-term care and their extensive evaluation and presents numerous and significant results. The results presented and their evaluation can thus be used as a significant tool for political decision-makers and experts in the field of social care and healthcare when transferring knowledge and seeking better solutions to bridge the gaps and challenges of the current arrangement of the long-term care system. The systemic regulation of long-term care, the foundations of which were set with the adoption of the Long-Term Care Act at the end of 2021, is certainly a challenge for Slovenian society and simultaneously an opportunity for our joint better tomorrow.

Mateja Nagode  
Social Protection Institute of the Republic of Slovenia

Klavdija Kobal Straus  
Ministry of Health

**CONTRIBUTION OF PILOT PROJECTS IN  
THE FIELD OF LONG-TERM CARE WHEN  
PLANNING SYSTEM SOLUTIONS IN THE  
REPUBLIC OF SLOVENIA**

Emilija Guštin  
Ministry of Health

Anita Jacović  
Ministry of Health

Klavdija Kobal Straus  
Ministry of Health

Mojca Počič  
Ministry of Health

*CONTRIBUTION OF PILOT PROJECTS  
IN THE FIELD OF LONG-TERM CARE  
WHEN PLANNING SYSTEM SOLUTIONS  
IN THE REPUBLIC OF SLOVENIA*

## KEY MESSAGES

The Long-Term Act has set the foundations for:

- ▶ uniformly and systematically regulated long-term care in the Republic of Slovenia,
- ▶ the citizens with comparable needs to have access to comparable rights,
- ▶ the beneficiaries to have the option to choose in what way they wish to exercise their right to long-term care (in the form of formal home care or formal care in an institution or cash benefits or a carer for a family member (in the case of beneficiaries with severe and the most severe limitation of independence or self-care abilities)),
- ▶ the beneficiaries to access comparable services in an institution or at home,
- ▶ the beneficiaries to access new services, services for strengthening and maintaining independence and e-care services and
- ▶ ensuring that a higher proportion of public funds will be earmarked for long-term care, which will provide a financial relief to persons in need of long-term care, their family members and local communities.

## Introduction

As per the international definition, also summarised in the December 2021 adopted Slovenian umbrella act (Long-Term Care Act (Zakon o dolgotrajni oskrbi (Uradni list RS, št. 196/21)), long-term care encompasses an array of measures, services and activities intended for persons who, due to the consequences of an illness, weakness related to old age, injury, disability, lack or loss of intellectual ability over a longer period of time which is not shorter than three months, or persons who are permanently dependent on the assistance of other persons in performing the basic and instrumental activities of daily living.

All EU Member States are facing the challenges of a long-lived society and an increase in the need for long-term care, which are being addressed in various ways. Irrespective of the tradition and diversity of organising the field of long-term care, its financing and the manner of integration in other social care systems, they nevertheless have certain common objectives, i.e. to ensure:

1. the equal accessibility and availability of long-term care services for everyone who needs it;
2. the high quality of long-term care services;
3. the long-term financial sustainability of the long-term care system, and
4. sufficient numbers of adequately trained staff and conditions for high-quality work and support for informal carers (European Commission, 2015; European Commission, 2021).

Numerous international documents testify to the importance of long-term care. In 2010, the EU Charter of Rights and Responsibilities of Older People in Need of Long-Term Care and Assistance (European Commission, 2010) was adopted, which defined the rights and responsibilities of people in need of long-term care in ten articles. The right to long-term care is determined in Principle 18 of the European Pillar of Social Rights (European Commission, 2017), which stipulates that everyone has the right to affordable long-term care services of good quality, in particular homecare and community-based services. Through The European

Pillar of Social Rights Action Plan, the Member States committed themselves to further work in the field of long-term care. In addition to the foregoing, the European Commission has been reminding the Republic of Slovenia of the urgency of a systemic arrangement of the field of long-term care since 2013 (European Commission, 2020). The urgency of a uniform systemic arrangement of long-term care has been highlighted by different public stakeholders due to changed needs and wishes of users, and social relations and the role of family, which have changed over time, including the expenditure growth linked to long-term care (Flaker et al., 2008; Hlebec et al., 2013; OECD, 2017; Ciccarelli & Van Soest, 2018; Mali, Flaker, Urek & Rafaelič, 2018; Wagner & Brandt, 2018; European Commission, 2021; Nagode et al., 2021). In regard to the aforementioned, it is not surprising that in 2021, after more than twenty years of attempting to draft systemic solutions by various stakeholders in the field of long-term care, the Government of the Republic of Slovenia prepared and submitted to the legislative procedure a draft Long-Term Care Act (Vlada Republike Slovenije, 2021). The fact that long-term care, as an important field, is in need of reform is also highlighted in the national Recovery and Resilience Plan (Služba Vlade Republike Slovenije za razvoj in evropsko kohezijsko politiko, 2021).

## Approaches to the arrangement of long-term care

When addressing the challenges relating to long-term care, the EU Member States apply various approaches. This is reflected in the various organisations, responsibilities in the field of long-term care, methods of financing and provision of long-term care. Certain countries treat long-term care as an independent field of social care, while in others the responsibility is divided between the healthcare and social care systems to varying degrees (Spasova et al., 2018; Institute of Macroeconomic Analysis and Development,

2021; Vlada Republike Slovenije, 2021), which can pose a challenge when establishing and ensuring high-quality and safe long-term care services and may lead to a fragmentation of rights (Cès & Coster, 2019), making it difficult to take a holistic approach to a person in need of long-term care and to develop a long-term care system. In some countries, long-term care is based almost exclusively on informal care, while there are other countries where formal care prevails (Institute of Macroeconomic Analysis and Development, 2021). Furthermore, significant differences exist between countries regarding the method of financing and the amount of funds earmarked for long-term care from public funds and relationships between resources that are intended for the health and social part of long-term care (MISSOC, 2021; OECD, 2021). As shown in Figure 1, the LTC costs are for the most part covered from the budget and social insurance in most countries.

For the most part, the EU Member States began addressing the issue of long-term care in 1997 and 1998 due to prominent demographic changes which not only affect the quality of life of all generations, but also call into question the sustainability of the existing social security systems as the likelihood of the need for long-term care increases with ageing. The latter is not only a challenge for an individual, but the ageing population became a challenge for the whole of society and it is thus not surprising that it was also recognised as one of the greatest challenges of the 21st century by the European Commission (Majcen, Eržen, & Stanovnik, 2015). Questions arise, due to the ageing population, about how to address the economic consequences resulting from a smaller proportion of the working population and an increasing proportion of persons who depend on the social protection systems, as well as the growth in the need for health and long-term care. The traditional approach, in which an extended family took care of an older person, and the industrial approach, which was composed of unrelated sections of domestic and formal care and unconnected services of healthcare and social care, no longer meet modern needs (Ramovš, 2020). The need for long-term care is not limited to a specific

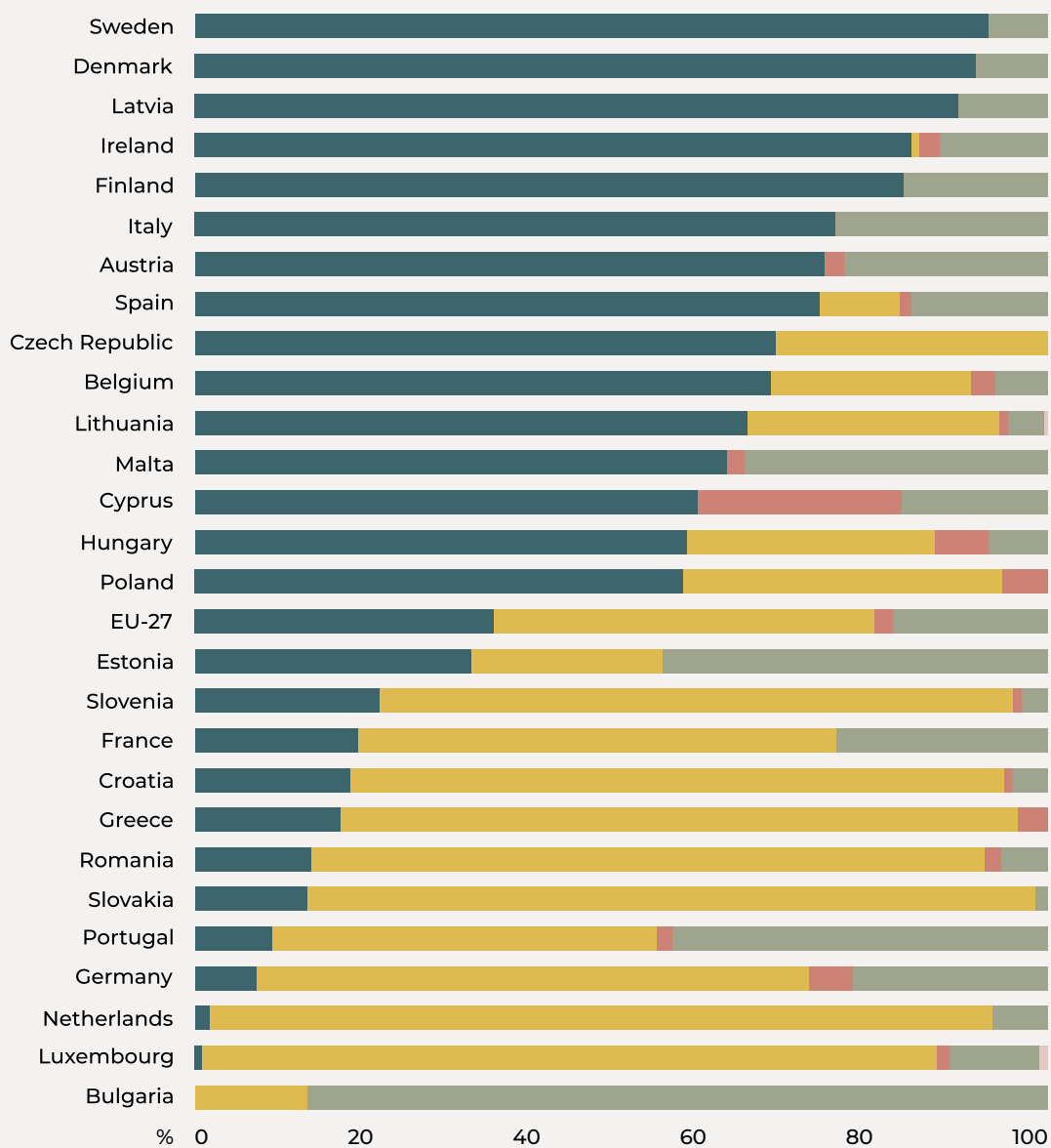
age group, but the risk of dependency on the help of another person for performing the basic and instrumental activities of daily living increases with ageing (Figure 2).

On average, 10.8 per cent of people aged 65 and more receive long-term care in the OECD countries (OECD, 2019), which shows a 5-per cent growth in comparison to 2007. The data reveals that the proportion of severely impaired persons above the age of 85 in Slovenia is significantly higher than the average in the EU countries. On average, 8.8 per cent of all Slovenian citizens were severely impaired when performing activities of daily living in 2019 (6.9 per cent was the EU average) in all age groups; the proportion was exceptionally high for people above the age of 85 (41 per cent) (Institute of Macroeconomic Analysis and Development, 2021). In addition to demographic changes, such as the rapid growth in the number of people above the age of 80, changed social roles also impact the increase in the needs for long-term care, which most frequently include the changed role of the family and the social role of women, increasing desires and expectations of individuals for high-quality long-term care and, last but not least, the development and access to various assistive technologies that enable people to stay in their home for the longest time possible despite various impairments (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011). Considering the foregoing, it is not surprising that the field of long-term care has been granted a more visible place within the social policies of the economically developed countries in recent years as a result of demographic changes.

To make long-term care accessible, attainable and available, a flexible response of countries to the challenges of the ageing population is urgent, including the development of new and more efficient care models for persons in need of long-term care (Cylus, Figueras, & Normand, 2019). The development of the field of long-term care not only results in the improved safety and quality of long-term care services, but also generates additional jobs and demand for a broader array



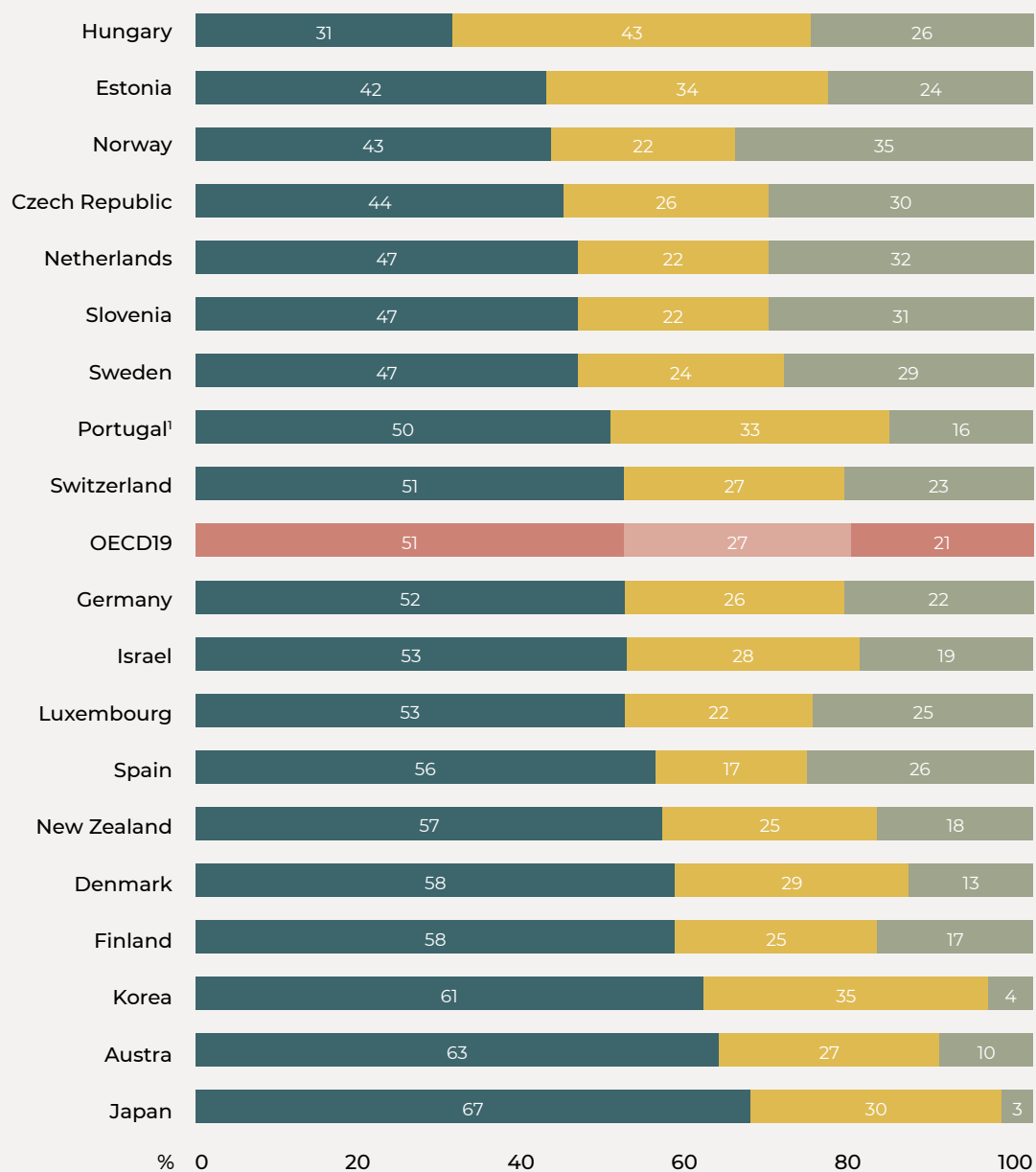
**Figure 1: Expenditure structure for the health part of LTC by financing sources, Slovenia and EU countries, 2018.**



■ Government schemes  
 ■ Voluntary health care payments schemes  
 ■ Compulsory contributory health insurance schemes  
 ■ Household out-of-pocket payment

Source: European Commission, 2021.

Figure 2: Recipients of long-term care by age groups, Slovenia and OECD countries, 2017



0-64  
65-79  
80+

Source: OECD, 2019.

of goods and services linked to age, including the development and enhancement of the use of information and communication technologies (Corsi-Nordblad & Strandell, 2020). In recent years, most EU Member States have made adjustments to the existing arrangements relating to long-term care, particularly by establishing coordination structures between healthcare and social care, improving infrastructure and local and regional system management, and establishing enhanced supervision and new tools and standards for measuring and monitoring the quality of long-term care. Reforms of cash benefits, the introduction of new social benefits, allowances and relief, measures to establish a balance between professional and private life, training of long-term care providers and provision of respite care have improved the situation of long-term care users and their family members. The Member States have also improved the conditions in the labour market by increasing funds for staff employment, higher wages and better working conditions (European Commission, 2021). The coronavirus pandemic also pointed to the urgency of changes regarding long-term care and better resilience of social protection systems (OECD, 2021, Sagan et al., 2021).

## Long-term care in the Republic of Slovenia

The first initiatives for a uniform systemic arrangement of long-term care in Slovenia were launched in 2002. The expert and political dialogue on the urgency of reforms regarding long-term care thus took place over twenty years. In this period, the Ministry of Labour, Family, Social Affairs and Equal Opportunities drafted two versions of the Act. One was formed by the Federation of Pensioners' Associations, one by the Association of Social Institutions of Slovenia, and two proposals were prepared by the Ministry of Health (Nagode, Zver, Marn, Jacović, & Dominkuš, 2014; Ministrstvo za zdravje, 2017; Vlada Republike Slovenije, 2021).

The regulation of long-term care was written down as one of the objectives in numerous strategic national documents, including the Resolution on the National Health Care Plan 2016–2025 “Together for a Healthy Society” (hereinafter: Resolution) adopted in 2016, which regulates the development of healthcare at the general level. The adoption of the Resolution was one of the important milestones in establishing an integrated long-term care system, as the Resolution is not only a politically binding act, but also a binding legal act based on law and providing key guidelines for the preparation and implementation of activities which will respond to the needs of a long-lived society. The Resolution determines general and specific objectives, activities and measures relating to long-term care which will ensure equal accessibility to high-quality and safe services, and the integrated and comprehensive care of individuals while considering the changing needs of the ageing population. For the approach to the introduction of the new paradigm in the functioning of the long-term care system to be as thoughtful as possible, the implementation of pilot projects relating to long-term care with testing of the single entry point mechanism and coordinated discussion of long-term care users in the community was planned among the measures provided in the Resolution. The National Council of the Republic of Slovenia (2016) expressed its support for the gradual and pilot-tested introduction of changes. In 2016, supported by the European Commission and in cooperation with the Ministry of Health and the Ministry of Labour, Family, Social Affairs and Equal Opportunities, the National Council organised a wide-ranging exchange of views on the further steps required for the arrangement of long-term care in Slovenia, in which practically the entire professional and other interested public participated, and adopted the conclusions which were taken into account to the greatest possible extent when drafting the Long-Term Care Act (2021). Other important documents followed the Resolution, which helped the policy-makers in their efforts to realise the long-standing development objectives of establishing a uniform

long-term care system. One of these was the Active Ageing Strategy (Government of the Republic of Slovenia, Ministry of Labour, Family, Social Affairs and Equal Opportunities and Institute of Macroeconomic Analysis and Development, 2017), which was adopted in 2017 and defines the vision and main objectives when forming responses to the challenges arising from the changed age structure of the Slovenian citizenry and provides strategic guidelines and operational objectives based on four pillars. Among these is the pillar, Independent, healthy, and safe life of all generations, which includes social protection systems, accessibility of healthcare services and long-term care, care for health, and a reduction of health inequalities.

The expert and other interested public have more or less intensively highlighted the urgency of establishing a uniform LTC system over the last twenty years. Furthermore, Slovenia has been receiving country-specific recommendations from the European Commission since 2013 with calls to systemically regulate long-term care as the relevant reform is defined as one of the key structural reforms necessary for the provision of the long-term sustainability of public finances due to an ageing population and unfavourable demographic trends (European Commission, 2022). The Court of Audit, which in 2019 issued the audit report entitled “Care for the elderly and those with physical or mental disabilities who are in need of assistance”, also drew attention to the inappropriate regulation of long-term care (Računsko sodišče Republike Slovenije, 2019) (hereinafter: Report). In the Report, which referred to the work of the Government of the Republic of Slovenia, the Ministry of Labour, Family, Social Affairs and Equal Opportunities and the Ministry of Health between 1 January 2007 and 30 June 2018, the Court of Audit of the Republic of Slovenia concluded that the concern of the country in the audited field to ensure assistance to everyone who needs it was not satisfactory.

Relating to the arrangement of long-term care, significant progress was made in 2016 with

the decision of the Government of the Republic of Slovenia to transfer certain tasks related to long-term care from the Ministry of Labour, Family, Social Affairs and Equal Opportunities to the Ministry of Health, a reason behind the transfer being the facilitated harmonisation of further development of integrated long-term healthcare and social care. With the transfer, the Ministry of Health also assumed the tasks of drafting the Long-Term Care Act and coordinating the implementation of pilot projects co-financed by the structural funds of the European Union in the field of long-term care.

As per the transferred tasks, the Ministry of Health published a public call for the selection of operations, “Implementation of pilot projects that will support the transition to the implementation of the systemic act on long-term care” (Official Gazette of the Republic of Slovenia [Uradni list RS], No. 24/2018) in the 2017–2021 period and ensured the coordination of the project activities that are the subject of the relevant monograph and the results of which contributed significantly to the planning of systemic solutions in the field of long-term care in Slovenia. In the relevant period, the Ministry of Health submitted two proposals of the Long-Term Care Act for public discussion; one in 2017 and the second in 2020. The second draft of the Long-Term Care Act was adopted by the Government of the Republic of Slovenia on 17 June 2021 (Vlada Republike Slovenije, 2021) and the National Assembly adopted it on 9 December 2021 (Zakon o dolgotrajni oskrbi [Uradni list RS, št. 196/21])). The content of the adopted Long-Term Care Act (2021) does not differ significantly from all preceding drafts in the objectives pursued, but upgrades them, especially in the sections highlighted by the Court of Audit (2019), the Covid-19 pandemic and the experience of other countries when establishing long-term care systems.

The adopted Long-Term Care Act (2021) is thus based on broadly supported baseline, the findings of the audit of the Court of Audit (2019), recommendations of the European Commission (2022) and good practices of other countries,

and addresses the following objectives with its solutions:

1. define long-term care in detail;
2. unify the legal bases governing the rights in the field of long-term care;
3. define content and the scope of rights and the selection of long-term care services;
4. establish a uniform assessment mechanism to enter the LTC system;
5. form a comprehensive, universally accessible, geographically and financially sustainable and available long-term care system;
6. enable a beneficiary who so wishes to stay in their home environment with suitable support for as long as possible;
7. place individuals who choose the mode of long-term care provision within their rights at the centre of the LTC system;
8. manage the growing private funding of individuals, which increases the risk of poverty, especially of the older population;
9. improve planning, managing and ensuring the quality, safety and efficiency of performing long-term care as a public service;
10. establish effective public scrutiny in the field of performing long-term care.

The Long-Term Care Act (2021) is a fundamental building block of the system and will enable long-term care in Slovenia to be accessible, available, safe and of high quality. Further activities necessary regarding education, labour, suitable rewarding of employees working in long-term care and the establishment of a methodology for monitoring long-term care quality at the national level should not be overlooked. To address the global shortage of staff in service activities, particularly in healthcare, social care and long-term care, opportunities to optimise processes, transfer competences between various occupational groups and introduce services with the application of various assistive technologies or e-care services must be sought, as research shows that the use of such services has a positive impact on user satisfaction, their sense of connection and safety in their home environment, promotes social

interaction and simultaneously shortens the time needed by the employees to reach users (Eurofund, 2020). The Ministry of Health approached the more flexible training of long-term care staff with an appeal to the Institute of the Republic of Slovenia for Vocational Education and Training by submitting a proposal in July 2021 to prepare a new professional qualification of a carer in healthcare, social care and long-term care within the healthcare professions.

In addition to the preparation of bases for a uniform systemic arrangement of long-term care, 2021 was also an important year for determining the foundations of the national model for quality monitoring and service safety of long-term care providers. As per the commitments of the Resolution to establish a comprehensive system for the monitoring and continuous improvement of the quality and safety of healthcare, the first national model for monitoring the quality and safety of healthcare in social care institutions or future long-term care providers was set up in 2021 (Bolčević et al., 2021; Farkaš Lainščak et al., 2022). Quality and safety monitoring of the healthcare service and long-term care, system assessment and result measurement are crucial for ensuring high-quality and safe services, implementing a safe working environment and recognising possible systemic shortcomings, including the best practices for system implementation (NHS, 2017; Duffy, 2018; OECD, 2020a; Chadborn, Devi, Hinsliff-Smith, Banerjee, & Gordon, 2021; European Commission, 2021).

## Implementation of pilot projects, which will support the transition to the implementation of the systemic act on long-term care

On 13 April 2018, the Ministry of Health published a public call "Izvedba pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi" (Implementation of

pilot projects which will support the transition to the implementation of the systemic act on long-term care), (Official Gazette of the Republic of Slovenia [Uradni list RS], No. 24/18) (hereinafter: project). The implementation of the project, which took place in the urban (the selected beneficiary was the Celje Health Care Centre), semi-rural (the selected beneficiary was the Koroška Care Home) and rural (the selected beneficiary was the Krško unit of the Posavje Centre for Social Work) environments, enabled the testing and calibration of the assessment scale for assessing eligibility for long-term care, the formation or management of cooperation protocols between various stakeholders, the identification of knowledge necessary for coordinated and comprehensive care of users, the search for optimum solutions addressing the needs and desires of people in need of long-term care, the acquisition of data not being collected at the national level, and the formation and testing of new services which the users received free of charge during the pilot activities due to the project activities being financed from the budget of the Republic of Slovenia and the European Social Fund.

The key objectives of the project were to test the key tools, mechanisms and services relating to the implementation of long-term care by means of a comprehensive approach and a defined model of integrated, coordinated and user-oriented care, i.e.:

1. testing of tools and procedures for the assessment of eligibility for long-term care (application, assessment tool, personal and implementation plan, informing of target public);
2. testing of new services and integrated care of a user in their home environment;
3. testing of new services and support mechanisms for informal and formal care providers to carry out high-quality and safe care;
4. testing of coordination mechanisms and the establishment of efficient coordination between social care and healthcare providers and the newly established entry points to ensure integrated services for the user;
5. testing of electronic documenting of procedures

from the eligibility assessment to the recording of service implementation (Ministrstvo za zdravje, 2018).

To test integrated service implementation, one of the project's requirements was that the providers selected in the project form a consortium, i.e. they had to connect at least with the providers of social care services assisting families at home, providers of institutional care for the older people or providers of institutional care for adults with mental and physical disabilities in the public network, a healthcare centre or reference outpatient clinics or a medical station in the project environment, providers of community care in the public network and the competent centre for social work. The condition to form a consortium was set with the aim of enhancing cooperation and integration between the healthcare, social care and long-term care (Ibid.) systems, which proved to be a unique challenge requiring further discussion in the future in order to attain comprehensive and user-oriented long-term care, in the process of which the user will be an active partner. The necessity of further discussion is also one of the conclusions of the evaluation of pilot projects in the field of long-term care.

## Discussion with key messages

In 2021, Slovenia made significant steps forward regarding a uniform systemic regulation of long-term care. With the adoption of the Long-Term Care Act (2021), the bases were provided for making long-term care accessible, available, safe and of high quality, and so that the beneficiaries with comparable needs will be able to access comparable rights. Several decades of attempts to uniformly and systemically regulate the field of long-term care, proposed acts and numerous other materials generated in this period and the possibility of pilot projects and their evaluation connected with implementation, which is also

the subject of the relevant monograph, represent important building blocks in the mosaic of solutions provided by the Long-Term Care Act (Ibid.) in order to respond to the needs of persons requiring long-term care. The results of the project showed important conclusions regarding the selection and application of the assessment tool for assessing eligibility for long-term care, the formation or management of cooperation protocols between various stakeholders, the search for optimum solutions addressing the needs of people who require long-term care and their informal carers, and the search for solutions enabling persons eligible for long-term care to choose from various modes of long-term care, including the option of co-financing the e-care services and access to new services for strengthening and maintaining independence. The findings and experience arising from the project are invaluable. They confirm that, despite incomplete self-care resulting from an illness, old age or disability, persons who need long-term care can live longer in their home with suitably organised professional long-term care and maintain or even improve

their physical and mental abilities and thus realise their active role in private and social life to the greatest extent possible. Long-term care is a story of new chances and opportunities to form various new types of institutional care and enable holistic care of a person in need of long-term care at their home. It is an opportunity for new jobs and a new opportunity for persons requiring long-term care, which is particularly evident from the statement of a user participating in the project, “I can sometimes be a bit of a workaholic and I like it when the carer comes and we start working with the tempo that suits me. She first told me what I was doing wrong because I was pursuing goals in physiotherapy that worked for me as I was before, and that’s not right. I have to follow the goals that are right for me now, she has taught me that already, for example. I got excited immediately.” Let us not forget that long-term care is a matter of the present and of the future. It is a need of an individual and a responsibility of society that, in the period of life when we are no longer capable of taking care of ourselves, no one is overlooked.

## BIBLIOGRAPHY

- Bolčević, S., Gorup, L., Jakac, S., Kobal Straus, K., Limonšek, I., Lipar, T., ... Štromajer, D. (2021). *Kakovost zdravstvene obravnave v socialnovarstvenih zavodih – priročnik*. Retrieved from <https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Dolgotrajna/Kakovost-zdravstvene-obravnave-v-socialnovarstvenih-zavodih-prirocnik-december-2021-v2.pdf>
- Cès, S., & Coster, S. (2019). *Mapping long-term care quality assurance practices in the EU*. Brussels: European Commission: European Social Policy Network.
- Chadbon, N. H., Devi, R., Hinsliff-Smith, K., Banerjee, J., & Gordon, A.I. (2021). *Quality improvement in long-term settings: a scoping review of effective strategies used in care homes*. European Geriatric Medicine, 12: 17–26.
- Ciccarelli, N., & Van Soest, A. (2018). Informal Caregiving, Employment Status and Work Hours of the 50+ Population in Europe. De Economist 166, 363–396 (2018). <https://doi.org/10.1007/s10645-018-9323-1>
- Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help Wanted? Providing and Paying for Long – Term Care*. Paris: OECD.
- Corselli-Nordblad, L., & Strandell, H. (ed.). (2020). *Ageing Europe: Looking at the lives of older people in the EU*. Luxembourg: Publications Office of the European Union.
- Cylus, J., Figueras, J., & Normand, C. (ed.). (2019). *Will Population Ageing Spell the End of the Welfare State?: A review of evidence and policy options*. Copenhagen: WHO.
- Državni svet, Republike Slovenije. (2016). *Strakovski posvet dolgotrajna oskrba*. Retrieved from <http://www.arhivds-rs.si/2012-2017/node/2319.html>
- Duffy, J. (2018). *Quality Caring in Nursing and Health Systems: Implications for Clinicians, Educators, and Leaders: Third edition*. New York: Springer Publishing Company.
- European Commission. (2010). *European Charter of rights and responsibilities of older people in need of long-term care and assistance*. Retrieved from [https://www.age-platform.eu/sites/default/files/European%20Charter\\_EN.pdf](https://www.age-platform.eu/sites/default/files/European%20Charter_EN.pdf)
- European Commission. (2015). *Long-term care – the problem of sustainable financing. Synthesis report*. Retrieved from <https://ec.europa.eu/social/BlobServlet?langId=sl&docId=13514&>
- European Commission. (2017). *The European Pillar of Social Rights in 20 principles*. Retrieved from [https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles\\_en](https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles_en)
- European Commission. (2022). *Country-specific recommendations provide policy guidance tailored to each EU Member State*. Retrieved from [https://ec.europa.eu/info/business-economy-euro/economic-and-fiscal-policy-coordination/eu-economic-governance-monitoring-prevention-correction/european-semester/european-semester-timeline/spring-package\\_en](https://ec.europa.eu/info/business-economy-euro/economic-and-fiscal-policy-coordination/eu-economic-governance-monitoring-prevention-correction/european-semester/european-semester-timeline/spring-package_en)
- Eurofund. (2020). *Public services. Impact of digitalisation on social services*. Retrieved from [https://www.eurofound.europa.eu/sites/default/files/ef\\_publication/field\\_ef\\_document/ef19043en.pdf](https://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef19043en.pdf)
- European Commission. (2021). *2021 Long-Term Care Report. Trends, challenges and opportunities in an ageing society*. Retrieved from <https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8396>
- Farkaš Lainščak, J., Grabar, D., Kobal Straus, K., Marušič, D., Polđrugovac, M., & Simčič, B. (2022). *Kakovost in varnost v zdravstvu – priročnik za zdravstvene delavce in sodelavce*. Ljubljana: Ministrstvo za zdravje.
- Flaker, V., Mali, J., Kodele, T., Grebenec, V., Škerjanc, J., & Urek, M. (2008). *Dolgotrajna oskrba: načrt potrebe in odgovor nanje*. Ljubljana: Fakulteta za socialno delo.
- Hlebec, V., Filipovič Hrast, M., Kump, S., Jelenc Krašovec, S., Pahor, M., & Domajnko, B. (2013). *Medgeneracijska solidarnost v Sloveniji*. Ljubljana: Fakulteta za socialno delo.
- Majcen, B., Eržen, I., & Stanovnik, P. (2015). *Značilnosti starejšega prebivalstva v Sloveniji – prvi rezultati raziskave SHARE*. Ljubljana: Inštitut za ekonomska raziskovanja.
- Mali, J., Flaker, V., Urek, M., & Rafaelič, A. (2018). *Inovacije v dolgotrajni oskrbi: primer domov za stare ljudi*. Ljubljana: Fakulteta za socialno delo.
- Ministrstvo za zdravje. (2017). *Predlog predpisa: Zakon o dolgotrajni oskrbi*. Retrieved from <https://e-uprava.gov.si/dzava-in-druzba/e-demokracija/predlogi-predpisov/predlog-predpisa.html?id=7885>
- Ministrstvo za zdravje. (2018). *Javni razpis »Izvedba pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi«*. Retrieved from <https://www.uradni-list.si/glasilo-uradni-list-rs/vsebina/2018002400003/javni-razpis-za-izbor-operacij-izvedba-pilotnih-projektov-ki-bodo-podpirali-prehod-v-izvajanje-sistemskega-zakona-o-dolgotrajni-oskrbi-st-303-1201816-ob-198618>
- MISSOC. (2021). *Comparative tables*. Retrieved from <https://www.missoc.org/missoc-database/comparative-tables/>
- Nagode, M., Zver, E., Marn, S., Jacovič, A., & Dominkuš, D. (2014). *Dolgotrajna oskrba – uporaba mednarodne definicije v Sloveniji*. Urad RS za makroekonomske analize in razvoj. Retrieved from [https://www.umar.gov.si/fileadmin/user\\_upload/publikacije/dz/2014/DZ\\_02\\_14.pdf](https://www.umar.gov.si/fileadmin/user_upload/publikacije/dz/2014/DZ_02_14.pdf)
- Nagode, M., Črnak Meglič, A., Dremelj, P., Dolničar, V., Hvalič Touzery, S., Istenič, A., ... Žakelj, M. (2021). *Dolgotrajna oskrba – izziv in priložnost za boljši jutri. Evalvacija pilotnih projektov s področja dolgotrajne oskrbe. Inštitut RS za socialno varstvo*. Retrieved from <https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Dolgotrajna/Dolgotrajna-oskrba-povzetek-dec21.pdf>
- NHS. (2017). *The Good Indicators Guide: Understanding how to use and choose indicators*. Retrieved from <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/The-Good-Indicators-Guide.pdf>
- OECD. (2018). *Accounting and mapping of long-term care expenditure under sha 2011*. Retrieved from <https://www.oecd.org/els/health-systems/AccountingMappingofLTC.pdf>
- OECD. (2019). *Health at a Glance*. Retrieved from <https://www.oecd-ilibrary.org/docserver/4dd50c09-en.pdf?expires=1644192824&id=id&accname=quest&checksum=247033AA2A126F45580B2FE6B64C969>
- OECD. *Health at a Glance: Europe 2020*. Retrieved from [https://ec.europa.eu/health/system/files/2020-12/2020\\_healthatglance\\_rep\\_en\\_0.pdf](https://ec.europa.eu/health/system/files/2020-12/2020_healthatglance_rep_en_0.pdf)
- OECD. (2020a). *The economics of patient safety Part III: Long-term care: Valuing safety for the long haul*. Retrieved from <https://www.oecd-ilibrary.org/docserver/be07475c-en.pdf?expires=1644204612&id=id&accname=quest&checksum=79114C5044A05CF856CB6C9A7FC9C54> (5 February 2022).
- OECD. (2021). *Health at a Glance 2021*. Retrieved from [https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-2021\\_ae3016b9-en](https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-2021_ae3016b9-en)
- Računsko sodišče Republike Slovenije. (2019). *Revizijsko poročilo: Skrb za tiste, ki zaradi starosti, duševne ali telesne prizadetosti potrebujejo pomoč drugih*. Retrieved from [https://www.rs-rs.si/fileadmin/user\\_upload/Datoteke/Revizije/2019/KAM/KAM-2\\_RSP\\_RevizijskoP.pdf](https://www.rs-rs.si/fileadmin/user_upload/Datoteke/Revizije/2019/KAM/KAM-2_RSP_RevizijskoP.pdf)
- Ramovš, J. (2020). *Integrirana dolgotrajna oskrba*. Ljubljana: Inštitut Antona Trstenjaka za gerontologijo in medgeneracijsko sožitje
- Resolucija o nacionalnem planu zdravstvenega varstva 2016–2025* »Skupaj za družbo zdravlja« (Uradni list RS, št. 25/16) Retrieved from <http://pisrs.si/Pisweb/pregledPredpisa?id=RESOI02>
- Sagan, A., Webb, E., McKee, M., Greer, S. L., Karanikolos, M., & Williams, G. A. (2021). *Health systems resilience during COVID-19: Lessons for building back better*. Retrieved from <https://eurohealthobservatory.who.int/publications/i/health-systems-resilience-during-covid-19-lessons-for-building-back-better>
- Služba Vlade Republike Slovenije za razvoj in evropsko kohezijsko politiko. (2021). *Načrt za okrevanje in odpornost*. Retrieved from [https://www.eu-skladi.si/sl/dokumenti/rf/01\\_si-rp-23-7-2021.pdf](https://www.eu-skladi.si/sl/dokumenti/rf/01_si-rp-23-7-2021.pdf)
- Spasova, S., Baeten, R., Ghailani, D., Peña-Casas, R., & Vanhercke, B. (2018). *Challenges in long-term care in Europe. A study of national policies 2018*. Brussels: European Commission: European Social Policy Network (ESPN).
- Institute of Macroeconomic Analysis and Development. (2021). *European Pillar of Social Rights – Slovenia 2000–2020*. Retrieved from [https://www.umar.gov.si/fileadmin/user\\_upload/publikacije/ESSP/2021/ESSP\\_splet.pdf](https://www.umar.gov.si/fileadmin/user_upload/publikacije/ESSP/2021/ESSP_splet.pdf)
- Government of the Republic of Slovenia, Ministry of Labour, Family, Social Affairs and Equal Opportunities and Institute of Macroeconomic Analysis and Development. (2017). *Active Ageing Strategy*. Retrieved from <https://www.gov.si/assets/ministrstva/MDPSZ/Direktorat-za-starejse-in-deinstitutionalizacijo/strategije/Active-Ageing-Strategy-2017.pdf>
- Vlada Republike Slovenije. (2021). *Predlog zakona o dolgotrajni oskrbi*. Retrieved from [https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Dolgotrajna/ZDO\\_parafa.pdf](https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Dolgotrajna/ZDO_parafa.pdf)
- Wagner, M., & Brandt, M. (2018). *Long-term Care Provision and the Well-Being of Spousal Caregivers: An Analysis of 138 European Regions*. J Gerontol B Psychol Sci Soc Sci. 2018 Apr 16;73(4):e24–e34. doi: 10.1093/geronb/gbx133
- Zakon o dolgotrajni oskrbi (Uradni list RS, št. 196/21). Retrieved from <http://www.pisrs.si/Pisweb/pregledPredpisa?id=ZAKO7621>



# **EVALUATION OF PILOT PROJECTS AND METHODOLOGY**

Mateja Nagode  
Social Protection Institute of the Republic of Slovenia

## KEY MESSAGES

- It is important for the evaluation that its planning starts at the right time: when the model that is the subject of the evaluation is being established, and in any case before the start of the intervention.
- It is important that several different stakeholders are involved in the evaluation, each with their own specific role: the contracting authority of the evaluation and the project, the consultative body (e.g. professional, research), project providers or employees, other important stakeholders from the local environment or the national level, participants or users in projects and their relatives, etc. Working and creating together can provide better conditions and circumstances and thus lead to better project results.
- Pilot projects are intended for testing the set solutions and creating new answers, pathways and good practices. Because such interventions are demanding, innovative and complex, it is recommended that as many different stakeholders as possible who are relevant to the tested field be involved in expert steering. In this case, in addition to the Ministry of Health and representatives of the pilot projects, at least the Health Insurance Institute of Slovenia, the Pension and Disability Insurance

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Institute, the Ministry of Labour, Family, Social Affairs and Equal Opportunities, municipalities, etc.

- ▶ The evaluation of the pilot projects was based on mixed research methods (linking qualitative and quantitative methods), which requires more research effort, but at the same time provides the results with greater validity. It also provides a broad range of different types of data that can be processed and displayed in different ways even after the conclusion of the project.
- ▶ The evaluation enabled the use of a relatively new research method in Slovenia, a democratic forum, which proved to be a very useful tool precisely for such projects, so it is recommended that it also be used and tested in the future.
- ▶ The course of the evaluation was influenced by both the Covid-19 epidemic and the fact that the pilot projects were not completed at the same time. All this has led to greater flexibility in data collection and processing. Based on the experience of evaluation of the pilot projects, it can be concluded that significantly more time should be devoted to the final phase of the evaluation, and especially to the final coordination of data and data analysis, as well as the drafting of the report.

## Introduction

Evaluation has today become almost an essential component of programmes and projects, especially development and pilot projects. However, there is no single answer to the question of why evaluations are made at all. Parsons (2017) states that one of the frequent answers to this question is “because we have to” or “because evaluation is necessary”, and this is mainly because evaluation is often a condition of project funding and certain pre-reserved funds or is part of a contractual obligation. However, this “must do” argument is part of a much larger picture, and behind it is the fact that different objectives and needs are related to evaluations. In the case of pilot programmes, initiatives and activities, the reason for evaluation is probably a combination of the following: preparation of an initial evaluation, checking whether the new idea works (or does it meet the requirements?); assessing whether it needs to be scaled up (for example, pilot programme) and whether it is cost-effective to introduce (and what adjustments would be needed); assessing whether the idea or procedure of intervention is transferable to other situations and in what circumstances (Parsons, 2017).

A combination of these ideas has also dictated the conditions, reasons and objectives of evaluation of pilot projects in the field of long-term care. As the group of experts and decision-makers was planning the intervention, i.e. implementation of pilot projects, they were also planning their evaluation. Evaluation was therefore an unavoidable and integral part of the pilot projects. It was separately funded, and it was external. As explained in the introductory chapter, it was carried out by the Social Protection Institute of the Republic of Slovenia, the Faculty of Social Sciences of the University of Ljubljana, and the Institute for Economic Research.

The purpose of the evaluation of pilot projects in the field of long-term care was to prepare a general assessment of pilot projects

with which the pilot environments could test new methods, procedures, mechanisms and services in the field of long-term care, while the key general goal is that the findings of the evaluation help create better solutions in the field of long-term care and possible projections of the future long-term care system in Slovenia.

In this article, the concept and course of the evaluation of the pilot projects in the field of long-term care is first presented, and then all research instruments that were used in conducting the evaluation are described in detail.

## Concept of evaluation of pilot projects

The pilot projects in the field of long-term care were a complex intervention, as was their evaluation. The evaluation covered a large number of objectives, included different target groups and featured various research methods, instruments and data of both a qualitative and a quantitative nature. In this chapter, the objectives of the evaluation, type of evaluation, research plan, procedure for establishing the methodology and key stakeholders in the evaluation are presented in more detail in individual sections.

## Objectives of the evaluation

As part of the evaluation, many objectives<sup>2</sup> were evaluated at four research levels:

### A. Effectiveness of new methods

- To assess the suitability and applicability of the selected assessment tool for assessing eligibility for long-term care.
- To prepare proposals for amendments for personal planning and coordination of services in long-term care.
- To prepare proposals for amendments for teamwork in long-term care.

<sup>2</sup> The objectives were already envisaged with the public procurement for evaluation.

## **B. Effectiveness of procedures in pilot projects**

- ▷ To prepare proposals for amendments to the procedures for assessing the eligibility for long-term care, including an assessment of the options for reducing bureaucratic burdens.
- ▷ To prepare proposals for amendments for the entire long-term care process, from entry to the provision of services.

## **C. Effects of the pilot project on people**

- ▷ To develop guidelines for the provision of services that will enable quality of life for informal carers.
- ▷ To develop guidelines for greater support for informal carers.
- ▷ To prepare guidelines for the quality working life of formal carers.

## **D. Preparation of content and financial projections for the long-term care system**

- ▷ To prepare proposals for the addition of new services in the home environment (integrated teams, services for maintaining an independent life, etc.).
- ▷ To prepare guidelines for the introduction of assistive technologies in the home environment.
- ▷ To prepare guidelines for the establishment and placement of the long-term care entry point.
- ▷ To prepare proposals for amendments related to the electronic management of procedures and services in the field of long-term care.
- ▷ To prepare a possible projection of financial and human resources in the long-term care system (with the provision of appropriate input data).
- ▷ To prepare guidelines for the development of organisational forms of cooperation and networking in the field of long-term care and with other areas that will support the transition to community forms of care.

The plan also included the possible preparation of a projection of financial and human resources for the long-term care system, although the pilot environments did not systematically monitor and collect the necessary input data, so this goal could not be evaluated.

## **Type of evaluation**

Depending on the content, it was a process and outcome evaluation. Both types of evaluation played an equally important role in the final evaluation of the pilot activities. Just as the effects (and results) of the pilot projects are important, so is the process itself, i.e. programme itself. At the same time, programme monitoring was carried out. It was evaluated whether the planned pilot activities were proceeding as planned, following the indicators from the public procurement for the implementation of the evaluation<sup>3</sup>.

Structural indicators were used to monitor how the pilot projects were set up and when. It was therefore monitoring of the basic structures in the project that enabled the projects to be implemented in the first place:

- ▷ establishing single entry points in the pilot environments and employing an adequate number of qualified assessors in the field of long-term care (1 February 2019).
- ▷ Each pilot environment employs at least one qualified long-term care coordinator with precisely prescribed education and years of work experience (1 February 2019).
- ▷ Each environment establishes an integrated care team consisting of precisely prescribed qualified professional profiles (1 February 2019).
- ▷ A local project council and a local project team is established in each pilot environment (30 November 2018).
- ▷ Protocols on the participation of all stakeholders in the pilot environment were established (1 February 2019).
- ▷ All relevant stakeholders of an individual pilot project were informed about all planned activities as part of the pilot project (introductory meeting by 15 September 2018, then updated communication with the environments for the entire duration of the project).

Process indicators were used to measure how the pilot activities were conducted. This part is important for understanding the final results, as

<sup>3</sup> Determined in Appendix I to the tender documentation.

it explains how the processes in the projects were conducted and what influences the results:

- ▷ 70% of the existing adult users of rights in the field of long-term care in the pilot environments are assessed by means of an assessment tool in the first nine months (until the end of the pilot activities).
- ▷ The proportion of persons assessed within three working days of the submission of the application (continuous monitoring).
- ▷ Proportion of assessed persons who will be eligible for long-term care and who will meet with a long-term care coordinator within three working days after the assessment of eligibility for long-term care (continuous monitoring).
- ▷ Proportion of persons who fail to meet the eligibility threshold and who are informed about the existing rights or care options in the field of social care and healthcare and about participation in the evaluation procedure (continuous monitoring).
- ▷ At least 80% of all long-term care beneficiaries are re-assessed after six months if they are still included in the pilot activities (every six months, continuous monitoring);
- ▷ Regular meetings between assessors at entry points and the expert team of the Ministry of Health, at which information is exchanged about possible challenges at work, open issues, etc. (at least six times a year).
- ▷ Regular supervision of formal carers and employees at the single entry point.
- ▷ Regular meetings between long-term care coordinators, care teams and assessors, at which information is exchanged about possible challenges at work, open issues, etc. (at least five times a year).
- ▷ Electronic real-time management of logs and documentation on work tasks, the time required to perform them and the possible workload.

The result indicators were used to measure the results of the pilot projects:

- ▷ Proportion of users whose satisfaction with the quality of life remains unchanged or has

increased due to the proposed solutions (at the beginning and end).

- ▷ Proportion of users with care plans that are being implemented (continuous monitoring).
- ▷ Proportion of users who transferred to institutional care (continuous monitoring).
- ▷ Proportion of users who were placed into another eligibility category after a repeated assessment (continuous monitoring).
- ▷ Proportion of users who have opted for e-care services, number of interventions (continuous monitoring).

Some indicators, mainly due to the lack of systematically collected required data, were not evaluated during the evaluation:

- ▷ Proportion of persons who currently do not exercise their rights in the field of long-term care who were assessed with the assessment tool (it can be partly explained by other indicators, e.g. proportion of users included in services).
- ▷ At least 50% of registered informal carers take part in training sessions organised for the duration of the pilot activities.
- ▷ Proportion of formal care users in terms of the place where the service is provided: at home or in institutions (at the beginning and end of the pilot activities; the objective is to increase the number of home care users by at least 10%).
- ▷ Proportion of unplanned hospital admissions or hospitalisations (at the beginning and end of the pilot activities).
- ▷ Number of trained long-term care coordinators (at least three) (31 January 2019) (it was evaluated by the “Each employment employs at least one qualified long-term care coordinator with precisely prescribed education and years of service” indicator. The latter is linked to each environment individually and thus provides better information about the employment of long-term care coordinators in projects).

During the evaluation, an initial report was prepared that, due to objective circumstances<sup>4</sup> was not made *ex-ante*, but at a time when the pilot activities and intervention were already

<sup>4</sup> The evaluation project was initiated relatively late, i.e. after the pilot environments started with the intervention for users.

under way. Four process reports and one interim report were prepared as part of the intermediate (mid-term) evaluation. Process reports were based mainly on the monitoring data, i.e. programme monitoring and process evaluation of the implementation of pilot activities, while the interim report was based on the presentation of the current course of pilot activities and the first intermediate results of these activities by individual pilot environments. The purpose of the intermediate evaluation was to become acquainted with the course of pilot activities and thus the possibility of reflection and influence on changing and improving the course of planned activities.

In accordance with the public procurement for the evaluation, the final joint evaluation should be prepared after the end of the intervention for users and after the completion of all pilot activities (ex-post). Due to the situation related to the Covid-19 epidemic and the extension of all three pilot projects, the evaluation was completed before all pilot activities were completed, i.e. at a time when one pilot environment had already ceased implementing pilot activities (September 2020), while the remaining two were in the final stages.

## Research plan and timeline

An experimental research plan was not possible, so the evaluation was based on a comparison of the situations and results before and after the pilot activities, thus identifying the change that occurred during the implementation of projects. For example, how the quality of life of the key evaluation target groups has changed. In order to rationalise data collection and in order to avoid burdening respondents, some effects of the projects were measured only at the end of the project (for example, what was the experience of users, employees and informal carers with the pilot

projects, perceived usefulness of services, etc.). The net effects of the intervention could not be accurately measured, as causality could not be determined due to the large number of pilot activities.

Four key time milestones were determined as part of the research plan:

- ▷ starting point M0 (January 2019). This is the point when users began to be included in the pilot activities. This is the point “before”, i.e. upon entry in the project.
- ▷ intermediate point M6, related to June 2019, which is an important point of evaluation, as it represents the period of the first six months of user inclusion in the project. The experience of being included in the pilot activities can already be observed;
- ▷ intermediate point M12, linked to December 2019, which means one year of implementation and monitoring of the pilot activities. Change can already be evaluated, so it can be treated as an “after” point;
- ▷ final point M18/M20, linked to June/August 2020<sup>5</sup>, which means more than a year and a half of implementation and monitoring of the pilot activities. Change can be evaluated, so it can be treated as an “after” point; This is the final point of evaluation.

As individuals became included in the project gradually, the timeline for each individual was unique. Each user therefore has “their” date for the starting point (M0) and, consequently, also for all the subsequent ones. For example, one joined the project in January 2019 (M0), another in May 2019 (M0), and a third in June 2019 (M0). If all users had joined the project at the same time, for example in January 2019, the change for all could have been evaluated for a period of a year and a half (until the end of June 2020), but because users were joining the project gradually, one year was determined as the shortest period for the “before-after” monitoring, which is the minimum period for the monitoring of changes and effects<sup>6</sup>. The key

<sup>5</sup> The pilot projects were originally expected to be completed in June 2020. The Dravograd pilot environment extended the contract until the end of September, and Celje and Krško until the end of December 2020. Accordingly, the observed period was extended until the end of August 2020.

<sup>6</sup> Due to a significant delay in the introduction of assistive technologies in the pilot environments, a minimum period of six months was set for the monitoring of changes and effects.

to the evaluation was therefore a comparison of the situation at the time of inclusion in the project (M0) with the situation after one year of inclusion (M12). An important circumstance that arose during the project (between M6 and M18) was the outbreak of the Covid-19 epidemic.

## Establishing methodology and important stakeholders in the evaluation process

Due to objective circumstances related to the public procurement procedure, the first measuring instruments began to be prepared only in February 2019<sup>7</sup>, after which the evaluation plan was coordinated with the contracting authority<sup>8</sup> and in the period when the intervention in the pilot environments was already being intensively implemented. The participation of two stakeholders was important for the evaluation during this period; the contracting authority and the European Centre for Social Welfare Policy.

Initially, there was no specific protocol of cooperation and communication with the contracting authority, and the evaluators were not updated on the instructions for the pilot environments, nor was there up-to-date information about all activities and events in the pilot projects. In June 2019, this deficit was bridged with an agreement on further regular meetings with the contracting authority twice a month. It was then that the cooperation, flow of information and role of the contracting authority as an important stakeholder in the evaluation that is also responsible for ensuring access to data and information, was strengthened and started to perform its function.

With its external consultative role, the European Centre for Social Welfare Policy was an

important stakeholder, especially in establishing and steering the methodology. The guidelines and recommendations prepared in the methodological manual *Monitoring and evaluating integrated LTC models* (Kahlert, Boehler, & Leichsenring, 2018) with proposals for standardised questionnaires for individual target groups were mostly followed in the preparation and selection of measuring instruments. The centre also organised two workshops for the evaluator and the contracting authority for the purpose of establishing the methodology and monitoring the evaluation of the pilot projects.

In February and March 2019, measuring instruments were selected on the basis of recommendations and the procedures for obtaining a permit for their use were initiated. They were adapted to the circumstances of the pilot projects, and they were presented together with consents<sup>9</sup> and other explanations (e.g. for whom the questionnaires are intended, how to implement them, etc.) in the *Instructions for surveying*. Employees in the pilot environments and the contracting authority were acquainted with them at the training session on 15 March 2019<sup>10</sup>. By that time, around 293 people had been assessed with the assessment tool in Celje, 68 in Dravograd and 82 in Krško, which meant that the M0 point had already been “missed” for these people. The delay thus affected some baseline data (in cases in which assessors did not survey applicants who had been evaluated before 15 March 2019, either), i.e. it contains data that is not really covered by M0 (for those who were surveyed in March 2019, for example, and evaluated in January 2019, the survey was delayed by three months).

It would therefore have been ideal if the methodology had been established before the start of the inclusion of users in the project, i.e. in

<sup>7</sup> The evaluation team signed the evaluation contract with the contracting authority on 9 January 2019, and the contracting authority approved the evaluation plan on 4 February 2019.

<sup>8</sup> The guidelines from *Developing an Effective Evaluation Plan. Setting the course for effective program evaluation* (CDC, 2011) were followed in the preparation of the evaluation plan.

<sup>9</sup> All respondents in the evaluation also signed a consent that they are willing to participate in the survey for the purposes of evaluation.

<sup>10</sup> The instructions for the M0 point were first prepared, after which they were upgraded several times, usually when it was time for a new intermediate point for the evaluation – M6, M12, M18, M24 – and especially at the onset of the Covid-19 epidemic, as some questions related to the new situation were added to the questionnaires. For each adjustment of the instructions, training sessions were organised for employees.



2018, and if employees in the pilot projects had also been intensively included in this process. Employees were another key stakeholder in the evaluation. In addition to being a link between us and the key target groups of the project (users, informal carers and stakeholders), they also performed a major part of the operational evaluation activities. They provided the conditions for the implementation of various evaluation activities (for example, rooms for meetings), surveyed users, completed surveys themselves and wrote reports themselves, provided data, participated in interviews and similar. They also participated in establishing an encryption system, which was essential for the evaluation.

By establishing encryption, i.e. assigning a unique code to each individual, only theoretical concepts could be included in the questionnaires and thus additional inquiries for the data about users collected by employees by means of other forms could be avoided. It turned out later that the applicants did not always provide all the information in the application for the eligibility assessment, the only document in which socio-demographic data was recorded, and the assessors did not subsequently request it (e.g. education, income, etc.), which caused a significant shortage in data. Otherwise, an advantage of encryption was mainly the rationalisation of data collection, less of a burden on users and informal carers and ensuring the flow of data (linking various databases with each other), while also enabling the anonymity of the participating users and informal carers. These two target groups were also key actors in the evaluation; the evaluators and employees in the pilot projects conducted a large number of interviews with them, and they were also constantly included in the survey. The pilot activities had a direct impact on them, which is why their experience in the evaluation project is extremely valuable.

## Implementing evaluation by means of mixed research methods

In order to support the findings and ensure valid results, quantitative and qualitative approaches, i.e. mixed research methods, were used. A concurrent triangulation plan (in accordance with Creswell and Plano Clark, 2007) was used, which is useful primarily in cases in which the results of one method are used to confirm the results of another method as well as the concurrent integrated plan (ibid.) which, unlike the concurrent triangulation plan, includes an extensive (predominant) quantitative or qualitative phase with an integrated less qualitative or quantitative part. This adds depth or breadth to the results of the predominant method.

## Quantitative instruments and data

The evaluation primarily relied on quantitative data drawn from the information system, while the questionnaires were developed or adjusted for different target groups (presented in Table 5) and for different time points (M0, M6, M12 and M18) and they were linked with the data from the information system.

### DATA FROM THE INFORMATION SYSTEM

The environments established the information system for the updated recording of data from the application, eligibility assessment, personal plan, monitoring of the implementation of services and recording of certain personnel data. They were building it gradually together with the system developer (for more, see chapter *Electronic management of procedures and services and information system suitability*), so aggregated semi-monthly data<sup>11</sup>, which was received from the

<sup>11</sup> Prepared in Excel.

pilot environments twice a month and contained data on the number of employees, applicants and assessed persons, persons included in the provision of services, the state of information support and organisation of e-care, waiting lists and difficulties in the implementation of the pilot activities, was first used for the updated monitoring of the pilot activities.

Aggregated semi-monthly data in the first three process reports was used as the main source of information, and it was also used in May 2020 in the latest process report, but only for comparison with anonymised micro data at the level of the individual from the information system, because the pilot environments at that time were still improving the data in the information system. Only a part of the micro data could be used for the preparation of the interim report, while the data for the preparation of the final report and the monograph was drawn entirely from anonymised data at the individual level exported from the information system.

A certain part of the data in the information system remained deficient. For example, when assessing eligibility, the assessors did not examine all socio-demographic data, such as that pertaining to education and income, provided by the applicant in the application, so some data was not included in the system. Such specifics are noted in the monograph in places where this data is analysed and presented.

An important part of the data collected at the individual level is also the data reported monthly by the pilot environments in cooperation with assistive technology service providers (more in chapter *Perception of the use of assistive technologies*).

## QUESTIONNAIRES FOR APPLICANTS AND USERS

The user questionnaire (M0) combines two standardised questionnaires: CASP-12, which measures the quality of life of the user,

i.e. applicant, and EQ-5D, which assesses their medical condition. The survey was conducted by the assessor during the first visit to the applicant, and was intended to assess their eligibility. After one year (M12) the assessor surveyed the user again, this time additionally about the experience of new services. In June 2020, a set of questions on life changes during the Covid-19 epidemic was added to the questionnaire (M12). In addition to the mentioned questionnaires, users also answered the questionnaire on the experience of care after six months of inclusion in the project activities (M6), with the aspect of coordination and the central role of users being of main interest. The questions were adjusted in accordance with P3CEQ<sup>12</sup>, which is a questionnaire for measuring the experience of coordinated care focused on the user, i.e. care and assistance organised and managed based on the needs and preferences of the user.

In all three cases, the survey was personal, and the assessor recorded the answers on an online platform on a mobile phone, which streamlined the data collection and avoided printing large numbers of questionnaires and the subsequent entry of data in electronic form. In cases where the online survey was inappropriate or impractical (e.g. in an area with a poor mobile signal), the assessors used printed questionnaires and entered the answers in the online questionnaire later. The M0 questionnaire was implemented from March 2019 to the end of February 2020, the M12 questionnaire from the end of January 2020 to August 2020, and the M6 questionnaire from June 2019 to August 2020.

A total of 258 users (59.4% of all assessed applicants) answered the M0 questionnaire in the Celje pilot environment, 198 users (54.9% of all assessed applicants) in Krško and 257 users in Dravograd (73% of all assessed applicants). The relatively low responsiveness is a consequence of several factors. One is that the assessors started the survey later than they started the eligibility assessment procedure. Applicants may also have refused to take part in the survey, or it may have been too demanding for some.

<sup>12</sup> Person Centred Coordinated Care Experiences Questionnaire.

Table 1: Survey response rate for users (M0, M6 and M12)

|                                                                             | Celje | Krško | Dravograd | Total         |
|-----------------------------------------------------------------------------|-------|-------|-----------|---------------|
| Number of assessed applicants living at home (M0)                           | 434   | 361   | 352       | <b>1147</b>   |
| Number of assessed applicants (M0)                                          | 258   | 198   | 257       | <b>713</b>    |
| Applicant response rate (M0)                                                | 59.4% | 54.9% | 73.0%     | <b>62.16%</b> |
| Number of applicants assessed for a second time (M6)                        | 208   | 127   | 100       | <b>435</b>    |
| Number of surveyed users with a second eligibility assessment (M6)          | 101   | 87    | 71        | <b>259</b>    |
| Response rate for users with a second eligibility assessment (M6)           | 48.6% | 68.5% | 71.0%     | <b>59.5%</b>  |
| Number of users with a third, fourth or fifth eligibility assessment (M12)  | 102   | 52    | 36        | <b>190</b>    |
| Number of surveyed users with at least a third eligibility assessment (M12) | 92    | 44    | 24        | <b>160</b>    |
| Response rate for users with at least a third eligibility assessment (M12)  | 90.2% | 84.6% | 66.7%     | <b>84.2%</b>  |
| Number of active e-care users                                               | 50    | 59    | 31        | <b>140</b>    |
| Number of surveyed e-care users                                             | 31    | 35    | 13        | <b>79</b>     |
| Response rate for e-care users                                              | 62.0% | 59.3% | 41.9%     | <b>56.4%</b>  |
| Number of active e-health users                                             | 7     | 2     | 12        | <b>21</b>     |
| Number of surveyed e-health users                                           | 4     | 1     | 9         | <b>14</b>     |
| Response rate for e-health users                                            | 57.1% | 50.0% | 75.0%     | <b>66.7%</b>  |

Upon the second eligibility assessment (M6), the questionnaire was answered by 101 users in Celje (48.6% of all applicants assessed for a second time), 87 users in Krško (68.5% of all applicants assessed for a second time) and 71 users in Dravograd (71% of all applicants assessed for a second time). In the second survey, the response rate decreased in the Celje pilot environment and increased in Krško, while in Dravograd it remained at approximately the same level. In the third time point (M12), 92 users were surveyed in Celje, 44 in Krško and 24 in Dravograd. Despite the low number of respondents, the response rate in relation to the number of users with a third assessment or more is quite high: 90% in Celje, 85% in Krško and 67% in Dravograd. In addition to the questionnaire related to life during the Covid-19 epidemic, 65 users from Celje, 21 from Krško and 23 from Dravograd answered at the M12 point.

Special emphasis was also placed on users of assistive technologies, for which two special questionnaires (e-care<sup>13</sup> and e-health<sup>14</sup>) were prepared, focusing on measuring the satisfaction, perceived usefulness and effects of the use of assistive technologies, and a special set was devoted to issues related to changes during the Covid-19 epidemic. The survey was conducted at one point in time (from May 2020 to August 2020), in the same way as for other questionnaires. During the survey, the users were included in e-care for between 58 and 526 days, or for 262 days on average. The questionnaire was completed by 79 e-care users (56.4% of active users) and 14 e-health users (66.7%).

## QUESTIONNAIRES FOR INFORMAL CARERS

The questionnaire for informal carers (M0) includes a standardised Zarit Burden Interview questionnaire on the subjective experience of the

burden of care (ZBI-22)<sup>15</sup>, additional questions on demography and the household in which they live, and on the provision of assistance and care. If present, the informal carer completed the questionnaire at the first assessment of eligibility of the relative included in the project and, if possible, in a room other than the one where the interview between the applicant and the assessor was conducted. They could also complete the questionnaire later<sup>16</sup>. After one year (M12), informal carers again responded to the same questionnaire by answering an additional set of questions related to the Covid-19 epidemic.

The survey in M0 was conducted from March 2019, in M12 from the end of January 2020, and in both cases it ended in August 2020. A total of 428 informal carers took part in the survey. The first questionnaire was answered by 395 (153 from Celje, 111 from Krško and 131 from Dravograd), the second by 94 (59 from Celje, 16 from Krško and 19 from Dravograd), and both were answered by 58 informal carers (26 from Celje and after 16 from Krško and Dravograd). As well as the addition to the questionnaire related to life during the Covid-19 epidemic, 16 informal carers (8 from Celje, 4 from Krško and 4 from Dravograd) answered in the point M0, and 42 (20 from Celje, 8 from Krško and 14 from Dravograd) in the M12 point.

The response rate was high given the type of survey (self-survey), as 64.8% of all informal carers registered in the pilot project<sup>17</sup> answered the first questionnaire (M0): 62.7% in Celje, 60% in Krško and 72.4% in Dravograd. In the second measurement (M12), the response rate was calculated with regard to the number of users assessed for a third time who indicated that they had a relative who helped them. The total response rate in this case was even higher - 79.7% (88.1% in Celje, 55.2% in Krško and 86.4% in Dravograd).

In the period from May 2020 to August 2020, informal carers whose relatives used assistive

<sup>13</sup> Users of the basic and premium e-care packages and users of the In Life smartwatch were included.

<sup>14</sup> Users of the package of vital function monitoring at home and users of telemedicine support were included.

<sup>15</sup> More about the questionnaire in chapter *Care for those who care: studying the quality of life of informal carers*.

<sup>16</sup> Each of them received an envelope with paid postage and was able to send the envelope directly to the evaluator.

<sup>17</sup> Data from the eligibility assessment application. If the data from the user questionnaire (M0) about whether the user has an informal carer or not was taken into account, the response rate would have been even higher, 80% on average.

Table 2: Response to the survey on informal carers (M0, M12)

|                                                                          | Celje | Krško  | Dravograd | Total        |
|--------------------------------------------------------------------------|-------|--------|-----------|--------------|
| <b>Number of informal carers, data from the information system (M0)</b>  | 244   | 185    | 181       | <b>610</b>   |
| <b>Number of surveyed informal carers (M0)</b>                           | 153   | 111    | 131       | <b>395</b>   |
| <b>Response rate in informal carers (M0)</b>                             | 62.7% | 60.0%  | 72.4%     | <b>64.8%</b> |
| <b>Number of informal carers, data from the information system (M12)</b> | 67    | 29     | 22        | <b>118</b>   |
| <b>Number of surveyed informal carers (M12)</b>                          | 59    | 16     | 19        | <b>94</b>    |
| <b>Response rate in informal carers (M12)</b>                            | 88.1% | 55.2%  | 86.4%     | <b>79.7%</b> |
| <b>Number of surveyed informal carers (M0 and M12)</b>                   | 26    | 16     | 16        | <b>58</b>    |
| <b>Number of surveyed informal carers in e-care</b>                      | 20    | 16     | 8         | <b>44</b>    |
| <b>Response rate in informal carers in e-care</b>                        | 40.0% | 27.1%  | 25.8%     | <b>31.4%</b> |
| <b>Number of surveyed informal carers in e-health</b>                    | 1     | 2      | 3         | <b>6</b>     |
| <b>Response rate in informal carers in e-health</b>                      | 14.3% | 100.0% | 25.0%     | <b>28.6%</b> |

Table 3: Survey response rate for stakeholders

**Number of contacted stakeholders (M0)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL     |
|-------|-------|------------|-----------|
| 45    | 18    | 32         | <b>95</b> |

**Number of stakeholders who responded to the survey (M0)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL     |
|-------|-------|------------|-----------|
| 15    | 16    | 8          | <b>39</b> |

**Stakeholder response rate (M0)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL        |
|-------|-------|------------|--------------|
| 33.3% | 88.9% | 25.0%      | <b>41.1%</b> |

**Number of contacted stakeholders (M18)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL      |
|-------|-------|------------|------------|
| 47    | 19    | 34         | <b>100</b> |

**Number of stakeholders who responded to the survey (M18)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL     |
|-------|-------|------------|-----------|
| 9     | 12    | 14         | <b>35</b> |

**Stakeholder response rate (M18)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL        |
|-------|-------|------------|--------------|
| 19.1% | 63.2% | 41.2%      | <b>35.0%</b> |

technologies as part of the project were separately interviewed in the same way with two questionnaires (on e-care and e-health). The e-care questionnaire was completed by 44 informal carers (31.4%), while the e-health questionnaire was completed by six informal carers (28.6%). Due to the very low number of responses from informal carers, the e-health questionnaires were not analysed in detail.

## QUESTIONNAIRES FOR STAKEHOLDERS

In the two time points - M0 (March 2019) and M18 (September 2020) - the positions or sensitivity for long-term care, assessment of availability, access, reach of the continuity of long-term care services, coordination and integration in the local environment, support for informal carers, sufficiency of resources in the field of long-term care, quality of services, assessment of the strength and impact of the user whose need for long-term care have been satisfied were measured with a questionnaire for stakeholders. The questionnaire consisted of 41 statements measured by an agreement scale. The questionnaire was followed by four open-ended questions, in which stakeholders were able to explain in detail how they assess certain important segments in the field of long-term care in the environment in which they live. The online questionnaire was answered by key stakeholders in the field of long-term care by individual pilot environments: representatives of decision-makers (e.g. municipalities), service and programme providers (e.g. care homes, pharmacies, community nursing), stakeholder, educational and research organisations (e.g. pensioners' association, folk high school, etc.). This also refers to stakeholders who were not necessarily involved in the pilot activities in any way. They were identified and invited to complete an online questionnaire by long-term care coordinators.

The response to the questionnaire varied by environment. Due to the poor responsiveness

of stakeholders, a longer period was determined for the survey: the first measurement lasted from 20 March 2019 to 15 June 2019, and the second from 24 September 2020 to 26 October 2020. At the first measurement, 15 different stakeholders responded to the questionnaire in Celje, or 33.3% of those invited, and nine or 19.1% of those invited responded at the second measurement (M18). Of the 18 stakeholders who participated in the project as partners (lead partner, mandatory consortium partners or additional partners), 12 completed the questionnaire at the M0 point and five at the M18 point. The questionnaire was also completed at the M0 point by three stakeholders who were not involved in the project as partners, and there were four such stakeholders at the M18 point.

In the Dravograd pilot environment, eight different stakeholders, or a quarter of those who had been invited to participate, answered the questionnaire at the M0 point, while 14 or 41.2% of the invited ones answered at the M18 point. Of the 32 stakeholders who participated in the project as partners, eight completed the questionnaire at the M0 point and 12 at the M18 point. Only project partners were invited to complete the survey at the M0 point, while two other stakeholders also completed the questionnaire at the M18 point.

In the Krško pilot environment, 16 stakeholders, or 88.9% of those invited, answered the questionnaire at the M0 point, while 12 or 63.2% answered at the M18 point. Of the 11 stakeholders who participated in the project as partners, nine completed the questionnaire at the M0 point and seven at the M18 point. The questionnaire was also completed at the M0 point by seven stakeholders who were not involved in the project as partners, and there were five such stakeholders at the M18 point.

As a large number of different persons from different organisations answered the questionnaire at both time points, the samples from M0 and M18 are treated as independent samples in the data analysis. In the results, more

emphasis was placed on the survey conducted in the second time point, as it already reflects the views on the situation in the field of long-term care in the environment on which the project has made an impact.

## QUESTIONNAIRE FOR EMPLOYEES

A questionnaire for employees was used to measure the quality of working life of employees in the pilot projects. It was implemented at two points of time, specifically in the period of the first half of a year of the project (M0/M6) and in the period between one year and a year and a half (M12/18).

The questionnaire consisted of several sets of questions. For the purpose of measuring the organisational climate and satisfaction, the questions from the SiOK questionnaire (Slovenian organisational climate) were slightly adjusted<sup>18</sup>. The organisational climate, employee satisfaction with certain aspects of working conditions, reconciliation of work and family life, contacts with various stakeholders in the field and positive and negative aspects of work as part of the project were measured. The assessors additionally answered a set of questions related to the eligibility assessment, evaluation of the usability and suitability of the assessment tool and the eligibility assessment guidelines. A set of questions for long-term care coordinators related to their work and questions related to help and support networks among team members were added at the second point of time.

The questionnaire was an online questionnaire sent by the project coordinator to all employees by e-mail. The survey was conducted for the first time in the second half of June 2019, and the second time in August and September 2020. At the M0 point, 43 out of 59 employees in the pilot environments answered the questionnaire: the response rate in Celje was 59.1%, in Dravograd 76.2% and in Krško 87.5%. 40 employees answered

<sup>18</sup> More in the chapter *Teamwork and integration of stakeholders as the foundations for ensuring integrated long-term care*.

<sup>19</sup> Because the surveys were answered partially, the total number of respondents (N) differs in individual results.

Table 4: Survey response rate for employees

**Number of employees (M0)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL     |
|-------|-------|------------|-----------|
| 22    | 16    | 21         | <b>59</b> |

**Number of employees who responded to the survey (M0)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL     |
|-------|-------|------------|-----------|
| 13    | 14    | 16         | <b>43</b> |

**Employee response rate (M0)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL        |
|-------|-------|------------|--------------|
| 59.1% | 87.5% | 76.2%      | <b>72.9%</b> |

**Number of employees (M18)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL     |
|-------|-------|------------|-----------|
| 25    | 16    | 18         | <b>59</b> |

**Number of employees who responded to the survey (M18)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL     |
|-------|-------|------------|-----------|
| 20    | 14    | 16         | <b>50</b> |

**Employee response rate (M18)**

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL        |
|-------|-------|------------|--------------|
| 80.0% | 87.5% | 88.9%      | <b>84.7%</b> |

the questionnaire in full, and three of them only partially. 50 employees responded to the survey at the M18 point, which represents an 84.7% response rate (Celje 80%, Krško 87.5% and Dravograd 88.9%).

As different persons answered the questionnaire at both points of time (significant staff turnover) and there were no attempts to identify the respondents, the sample of respondents is considered as independent. Changes in attitudes thus cannot be monitored at the level of the employee, but at the level of all employees together, which are not necessarily the same in both samples.

At the M12 time point, employees also completed a questionnaire on social support networks, which were used to measure how and in which cases employees offer support, connect and cooperate with each other. Everyone who was employed in the pilot environments during the implementation of the project, as well as project managers who were not necessarily formally employed as part of the project, were invited to complete the questionnaire. The questionnaire was answered by 18 employees from the Celje pilot environment, 17 from Krško and 14 from Dravograd.

## QUANTITATIVE DATA ANALYSIS

Quantitative data was analysed in different ways. A descriptive (e.g. presentation of proportions, median, arithmetic mean or average, standard deviation, mode), bivariate (e.g. chi-square, t-test, Mann-Whitney test, etc.) or multivariate data analysis (e.g. hierarchical clustering, regression) were performed, depending on the research question and the type of data or sample. Depending on the nature of the data, either parametric or non-parametric methods were used accordingly. The use of the method is explained with each analysis, in which key statistical parameters are also assigned. SPSS and STATA were used for data analysis, and the Pajek programme for analysis and display of large networks was used in the analysis of networks.



Table 5: Review of questionnaires and the course of the survey

| Respondent                                | Time point     | Interviewer                                                                        | Type of questionnaire                                 | Content                                                                                                                                                  |
|-------------------------------------------|----------------|------------------------------------------------------------------------------------|-------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Applicants/users</b>                   | M0, M12        | assessor                                                                           | face-to-face survey, online survey entry              | CASP-12 and EQ-5D (quality of life), in M12 also the experience of the new services and, in June 2020, life during Covid-19.                             |
| <b>Users</b>                              | M6             | assessor                                                                           | face-to-face survey, online survey entry              | P3CEQ, tailored (experience of reception of services as part of the pilot activities - mainly in terms of coordination and the central role of users).   |
| <b>Informal carers</b>                    | M0, M12        | assessor submits the survey                                                        | self-survey of informal carers, printed questionnaire | ZBI-22, objective burden, provision of care.                                                                                                             |
| <b>Stakeholders</b>                       | M0, M18        | long-term care/project coordinator makes an invitation to complete a questionnaire | self-survey of stakeholders, online survey            | In M12, also the experience of the pilot activities and, in June 2020, also life during Covid-19.                                                        |
| <b>Employees in the project</b>           | M0/M6, M12/M18 | long-term care/project coordinator makes an invitation to complete a questionnaire | self-survey of employees, online survey               | Attitudes towards the development and quality of long-term care services.                                                                                |
| <b>E-care users</b>                       | M17-M20        | assessor                                                                           | face-to-face survey, online survey entry              | Quality of working life, experience of assessment and assessment tools, experience of coordination and teamwork and social support networks.             |
| <b>E-health users</b>                     | M17-M20        | assessor                                                                           | face-to-face survey, online survey entry              | Experience of service, satisfaction and usefulness assessment, intent for future use, impact assessment (PIADS-10), change of positions during Covid-19. |
| <b>Informal carers for e-care users</b>   | M17-M20        | assessor submits the survey                                                        | self-survey of informal carers, printed questionnaire | Experience of service, satisfaction and usefulness assessment, intent for future use, change of positions during Covid-19.                               |
| <b>Informal carers for e-health users</b> | M17-M20        | assessor submits the survey                                                        | self-survey of informal carers, printed questionnaire | Experience of service, satisfaction and usefulness assessment, intent for future use, impact assessment, change of positions during Covid-19.            |

## Qualitative instruments and data

As part of the qualitative approach, various methods and techniques or instruments were developed and used and materials of various types, both primary and secondary, were collected. Semi-structured interviews and focus groups with various stakeholders and a democratic forum with assessors were organised and reports from employees were collected. Material that was not created in the projects for the needs of evaluation but were an integral part of the course of pilot projects - personal plans and annexes and various minutes - were also collected and analysed. All listed instruments are presented below.

### SEMI-STRUCTURED INTERVIEWS

Ten types of semi-structured interviews and a total of 83 various interviews with stakeholders relevant for the pilot projects and evaluation were conducted<sup>20</sup>. The conversations were based on pre-prepared systematic talking points. In agreement with the interviewees, the conversations were recorded, with the exception of the interview with a user who did not permit recording, and transcribed literally or paraphrased. They were conducted mostly in person, and due to measures related to the Covid-19 epidemic, some were also conducted online or by phone. Most of the interviews were interpreted in the analysis directly from the literal transcripts or by thematic sections, while a thematic analysis was performed in the case of users and informal carers.

A semi-structured interview was conducted on the first visit to all three pilot environments in February 2019. Two people took part in the interviews - the project manager (Celje, Dravograd, Krško), also and the project coordinator (Krško) or long-term care coordinator (Celje, Dravograd). We were interested in the preparatory phase of

applying for the public call for applications and the initial organisation of work in the pilot projects: key motivation for applying for the public call, the course of preparations for applying and forming a consortium group, the course of activities relative to the set goals, creation of a single entry point, cooperation with stakeholders and similar.

In the period between April and June 2019, initial interviews were conducted with long-term care coordinators with the purpose of finding out how they experience and understand the role of long-term care coordinator. The interview was conducted again at the end of the project (between August 2020 and November 2020). Its content was adjusted and the aspect of the experience of employment in the pilot project was added. During the pilot projects, quite a few long-term care coordinators were replaced, which is why various starting points were prepared for interviews, and those who started performing the role of long-term care coordinator in the interim were asked in detail about their experience in assuming and concluding this role and the transfer of knowledge and work. In Dravograd, an additional interview was conducted with the long-term care coordinator who had a job in the general hospital, in which the conversation also focused on the experience of coordination of discharges from the hospital.

In September 2019, an interview with representatives of the Dravograd pilot environment and a representative of the smartwatch provider was conducted, with the conversation focusing on the description of the functionality of the smartwatch, its functionality in relation to different target groups, use in the pilot project, advantages and disadvantages of the smartwatch and recommendations regarding its use. In October 2019, a semi-structured interview was conducted with a representative of the e-care provider on the development and procedures for introducing assistive technologies in all three pilot environments.

<sup>20</sup> A semi-structured interview with the contracting authority, the Ministry of Health, had also been planned, but it was not conducted due to objective circumstances on the part of the contracting authority.

Table 6: Characteristics of the interview procedure

| Type of interview                                                                                         | Time point                                                                                                                                                                                           | Method of interviewing                                        | Number of interviews |
|-----------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------|----------------------|
| <b>Project manager and project/long-term care coordinator</b>                                             | February 2019 (Krško, Dravograd, Celje)                                                                                                                                                              | face-to-face                                                  | 3                    |
| <b>Long-term care coordinator</b>                                                                         | April 2019 (Dravograd), May 2019 (Krško), June 2019 (2 in Celje), July 2020 (Celje, Krško), August 2020 (Celje), September 2020 (Krško, 2 in Dravograd), October 2020 (Celje), November 2020 (Krško) | face-to-face, with the exception of two that were done online | 12                   |
| <b>Representatives of the Dravograd pilot environment and a representative of the smartwatch provider</b> | September 2020                                                                                                                                                                                       | online                                                        | 1                    |
| <b>Representative of the e-care provider</b>                                                              | October 2019                                                                                                                                                                                         | face-to-face                                                  | 1                    |
| <b>E-care users</b>                                                                                       | April and May 2020                                                                                                                                                                                   | by telephone                                                  | 7                    |
| <b>Informal carers for users of assistive technologies</b>                                                | April and May 2020                                                                                                                                                                                   | by telephone                                                  | 9                    |
| <b>Users</b>                                                                                              | from July to September 2020; three in September 2019 as trial                                                                                                                                        | face-to-face                                                  | 20                   |
| <b>Informal carers</b>                                                                                    | from July to September 2020; three in September 2019 as trial                                                                                                                                        | face-to-face                                                  | 21                   |
| <b>Representatives of municipalities</b>                                                                  | September 2020 (Slovenj Gradec, Ravne na Koroškem, Dravograd, Krško), October 2020 (Celje, Štore, Vojnik, Dobrna)                                                                                    | face-to-face                                                  | 8 <sup>21</sup>      |
| <b>Representative of the information system developer</b>                                                 | November 2020                                                                                                                                                                                        | online                                                        | 1                    |

21 One interview was not recorded due to technical difficulties, so seven interviews were used in the analysis.

To better understand the experience of users and informal carers included in assistive technologies, seven semi-structured interviews with e-care users in April and May 2020 and nine interviews with their informal carers from the Krško pilot environment were conducted. The purpose was to make a list of the experiences of users who tested a combination of the basic package and a fall detector.

The criteria for the inclusion in the interview were: consent to the conversation of both the user and the informal carer (dyad) and active involvement of the informal carer in care; eloquence and willingness to share one's experience, feelings and opinions; use of the basic package and a fall detector (both). The additional criteria were that users live alone in their own household (they can live in a multi-apartment building, e.g. relatives live in the same building, but in a different household), i.e. that they spend most of the day alone, and the probability of a fall was higher.

Despite the relevant criteria, dyads did not exclusively participate in the interview; six dyads were interviewed, plus an additional two informal carers and one user. We were interested in the use and their experience, changes, e-care during the Covid-19 epidemic, recommendations and (only for informal carers) the burden of care. Interviews were conducted by telephone, and they were relatively short as a result, lasting an average of 27 minutes. All interviewees were women, who were 87 years old on average - three in the first category, three in the second and one in the third category of long-term care. With the exception of one, they have not yet had pronounced and serious needs for long-term care. Among the informal carers, six women and three men were interviewed - one was the spouse, and the others were either children or their partners (i.e. daughter-in-law).

A three-tier coding system (same for interviews with users and with informal carers) was created, which initially included five main topics. After an inductive analysis of the interviews was performed, the topics, their categories (factors)

and codes were accordingly supplemented with a deductive analysis by using Tsertsidis' (2019) coding scheme. The Atlas.ti qualitative analysis programme was used for coding and analysis.

In order to gain a comprehensive understanding of the experiences of users and informal carers included in the pilot activities, 20 semi-structured interviews were conducted with users and 21 with informal carers. A quota sample was selected, and seven users and seven informal carers were systematically selected in each pilot environment with the help of the project staff. Users from institutional care or their relatives were not interviewed. Users not involved in assistive technologies were not interviewed either as a sample of the latter, as already mentioned, was interviewed separately.

Based on the criteria, the interviewees were selected by the long-term care coordinators, who contacted them and agreed on a date for the visit. In certain cases, given the difficulties in the selection of interviewees who would meet all the criteria, the option was allowed of a slight deviation from the sample and the criteria were adjusted to the actual situation in the pilot environments. Four informal carers in a dyad with users were thus selected as interviewees (i.e. informal carers who provide care to the interviewed users).

The criteria for the selection of users were: ability to conduct an interview and diversity of the category of eligibility for long-term care, gender, age, reception of new services, existence of informal carer and assessment of eligibility by several assessors and, for informal carers, in addition to the ability to conduct an interview, diversity of the category of eligibility, gender, employment status and residence.

The final sample of users included eight from the first, ten from the second, third or fourth, and two from the fifth eligibility category, six men and 14 women, two adults and 18 older adults, 15 who received independence maintenance services and five who did not, 11 who had an informal carer and nine who did not. With the exception of one,

they were assessed by different assessors as part of different assessment. The final sample of informal carers included four from the first, 12 from the second, third or fourth, and five from the fifth eligibility category, five men and 16 women, eight employed people, one unemployed and 12 retired or homemakers, 16 people who lived in the same building as the user and five who resided elsewhere.

The guidelines for the interview followed the main research objectives of the evaluation, and covered the framework questions related to the procedures of the entire project, to the assessment, personal planning, coordination and implementation from the aspect of method and procedure, to a comparison of the people's lives before and after the project, to the system (satisfaction with the independence maintenance services and proposals for systemic regulation of long-term care) and to the provision of services during the Covid-19 epidemic. The guidelines for the interview were adapted to the aspect of each target group, while they otherwise covered the same key topics. The interviews were conducted in person, mostly at users' homes.

The interviews were thematically analysed in a deductive way (Boyatzis, 1998; Braun & Clarke, 2006; Hayes, 1997) in accordance with the principle of systematic coding as proposed by Saldana (2012). Two coding systems were developed (separately for informal carers and users) that followed the logic of the interview guidelines and were hierarchically divided into several levels. In the analysis of codes, mixed methods were used, and the content was compared on the basis of the characteristics of users and informal carers in accordance with the previously mentioned criteria. The MaxQDA qualitative analysis programme was used for this.

In the autumn of 2020, eight semi-structured interviews were conducted with representatives of the municipalities in the areas where the pilot activities were carried out: Slovenj Gradec, Ravne na Koroškem, Dravograd, Krško, Celje, Štore, Vojnik, Dobrna. The interview included

the following thematic sets: situation related to issues faced by older people (existing services and programmes, informal care, analysis of the situation, etc.), cooperation of the municipality with formal service providers, non-governmental organisations, other municipalities and local communities, etc., knowledge of the needs of the population, involvement and experience of the pilot project, thoughts about the existing system and the latest bill dealing with the field of long-term care.

Due to technical difficulties, one interview was not recorded, and it was excluded from further consideration. The other seven were coded in accordance with a pre-prepared multi-level coding system, which followed the questions in the guidelines for the interview. In the next step, the codes of the municipalities of the same pilot environment were combined and then all seven municipalities were combined.

At the end of the project, a semi-structured interview was conducted with a representative of the developer in November 2020 in order to gain better insight into the construction of the information system. The following topics were focused on: a review of the chronology of the construction of the information system as part of the pilot projects, information on possible differences in the developed information system for an individual pilot environment and access to data, and an assessment of suitability of the information system developed as part of the pilot projects as a basis for developing a new long-term care system throughout Slovenia.

## FOCUS GROUPS

For the purpose of the evaluation, three types of focus groups, and a total of seven focus groups were conducted: one on the eligibility assessment, three on the introduction of assistive technologies and three on the work in the independence maintenance unit. All seven were recorded in agreement with the participants,

**Table 7: Characteristics of focus groups****Type of focus group****► ON THE ELIGIBILITY ASSESSMENT****PARTICIPANTS IN FOCUS GROUP**

expert assessors (six of seven)

**TIME POINT**

June 2019

**LOCATION OF IMPLEMENTATION**

Ministry of Health

**NUMBER OF FOCUS GROUPS**

1

**► ON THE INTRODUCTION OF ASSISTIVE TECHNOLOGIES****PARTICIPANTS IN FOCUS GROUP**

long-term care coordinators, project coordinator and assessors

**TIME POINT**oktober 2019 (Krško, Celje),  
november 2019 (Dravograd)**LOCATION OF IMPLEMENTATION**

in the pilot environments

**NUMBER OF FOCUS GROUPS**

3

**► ON THE INDEPENDENCE MAINTENANCE SERVICES****PARTICIPANTS IN FOCUS GROUP**

long-term care coordinators, project coordinator and employees of the independence maintenance unit.

**TIME POINT**oktober 2019 (Krško, Celje),  
november 2019 (Dravograd)**LOCATION OF IMPLEMENTATION**

in the pilot environments

**NUMBER OF FOCUS GROUPS**

3

literally transcribed, interpreted by thematic sets, and quotes were used in the analysis to illustrate the findings.

Prior to the start of the pilot projects, the Ministry of Health trained a team of expert assessors to support the newly employed assessors in the pilot projects. The focus group that was conducted in June 2019 was focused on how expert assessors evaluate the training that they have received, how they evaluate the transfer of their knowledge to assessors in the pilot environments, and how they evaluate assessment as a method and procedure, and as a tool for the eligibility assessment. The focus groups were attended by six of the seven expert assessors.

For the purposes of analysing the introduction of assistive technologies, three focus groups were conducted in October and November 2019, one in each pilot environment. They were attended by the long-term care coordinators, project coordinator and assessors. The topic of discussion was the process of the introduction of assistive technologies, the process related to users (finding suitable candidates, user responses, concerns, delays, complications in providing services), the advantages and disadvantages of assistive technologies and proposals related to the provision of such services to users after the conclusion of the project. Three more focus groups were conducted in the pilot environments on the same day on the topic of independence maintenance services in the home environment. They were attended by the long-term care coordinators, project coordinator and employees of the independence maintenance unit. The discussion focused on the process of recruitment of staff and the challenges of acquiring staff for the independence maintenance unit. Each of the ten new services (description of service, key service provider, proposal of service according to user types, responses from users), the work process in their pilot environment (distribution of responsibilities, distribution of hours) and a proposal to reorganise the provision of new services was systematically discussed with the participants.

PERSONAL PLANS AND ANNEXES TO PERSONAL PLANS

A total of 576 anonymised personal plans (181 from Celje, 159 from Dravograd and 236 from Krško) and 71 annexes to personal plans were received. The rate of created personal plans in terms of the number of beneficiaries was 64.2% - it was the highest in Krško (81.7%), followed by Dravograd (69.1%), and the lowest in Celje (47.9%). The gap between the number of beneficiaries and the number of users with personal plans was mainly a result of some deciding not to use the service despite being eligible, or because death occurred before the plan was created. In Celje<sup>22</sup>, a long waiting list for inclusion in services also contributed to this, as personal plans were not created in advance.

Most of the personal plans and annexes were received in the form of a spreadsheet in Excel, while a part of the plans, especially those the environments prepared before the information support for creating personal plans was established, were received as a Word or pdf document. The latter, which accounted for more than a tenth of all, were converted into the xls format and subsequently, in cooperation with the long-term care coordinator, additional data was added (such as the date of the plan, because the printout from the information system showed the date of entry and last changes in the system and not the actual date of production). More about the sample and analysis of personal plans is available in the chapter *Personal planning and coordination in long-term care: identifying needs and planning care together with the user*.

REPORTS BY EMPLOYEES ON ACTIVITIES AS PART OF THE PILOT PROJECTS IN THE FIELD OF LONG-TERM CARE

For the purposes of the evaluation, employees prepared reports with: (1) a chronology of the pilot project in terms of their work and role in

Table 8: Characteristics of personal plans and annexes to personal plans

Number of beneficiaries who live at home

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL |
|-------|-------|------------|-------|
| 378   | 289   | 230        | 897   |

Number of users with a personal plan

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL |
|-------|-------|------------|-------|
| 181   | 236   | 159        | 576   |

Rate of personal plans made

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL |
|-------|-------|------------|-------|
| 47.9% | 81.7% | 69.1%      | 64.2% |

Number of users with an annex to a personal plan

| CELJE | KRŠKO | DRAVO-GRAD | TOTAL |
|-------|-------|------------|-------|
| 35    | 27    | 9          | 71    |

22 In the Dravograd and Celje pilot environments, the reasons why the pilot activities were discontinued were not consistently recorded.

Table 9: List of received semi-annual reports in the three reporting environments by pilot environment

| Reports by employees |                     | Celje  | Dravograd | Krško  | Total |
|----------------------|---------------------|--------|-----------|--------|-------|
| 1st reporting period | number of reports   | 22     | 16        | 14     | 52    |
|                      | number of employees | 22     | 21        | 14     | 57    |
|                      | response rate       | 100.0% | 76.2%     | 100.0% | 91.2% |
| 2nd reporting period | number of reports   | 9      | 12        | 11     | 32    |
|                      | number of employees | 23     | 21        | 14     | 58    |
|                      | response rate       | 39.1%  | 57.1%     | 78.6%  | 55.2% |
| 3rd reporting period | number of reports   | 11     | 9         | 15     | 35    |
|                      | number of employees | 21     | 21        | 15     | 57    |
|                      | response rate       | 52.4%  | 42.9%     | 100.0% | 61.4% |
| Total                |                     | 42     | 37        | 40     | 119   |



the project, (2) their thoughts on the events and positive and negative aspects of their work, (3) a vision of their role, work and profession and proposals for improvement and (4) an assessment of the scope of their work by pre-determined items. They submitted reports three times and reported on the content for the period from August 2018 to July 2019, from August 2019 to January 2020 and from February 2020 to April 2020. A total of 119 reports were received. The response rate was the highest in the first reporting period, at 91.2%, it declined to 55.2% in the second, and in the third reporting period it was 61.4%. The largest proportion of employees who prepared the report was in Krško at all points in time.

The received reports were technically processed and, based on the code and the initial letter of the field of work in the project, it was possible to link the reports by the same person from different periods and compare their development and changes over time (two reports are an exception, as the employees did not record this information). A qualitative analysis was performed by means of the MaxQDA qualitative analysis and mixed method programme. The coding system was initially designed in an inductive way and the three umbrella codes (identical to the three main questions) for each reporting period were assigned a different number of sub-codes depending on the recurring content. In the next phase, the structure of the coding system was partially changed in a deductive way so that the codes (and their content) followed the objectives of the evaluation, while the quotations were redistributed in accordance with the new codes. The content of the codes was compared in accordance with the pilot environment of the employee, unit of employment and their field of work (and in accordance with the employment profile, where possible) and reporting period and changes and similarities of individual content over time were observed by means of the entered code (with the exception of a few persons who did not enter the mentioned data in the report form).

Reporting by employees varied considerably, which is why caution was needed in interpreting the results. The records by employees from one pilot environment are generally much more detailed and extensive when it comes to work tasks (first question) compared to the other two environments, which somewhat hinders the comparison of results on the presence of topics at the level of environment. Some employees recorded the same content in both periods, and in some cases the reports within the teams were (almost) identical. Despite the mentioned limitations, the reports are an important source of information, as they clearly support quantitative data and highlight topics that were not detected in other measuring instruments during the evaluation.

## DEMOCRATIC FORUM WITH ASSESSORS

The democratic forum called *“Assessing eligibility for long-term care as a method and procedure”* was organised on 3 September 2020 for the needs of the evaluation. The purpose of the democratic forum was to have an argument-based discussion on various aspects related to the work of the assessor and the eligibility assessment. Four thematic fields were discussed: the single entry point and assessors, assessing in accordance with the new paradigm and consideration of the context, ensuring objectivity of the tool and the role of the life story, and assessment as a procedure.

Assessors from all pilot environments and all expert assessors were invited to the event. It was attended by ten of the fifteen assessors (five of the seven from Celje, all four from Krško, one of the four from Dravograd) and three expert assessors.

At the democratic forum, with the help of a moderator, the participants exchanged views and opinions by presenting arguments and sought to reach a consensus on each topic discussed. For each topic, the evaluators first presented all the data they had collected during the evaluation and the results of an online questionnaire that was completed by the assessors and expert assessors

for the purpose of conducting the democratic forum a week before the event. The presentation of the data was followed by a plenary discussion, and this was followed by a discussion in two groups, and group reporting and a final joint discussion in which a consensus was reached with the participants on the discussed topic. At the end, the participants once again completed the same online questionnaire as before the democratic forum. The first online questionnaire was answered by 17 assessors and expert assessors (out of 21 assessors), and the second by all 13 participants in the democratic forum.

## MINUTES AND OTHER QUALITATIVE MATERIAL

An important source of qualitative data are the notes and minutes made during the implementation of pilot projects. For the purposes of evaluation, we relied mainly on the minutes of evaluators from visits to the environments (five in Celje, seven in Dravograd, four in Krško), with the contracting authority (22), on the minutes of the contracting authority with coordinators from the environments (13) and on internal minutes prepared in the project environments (52 in Celje, 91 in Dravograd, 82 in Krško). We have a total of 225 such pieces of material.

## Discussion with key messages

While the pilot projects were complex in terms of organisation and implementation, just as complex was their evaluation, as part of which a number of evaluation objectives was evaluated and by using various research methods and techniques. An experimental research plan was not possible, and it was not possible to determine causality due to the large number of pilot activities. We were therefore careful in attributing the effects of the pilot projects. However, by using a before-

after research plan, we were able to provide an appropriate basis for updated, process-oriented steering of the pilot projects, as well as for providing guidance to the contracting authority in finding system solutions.

Due to objective circumstances, the methodology began to be established at a time when the pilot projects were already being intensively implemented, which is considered one of the weak spots of the evaluation, as the starting point of the pilot projects was missed, which is the key observation point from the aspect of monitoring of changes. It would be ideal if the methodology was established before the inclusion of users in the project, and if employees in the pilot projects were also intensively included in this process.

It was crucial for the evaluation that it took place in intensive cooperation with other stakeholders, the main ones being employees in the pilot environments, users and their relatives or informal carers, the Ministry of Health as the contracting authority of the evaluation, and the European Centre for Social Welfare Policy. Each of them, with their specific role, has made an important contribution to creating better conditions and circumstances for the evaluation. As the pilot projects were demanding and innovative, in addition to the listed stakeholders, an important advisory or steering role could also be played by a broader expert group that would monitor the progress of the pilot projects and evaluation results and provide expert bases and proposals for solutions to the challenges that constantly arise during such projects. For example, in preparation for the pilot projects in the field of long-term care, the establishment has been planned of a national project council for long-term care, which would comprise representatives of the Ministry of Health, Ministry of Labour, Family, Social Affairs and Equal Opportunities, Health Insurance Institute of Slovenia, Pension and Disability Insurance Institute, Association of Municipalities and Towns of Slovenia, Slovenian Federation of Pensioner

Associations, local project council and project managers from the pilot environments.

The evaluation was based on mixed research methods in order to support the findings and ensure valid results. Such an approach also allowed depth and breadth to be added to the results of the prevailing method. In cooperation with the employees in the pilot projects, a large variety of material and data has been collected that enables very detailed and extensive quantitative and qualitative analyses. A democratic forum with assessors, a method that is not yet very well-known and widespread in research in Slovenia, was also conducted, contributing to the further development of the method in our country.

It was not possible to collect all the desired data as part of the evaluation in the way that had initially been anticipated, or they were collected in an unsystematic way (for example, insufficient number of units of analysis, data unevenly or deficiently entered into the information system), so it was not possible to verify and evaluate all the evaluation objectives and indicators in the way

that had been originally planned. Several factors had an impact on this, including the Covid-19 epidemic, which has strongly marked the course of the project activities and people's lives. In addition, the evaluation was marked by the fact that all three pilot projects were not completed at the same time and that in two pilot environments they ended simultaneously with the completion of the evaluation. This has led to greater flexibility in both data collection and processing. Our experience is that for evaluations of such innovations, it is necessary to ensure more time for coordination of data with the providers after the completion of their activities, and then also more time for a thorough preparation of analyses and final results.

It was not possible to analyse all opinions and all obtained data, but they certainly represent a wealth of experience and a wealth of data that could provide support and important guidance to planners of the long-term care system even after the completion of the projects and the evaluation.

## BIBLIOGRAPHY

- CDC (2011). *Developing and Effective Evaluation Plan*. Atlanta, Georgia: Centres for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; Division of Nutrition, Physical Activity, and Obesity.
- Creswell, J. W., & Plano Clark, W. L. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, California: Sage Publications, Inc.
- Boyatzis, R. E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development*. Thousand Oaks, CA: Sage.
- Braun, V., & Clarke, V. (2006). *Using thematic analysis in psychology*. *Qualitative research in psychology*, 3, 2, 77–101.
- Hayes, N. (1997). *Theory-Led Thematic Analysis: Social Identification in Small Companies*. V Hayes N. (ed.). *Doing Qualitative Analysis in Psychology*. Hove, UK: Psychology Press.
- Kahlert, R., Boehler, C., & Leichsenring, K. (2018). *Monitoring and Evaluating Integrated LTC Models*. Vienna: Euro Centre Publication.
- Kustec Lipicer, S. (2009). *Vrednotenje javnih politik*. Ljubljana: Fakulteta za družbene vede.
- Ministrstvo za zdravje. (2018). Javni razpis »Izvedba pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi«. Retrieved from <https://www.uradni-list.si/glasilo-uradni-list-rs/vsebina/2018002400003/javni-razpis-za-izbor-operacij-izvedba-pilotnih-projektov-ki-bodo-podpirali-prehod-v-izvajanje-sistemskega-zakona-o-dolgotrajni-oskrbi-st--303-1201816-ob-198618>
- Ministrstvo za zdravje. (2018). *Javno naročilo za Evalvacijo pilotnih projektov s področja dolgotrajne oskrbe*. Retrieved from [https://www.narocanje.si/Obrazci/?id\\_obrazec=280003](https://www.narocanje.si/Obrazci/?id_obrazec=280003)
- Parsons, D. (2017). *Demistifying evaluation. Practical approaches for researchers and users*. Bristol: Policy Press.
- Saldana, J. (2012). *The Coding Manual for Qualitative Researchers*. London: Sage.
- Tsertsidis, A., Kolkowska, E., & Hedström, K. (2019). *Factors influencing seniors' acceptance of technology for ageing in place in the post-implementation stage: A literature review*. *International Journal of Medical Informatics*, 129, 324–333. doi:10.1016/j.ijmedinf.2019.06.027

**TRANSITION TO INTEGRATED LONG-TERM  
CARE BY ESTABLISHING A SINGLE ENTRY  
POINT, INTEGRATED CARE TEAM AND  
CONNECTING STAKEHOLDERS**

Aleš Istenič  
Social Protection Institute of the Republic of Slovenia

Mateja Nagode  
Social Protection Institute of the Republic of Slovenia

## KEY MESSAGES

- The pilot projects were implemented in different types of environments (urban, semi-rural and rural environment), with different social contexts and organisation of work: the leading project partners varied as regards type of organisation (health care centre, centre for social work and care home), and consortia were also composed differently. The pilot projects thus provided insight into different structures and methods of operation and organisation of long-term care in different environments and circumstances.
- Based on the results of the project, none of the organisations was singled out as the only one suitable for establishing a single entry point. In no pilot environment was a single entry point established at the regional unit of the Health Insurance Institute of Slovenia, which would be an important contribution to testing appropriate solutions, given the long-term care bill (2021), which envisages this.
- The establishment of the pilot projects and all planned structures and teams has drawn attention to the already recognised problem of staff shortages in the field of long-term care and provided insight into the challenges that will be faced in Slovenia in the future. All environments have faced employment challenges to a lesser or greater extent, as some profiles were

*TRANSITION TO INTEGRATED  
LONG-TERM CARE BY ESTABLISHING  
A SINGLE ENTRY POINT, INTEGRATED  
CARE TEAM AND CONNECTING  
STAKEHOLDERS*

more difficult to employ or have not been employed at all (e.g. nursing carer, master of kinesiology). It will be necessary to make care professions more attractive.

- ▶ The turnover of staff, which was also due to the limited time of implementation of the project and thus the inability to maintain the sustainability of employment, was a special challenge of the pilot projects.
- ▶ Integrated care contributes to the easier access to services, their higher quality and efficiency and, consequently, greater user satisfaction, which is why it is necessary for various stakeholders in this field to connect and cooperate.
- ▶ Cooperation between stakeholders must reflect a common interest in identifying and satisfying the needs of the local population, which shows in active and effective cooperation in providing long-term care.
- ▶ The key stakeholders in the field of long-term care in the pilot environments are aware that integrated and coordinated social care and healthcare is important for care, and at the same time they perceive that the various organisations that provide long-term care are not yet well connected and that transfer of information between them is not efficient enough.

## Introduction

Integrated care is a concept that is widely accepted and used throughout the world (Goodwin, 2016), although there is no universal definition of integrated care (Goodwin, Sonola, Thiel, & Kodner, 2013; World Health Organisation, 2016), as different definitions of integrated care are being used. This diversity is mainly the result of the different intentions attributed to integrated care by various stakeholders as part of integrated care systems. Goodwin (2016) notes that integrated care cannot be defined even narrowly, and that it should be seen as a general term for a broad and multidimensional set of ideas and principles that aim to better coordinate care in accordance with people's needs. It could be said in the simplest terms that integrated care is an approach to bridging fragmentation, especially where such fragmentation leads to detrimental effects for the care experience and for the results of care itself. At the core is the commitment to improving the quality and safety of services through permanent and co-productive partnership (*ibid.*).

In Slovenia, coordination between institutions that provide services in the field of long-term care is not good, which makes it difficult for people to access services and reduces their quality (Nagode, Zver, Marn, Jacovič, & Dominkuš, 2014). Services are not integrated in practice, users are not fully provided with quality, equal and necessary access to services, administrative procedures are complex and access to information is not centralised, as authors of various articles have been pointing out for many years (e.g. Dominkuš & Peternelj 2006; Ministrstvo za delo, družino socialne zadeve in enake možnosti, 2008; Dominkuš, Zver, Trbanc, & Nagode, 2014; Črnak Meglič et al., 2014; Ministrstvo za zdravje, 2021). In Slovenia, the effort is being made to overcome this by adopting an act that would uniformly and systemically regulate the field of long-term care (MH, 2021). The need for an integrated method of long-term care in which healthcare and social care services are connected, and users have access

to services in one place, is being increasingly pronounced (Črnak Meglič et al., 2014).

How to overcome the mentioned challenges and find related solutions in the direction of better integration in the field of long-term care was also explored by pilot projects in the field of long-term care. The article focuses mostly on the following important elements that have been tested: establishing single entry points and an integrated care team, employing a long-term care coordinator and connecting various stakeholders in the field of long-term care in pilot environments.

The single entry point as an important part of integrated care is mentioned by many authors in their work (e.g. Pan, 1995; Flaker et al., 2007; Flaker, Nagode, Rafaelič, & Udovič, 2011; Črnak Meglič et al., 2014; Lebar et al., 2017). As early as the 1990s, Pan comprehensively discussed the importance of a single entry point and wrote that it was a local or regional point that facilitated access to long-term care services. At this point, interested parties receive information on long-term care, and this is also where a needs assessment and a care plan are made. The procedure at the single entry point can run completely independent from the further process of provision of service. This means that a procedure is carried out at a single entry point by means of which persons are assessed, advised and referred to appropriate services, regardless of what services these are or who provides them. From the point of view of users, a single entry point brings easier and faster access to services, and from the point of view of the state, it can mean a more efficient way of managing services. The use of uniform eligibility assessment and referring users to services provides a better overview of the use of services and their costs. The operation of a single entry point increases the chances of interested persons receiving information about different types of assistance and care. Raising people's awareness of the possibilities of community-based care can thus make an important contribution to delaying entry into institutional care. The concept of a single entry point implies some degree of integration of the



long-term care system. However, its establishment does not imply an integrated long-term care system in its entirety, as it is only one component of that system (Pan, 1995).

One of the important discussions and decisions in the introduction of integrated long-term care is thus certainly where and what kind of a single entry point to establish, i.e. which organisation will take over this task and what will be its role in the long-term care system. Various discussions on this topic have been published (e.g. Flaker et al., 2007; Flaker et al., 2011; Črnak Meglič et al., 2014; Lebar et al., 2017), and the latest draft of the act on long-term care (MH, 2021) provides for the organisation of entry points at regional units of the Health Insurance Institute of Slovenia.

What is also important for integrated care is that an integrated team is established for the implementation of care which includes professional groups in the field of healthcare and social care. The only comprehensive analysis of staff in long-term care that has so far been made for the situation in Slovenia (Smolej Jež, Nagode, Jacovič, & Dominkuš, 2016) has shown that about 70% of staff in long-term care provide care in institutions, 30% at home or in community forms, which roughly mirrors the ratio of total expenditure on long-term care (77.7% vs 22.3%). By occupational groups, the most staff in long-term care are nursing carer (22.4%), followed by nursing assistant or state enrolled nurses (17.7%), family assistants and recipients of partial compensation for lost income (14.7%), registered nurses (13.4%), (social) carers (11.4%) and custodians (8.8%), providers of community nursing (4.9%) and personal assistance at home (2.9%), homemakers (2.8%), persons employed in housing groups (0.7%) and staff in psychiatry (9.4%).

Smolej Jež et al. (2016) also report that in 2015, for every 100 people aged 65 or older, 3.1 formally employed persons provided long-term care in Slovenia, and that for every person providing long-term care in Slovenia there were 5.3 recipients of long-term care services. According to the authors, the workload on staff in

Slovenia is high, given the above-mentioned data and compared to the average of fourteen OECD countries, which amounts to 3.7.

If we focus, for example, only on staff providing home help, as was the focus of the pilot projects, the research shows that staff providing home help are ageing (Kovač, Orehek, & Črnič, 2020) and that this results in a higher proportion of sick leave of social carers and greater difficulty in performing more demanding, physically strenuous tasks. There is also a shortage of staff for the provision of home help, which is overburdened, and interest in such employment is especially low among the younger population (Nagode, Kovač, Lebar, & Rafaelič, 2019). The situation is also similar in the field of community nursing; data from Džananović Zavrl (2021) for example show that the staffing norm for community nursing in Slovenia (2,500 inhabitants per one registered nurse) is exceeded by an average of 8%. The norm has been exceeded in two-thirds of statistical regions in Slovenia (data for January 2020). This is especially important given the fact that an effort is being made in Slovenia to promote community-based care or home care, which was also the subject of the pilot projects, and which means an even greater need to employ staff in these two long-term home care services. It is necessary to think about how to acquire staff at the national level, especially in the sense of incentives for (potential) interested persons from Slovenia and in the sense of attracting a labour force from the neighbouring countries; quality data support will be required to prepare projections.

Coordination must be established between all teams involved in providing integrated long-term care. The coordinating role is performed by the long-term care coordinator, who also prepares personal plans with the beneficiaries. In addition to the coordination of the teams involved in providing long-term care, in order to ensure the most integrated care possible it is also necessary that all stakeholders working in the field of long-term care in the environment are connected and

that they cooperate. Their common interest in identifying and satisfying the needs of the local population for long-term care and the vision and commitment in providing quality long-term care is needed, which was precisely the purpose of the pilot projects. In order to ensure quality and efficient integrated care, it is also necessary to coordinate and unify a number of procedures. To this end, it is necessary to establish protocols and standards that are created and used by all those involved in providing long-term care. On the one hand, it is therefore important to formalise the cooperation process, which ensures that all stakeholders work in unison, and on the other hand, the process of creating protocols that encourages stakeholders to find appropriate solutions and methods of cooperation is also important.

## Methodology

One of the goals of the evaluation of the pilot project was to evaluate the establishment and placement of an entry point for long-term care. In doing so, we determined whether the single entry point for long-term care was established as planned in the public call for applications, and whether its placement was appropriate from various aspects. The establishment of a team for integrated care and networking of stakeholders in the pilot environments was also crucial for the establishment and launch of projects in the environments. To this end, we monitored whether organisational forms of cooperation and networking in the field of long-term care and other areas suitable for the integrated implementation of long-term care have developed in the environments.

In this part, the project was evaluated mainly by means of structural indicators. We were therefore interested in when the single entry point was set up, how the employment of professional workers (assessors, long-term care coordinators and service providers in the integrated care team) was conducted and how and with which partners

cooperation was established in the environments. It is therefore the concern with monitoring the basic structures in the project that enabled the projects to be implemented in the first place.

The following structural indicators were monitored:

- ▷ establishment of a single entry point by 1 February 2019,
- ▷ employment of an adequate number of qualified assessors in the field of long-term care by 1 February 2019,
- ▷ employment of at least one qualified long-term care coordinator with precisely prescribed education and years of work experience by 1 February 2019,
- ▷ establishment of an integrated care team consisting of precisely prescribed qualified professional profiles by 1 February 2019,
- ▷ all relevant stakeholders of the pilot project informed about all planned activities as part of the pilot project, an introductory meeting by 15 September 2018, then updated communication with the environments for the entire duration of the project,
- ▷ a local project council is established in each pilot environment by 30 November 2018,
- ▷ protocols on the participation of all stakeholders in the pilot environment established by 1 February 2019.

Data and information on the establishment of single entry points, employment of staff in the project and networking of stakeholders in the pilot environments was obtained through various research methods. We first conducted in February 2019 semi-structured interviews with project managers and long-term care coordinators in all pilot environments in which we were interested in what the main reasons were for them to apply for the call for applications and how this took place, how the consortium group was formed in the environment, how the initial organisation and implementation of the project took place and how the computerisation of processes took place. To monitor and study the establishment of single entry points, we also used some findings or results

of the deliberative discussion at the democratic forum that featured assessors employed at single entry points and expert assessors<sup>23</sup> and findings from the focus group with expert assessors. Employment in the pilot environments was monitored through a list of employees, to which the pilot environments added information about new employments or terminations of employment. The evaluation team obtained the updated lists from the pilot environments at its own request. The data for this part of the evaluation and for monitoring of the cooperation between stakeholders was also obtained during the project by means of visits to the environments and communication via e-mail or telephone. This communication was particularly intensive before the drafting of all, and especially the process reports. The participation of stakeholders in the environment was also studied by means of a survey that included all relevant stakeholders in the field of long-term care in the pilot environments (i.e. not only consortium and additional partners of the pilot projects) and that was completed at the end of the project (more in the Evaluation of pilot projects and methodology chapter).

## Results

We present below how the establishment of the single entry point took place in the pilot environments, in particular when and where it was established, and how the employment of assessors at the single entry points took place. We describe the process of establishing integrated care teams and employment of long-term care coordinators, and at the end we present how different stakeholders in the field of long-term care were integrated in the pilot environments.

### Establishment of single entry points

In the Celje pilot environment, it was initially planned that the single entry point would be in the premises of the Health Insurance Institute of Slovenia, but because cooperation has not materialised, the single entry point was established in the premises of the leading partner - the Celje Health Care Centre. In the Dravograd pilot environment, the single entry point was established at the Ravne na Koroškem Health Care Centre and not at the premises of the leading partner in the project, i.e. the Koroška Care Home. It was established at the Ravne na Koroškem Health Care Centre with the aim of continuing with the construction of a long-term care centre after the completion of the project in Ravne na Koroškem. The leading partner in the project later estimated that it would be better to place the single entry point in a unit of the Koroška Care Home in Slovenj Gradec, as it faced organisational problems due to the locations (care providers, long-term care coordinators and the single entry point) being dispersed. In the Krško pilot environment, the single entry point was established as part of the Krško unit of the Posavje Centre for Social Work, which was the leading partner of the project, although not in the same location as the centre for social work, but in new premises in its immediate vicinity. The single entry points were therefore not placed in the existing infrastructure, as was done in Celje and Dravograd, but the premises for the project were completely refurbished and adapted.

In Krško, the single entry point was established a few months later than in the other two environments (Dravograd in October 2018 and Celje in November 2018), in early March 2019, as the new premises were approved for use only in February 2019. The structural indicator that was monitored as part of the evaluation determined, as a criterion for fulfilling the indicator, that single entry points should be established by 1 February

<sup>23</sup> Prior to the start of the pilot activities, the Ministry of Health trained a team of expert assessors to serve as support to the newly employed assessors in the pilot projects.

2019, which means that, if the official opening of single entry points is taken into account, the criteria were met by the Celje and Dravograd pilot environments, while the criteria of the indicator was not met in Krško. It should be taken into account that applications were accepted, and eligibility assessments were performed in Krško even before the opening of the single entry point in the new premises, so the process of inclusion of applicants in the project was not delayed for this reason. As in Celje and Dravograd, applications were accepted as early as at the end of 2018.

Based on the experience of the project, the participants in the democratic forum agreed at the end of the project that it is important for a single entry point to be established as part of the same type of organisation throughout Slovenia. This will ensure that people, regardless of where in Slovenia they will need care or information on care, will know where the single entry point is located. However, the participants in the democratic forum did not identify one type of organisation that would be the most appropriate in which to establish a single entry point. They thought that it could be established either in the municipality, at the regional unit of the Health Insurance Institute of Slovenia or at a new location, independent of other organisations. The participants agreed that a single entry point should be as independent as possible from long-term care providers, i.e. autonomous, although it should be noted that single entry points in the pilot environments were not completely separate from the implementation team, as assessors and care providers in Celje and Krško were situated at the same location, and they also had joint meetings. The employees in the project also noted the positive side of the cooperation between the assessors and providers, as they also benefited from the mutual exchange of information in certain situations.

The course of employment and the provision of the estimated number of assessors at the single entry points varied considerably between the environments during the project. While there were no such problems in Krško, there were such

problems in Dravograd, and they were especially pronounced in Celje. In the Krško and Celje pilot environments, all four different profiles of assessors as envisaged in the public call for applications (graduate social worker, registered nurse, graduate occupational therapist and graduate physiotherapist) were employed, while in Dravograd, a graduate occupational therapist and a graduate physiotherapist were not employed, despite efforts being made, as such staff did not apply for the job vacancy.

In Krško and Dravograd, an appropriate number of assessors were employed by 1 February 2019 and thus the criterion of the structural indicator was met. All assessors were employed in these two environments for the entire duration of the project. In Celje, the challenges in ensuring an adequate number of assessors were significant and lasted throughout the project. Despite the fact that there was a great need for assessors in the environment, the plan to employ seven assessors as envisaged in the public call for applications by 1 February did not materialise. There were seven employed assessors in the environment only in the periods from 1 August 2019 to 30 November 2019 and from 8 February 2020 to 31 August 2020, which means that for most of the duration of the project there were not enough assessors, and the criteria of the structural indicator were not met. Contributing to this were the challenges in employing an adequate number of assessors, while five assessors left their jobs during the project.

## Employing a long-term care coordinator and establishing an integrated care team

The central profile in integrated care is the long-term care coordinator, for whom it was envisaged in the call for applications that they will, among other things, coordinate the care team, the newly established single entry point and informal carers, including organised volunteers (JR 2018) (more in the chapter *Personal planning and*

Table 1: Employees in the integrated care team on 1 February 2019

|                               |                                 | Celje       | Krško       | Dravograd   |
|-------------------------------|---------------------------------|-------------|-------------|-------------|
| Single entry point            | Graduate social worker          | 3           | 1           | 1           |
|                               | Graduate physiotherapist        | 1           | 1           | 0           |
|                               | Graduate occupational therapist | 0           | 1           | 0           |
|                               | Registered nurse                | 0           | 1           | 3           |
|                               | <b>Total</b>                    | <b>4/7*</b> | <b>4/4*</b> | <b>4/4*</b> |
| Long-term care coordinator    | Graduate social worker          | 0           | 1           | 0,5         |
|                               | Registered nurse                | 1           | 0           | 0,5         |
|                               | <b>Total</b>                    | <b>1/1*</b> | <b>1/1*</b> | <b>1/1*</b> |
| Care team                     | Social carer                    | 2           | 0           | 3           |
|                               | Nursing carer                   | 1           | 0           | 0           |
|                               | Nurse assistant                 | 3           | 4           | 4           |
|                               | <b>Total</b>                    | <b>6/9*</b> | <b>4/7*</b> | <b>7/7*</b> |
| Independence maintenance team | Graduate occupational therapist | 1           | 1           | 1           |
|                               | Graduate physiotherapist        | 1           | 1           | 1           |
|                               | Graduate social worker          | 0           | 1           | 2           |
|                               | Master of kinesiology           | 0           | 1           | 0           |
|                               | <b>Total</b>                    | <b>2/6*</b> | <b>4/4*</b> | <b>4/4*</b> |

\* number of jobs envisaged in the public call for applications

*coordination in long-term care: identifying needs and planning care together with the user).*

In the pilot environments, one post was planned for this work. In the Dravograd pilot environment, two people were employed for this purpose, both of them part-time: a graduate social worker and a registered nurse. A graduate social worker was employed at the Koroška Care Home, while a graduate social worker was employed at the Slovenj Gradec General Hospital. Both long-term care coordinators performed their job from the beginning to the end of the project.

In the Celje pilot environment, three long-term care coordinators were replaced during the project; all of them were full-time employees. The first of these, who had a master's degree in nursing care, was in the post from 1 October 2018 to 31 March 2019, the second, a social worker, worked from 15 March 2019 to 31 December 2019, while the third, also a social worker, worked from 1 January 2020 onwards.

In the Krško pilot environment, a social worker was employed as a long-term care coordinator at the beginning of the project, but stopped working on 30 November 2019. The environment was without a long-term care coordinator until 21 May 2020, and their duties were performed by a graduate social worker, who otherwise performed the work of an assessor at a single entry point, and who also met the requirements for the post of a long-term care coordinator. On 21 May 2020, a new social worker was hired in the post of a long-term care coordinator, who worked until the end of the project.

The structural indicator criterion envisaged that at least one qualified long-term care coordinator will be employed in each pilot environment by 1 February 2019. The long-term care coordinator had to hold a valid licence for independent provision of nursing care or have the education level of a graduate social worker with a professional examination and have at least three years of work experience in the field of healthcare or social care and additional knowledge in the

field of organisation. A long-term care coordinator was employed in all pilot environments by 1 February 2019, which means that the indicator has been fulfilled.

In order to provide long-term care services in the project, an integrated long-term care team was established in each environment, consisting of a care team and an independence maintenance team. As in the employment of assessors, there were significant challenges in the Celje project environment in regard to ensuring staff in these two teams, and there were also some problems in ensuring adequate staff in the Dravograd pilot environment, while in Krško there were no major challenges in the employment of an integrated team for long-term care. In Krško, the staff structure was adjusted from the very beginning, and the care team did not employ the entire staff as envisaged in the public tender. Four nurse assistants were employed, while a nursing carer position and a social worker position were not filled. It was noted already in the application for the public call for applications that only four instead of seven professional workers will be employed, as home help had already been well developed in the environment and there was a sufficient number of social carers (25). Later, in November 2019 and in February 2020, an additional two nurse assistants were employed because a need for this emerged and in order to prevent a waiting list from being created. The independence maintenance team employed four professional workers, specifically a graduate occupational therapist, a graduate physiotherapist, a graduate social worker and a master of kinesiology. All worked in both teams until the end of the project.

In Dravograd, the care team employed seven professional workers, as envisaged in the public call for applications, but despite efforts being made, it was not possible to employ a nursing carer, as none applied for the job vacancies. During the project, a total of nine professional workers were employed in the team, specifically seven nurse assistants and two social carers. One

registered nurse changed jobs and continued to work as an assessor at a single entry point, while three nurse assistants stopped working on the project, which left five professional workers on the team in the environment in the last months of the implementation of the project, instead of seven. A total of six professional workers were employed in the independence maintenance team, specifically three graduate social workers, two graduate physiotherapists and one graduate occupational therapist. Two employees in the team stopped working on the project during its implementation. A master of kinesiology was not employed despite efforts being made, as no one applied for the job vacancy.

In the Celje pilot environment, there were significant challenges in ensuring an adequate number of professional workers in the integrated care team. The number of employees in the care team envisaged in the call for applications was reached only in April 2019. Due to the perceived need for care, the care team was increased to 11 employees in May 2019 (the call for applications envisaged nine). The goal was to employ 12 of them in the environment, and to employ relatively fewer professional workers (than envisaged in the public call for applications) in the independence maintenance team (three instead of six). The higher number of employees in the care team than was envisaged in the public call for applications was maintained until July 2020, after which the team was reduced to nine professional workers in accordance with the instructions of the contracting authority of the project. During the project, a total of 19 professional workers were employed in the team, specifically nine social carers, six nurse assistants and four nursing carers. Ten employees in the team (four social carers, three nursing carers and three nurse assistants) stopped working on the project during its implementation. The envisaged number of employees in the independence maintenance team was reached in the environment only in May 2020. A total of nine professional workers were employed in the independence maintenance team during the

project, specifically six graduate physiotherapists, two masters of kinesiology and one graduate occupational therapist. Three employees in the team (one master of kinesiology, one graduate physiotherapist and one graduate occupational therapist) stopped working on the project during its implementation.

The indicator criterion envisaged that one integrated care team consisting of precisely prescribed qualified professional profiles will be established in each pilot environment by 1 February 2019. The indicator was not met in any of the environments. In Krško, all the planned profiles and the appropriate number of professional workers were employed in the independence maintenance unit, while four instead of seven professionals were employed in the care team by 1 February 2019. In the Dravograd pilot environment, an adequate number of professional workers were employed both in the independence maintenance team and in the care team, although the latter did not employ a nursing carer, who was envisaged as mandatory staff in the team. In the Celje pilot environment, an appropriate number of professional workers were not employed either in the independence maintenance team or in the care team by 1 February 2019, and both teams combined had eight employees instead of the envisaged fifteen.

## Networking and cooperation of stakeholders in the environment

An important element in providing integrated long-term care is networking and cooperation of various stakeholders in this field. It was envisaged in the project that, in addition to the project applicant (leading partner), other long-term care providers in the local environment would be included in the consortium in an individual pilot environment as mandatory partners (home help providers, institutional care providers, health care centres, community nursing service providers in



the public network and the competent centre for social work). In addition, it was possible to involve other stakeholders in the field of long-term care in the environments as additional partners. As part of networking and cooperation between stakeholders, the project envisaged an introductory event at which all stakeholders in the environment would be acquainted with project activities, the establishment of a local project council and the creation of stakeholder cooperation protocols in the field of long-term care.

In the Celje pilot environment, the leading partner in the project was the Celje Health Care Centre, which provides community nursing, while also included in the consortium as mandatory partners were the Celje unit of the Celje Centre for Social Work, the Dom Sveti Jožef Celje Educational and Pastoral Centre and the Public Institute Socio. Another 14 partners participated in the pilot project. The leading partner in the Dravograd pilot environment was the Koroška Care Home, which also provides home help in the environment. Also included in the consortium as mandatory partners were the Ravne na Koroškem Health Care Centre, the Slovenj Gradec General Hospital, the Koroška Intergenerational Centre and the Ravne na Koroškem unit of the Koroška Centre for Social Work. In addition, another 28 stakeholders from the Mežica Valley, Dravograd and Slovenj Gradec were involved in the project. In the Krško pilot environment, the leading partner in the project was the Krško unit of the Posavje Centre for Social Work, which provides home help in the environment, while also included in the consortium as mandatory partners were the Municipality of Krško, Krško Health Care Centre, Brežice General Hospital, Krško Care Home and the Krško-Leskovec Special Social Care and Employment Centre. Another five partners participated in the pilot project.

In the Celje pilot environment, stakeholders in the field of long-term care were informed about all planned activities in the project in October 2018, in Dravograd in November 2018 and in Krško in September 2018. The Krško pilot environment is also the only environment that has met the

indicator criterion that all relevant stakeholders must be informed about all planned activities as part of the pilot project by 15 September 2018.

During the project, the leading partner in the Celje pilot environment had regular monthly meetings with the consortium partners, resulting in a total of 15 meetings. In the first months of the project until February 2019, four meetings of the consortium partners with the Ministry of Health also took place. Seven meetings of formal long-term care providers in the local community with representatives of the pilot project, three meetings of services in the field of care for older people at home in the environment, and two meetings of representatives of the pilot project with the community nursing were also held.

Nine meetings with the consortium partners were held in the Dravograd pilot environment during the project. Five meetings were held in the environment with representatives of the smart watch developer, and two with the e-care provider. Two meetings were held with home help providers and one each with the Paraplegics Association and the Credit Point Club. The pilot environment often cooperated with municipalities in the environment, especially in the preparation of training sessions for informal carers.

In the Krško pilot environment, many stakeholders in the environment had one meeting each with most of the support partners. They met twice with all project partners, and twice with all consortium partners. In addition to meetings, the environment was also often in contact with stakeholders by telephone, and also cooperated with them in organising various activities and implementing long-term care, which are listed in Table 2.

A local project council was established in all pilot environments, consisting of all partners involved in the project, and in the Krško pilot environment, 12 other stakeholders from the environment were included. The indicator criterion envisaged that local project councils would be established in the environments by 30 November 2018, which was achieved only



Table 2: Other forms of cooperation with stakeholders in the Krško pilot environment

| Stakeholder                                                     | Type or content of cooperation                                                                                                                                                                                                     |
|-----------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Various stakeholders</b>                                     | Regular cooperation in the creation of informative material with which potential users were informed about the services provided by individual stakeholders in the environment.                                                    |
| <b>Brežice General Hospital</b>                                 | Contacts were frequent in order to ensure safe discharge from the hospital, which was also defined in the protocol on cooperation.                                                                                                 |
| <b>Krško Care Home</b>                                          | Cooperation in the absence of informal carers - it temporarily took in users of long-term care services at home (in a limited number).                                                                                             |
| <b>Krško Health Care Centre</b>                                 | Cooperation with the community nursing took place on a daily basis. Occasionally, direct contact with their personal physicians was also needed for certain users.                                                                 |
| <b>Health Insurance Institute of Slovenia (HISS)</b>            | Together with the HISS, single entry point informed users about the rights that individuals have in the field of health or social insurance. An example of such cooperation is the leaflet entitled The Right to Assistive Devices |
| <b>Aristotel Health Centre</b>                                  | Cooperation was established with the centre's nurses and doctors as needed.                                                                                                                                                        |
| <b>Posavje Adult Mental Health Centre</b>                       | The pilot project represented a link between the Mental Health Centre and the Brežice General Hospital in regard to treatment of users.                                                                                            |
| <b>Pharmacies</b>                                               | Carers brought the necessary medications to the homes of some users.                                                                                                                                                               |
| <b>Sožitje Association</b>                                      | Organised a "Lifelong Camp", which was also attended by an employee of the care unit in the pilot project, who accompanied three people with intellectual disabilities at the camp.                                                |
| <b>Brežice Secondary School of Commerce and Economics</b>       | Together, these worked to open a department for the training of medical technicians. A joint visit to the Ministry of Education, Science and Sport was also planned.                                                               |
| <b>Brežice Health Care Centre: Health Promotion Centre:</b>     | Cooperation was established in the field of prevention in user healthcare.                                                                                                                                                         |
| <b>Tačke pomagačke Association</b>                              | The user was provided with assistance by means of therapy with dogs. The occupational therapist employed in the project also attended a 2-day professional training session entitled: Basics of Work with a Therapy Dog.           |
| <b>Posavski obzornik newspaper</b>                              | Informed the public about the activities of the project.                                                                                                                                                                           |
| <b>Sonček Posavje Association for Cerebral Palsy</b>            | Organisation of workshops in which a kinesiologist employed in the project also participated.                                                                                                                                      |
| <b>Krško-Leskovec Special Social Care and Employment Centre</b> | A kinesiologist performed exercises with protégés of the special social care and employment centre twice a week.                                                                                                                   |

Source: Data from the Krško pilot environment

in the Dravograd pilot environment, while the local project council in Krško was established in December 2018 and in Celje in February 2019. The local project council met twice in Celje, three times in Krško and four times in Dravograd. The Covid-19 epidemic affected the number of meetings, as no meeting took place in the Celje pilot environment in 2020, and only one meeting each was held in Dravograd and Krško. In Krško, this meeting took place online. The environments also noted that it was challenging to coordinate the dates of meetings with numerous stakeholders.

Protocols on the participation of stakeholders involved in the project were also developed in the environments. In the Celje pilot environment, a shorter protocol was developed in the second half of 2019 and in Dravograd at the beginning of 2020, which means that the indicator criteria had not been met, as it envisaged that the protocol would be developed by 1 February 2019. In the Krško pilot environment, the protocol was established as early as in October and November 2018, so the indicator was met.

At the end of the project, the stakeholders<sup>24</sup> of key importance for the field of long-term care in the pilot environments who responded to the questionnaire (39 stakeholders from all environments participated) agreed in the vast majority (92.6%) that, in order to provide long-term care, healthcare and social care services should be combined and coordinated. Fewer than half (43.6%) of the participating stakeholders agreed that the various organisations involved in the provision of long-term care are well connected. Less than a third (30.7%) of stakeholders also agreed that the transfer of information between different long-term care providers is effective. Responses of stakeholders indicate that they are aware that integrated and coordinated long-term care services are essential, while networking and cooperation between stakeholders in the existing system is not yet satisfactory.

## Discussion with key messages

For many years, Slovenia has been striving to regulate the field of long-term care in an integrated way and thus provide people with quality and accessible services. One of the important elements of how to ensure this is primarily to ensure a single entry or single entry points.

As regards the form of organisation as part of which it would be most appropriate to establish a single entry point, taking into account the experience of the project, it is not possible to determine what organisation is most suitable for this. It can be established either in the municipality, at the Health Insurance Institute of Slovenia (local unit), within another organisation (e.g. health care centre or centre for social work) or at a new location, independent of other organisations. While the long-term care bill (2021) envisages that single entry points will be established at the regional units of the Health Insurance Institute of Slovenia, this has not been tested in the pilot projects. If any of the environments managed to test a single entry point at a regional unit of the Health Insurance Institute of Slovenia, this would be an important contribution to testing the solutions provided for in the bill (2021). It is important that the single entry point is recognised in the environments and be accessible to potential users or applicants and their relatives, i.e. that it is not located too far from them, that free parking spots are provided in its vicinity and that it is also accessible to people who may have difficulties with access due to disability. The premises of the single entry point must be arranged in such a way as to ensure discretion in communication between assessors and the applicant, their relative or another person who visits the single entry point.

In the project, the single entry point was separated from the service providers in the Dravograd pilot environment, while the single entry points in Celje and Krško were located at

24 For more information about the questionnaire for stakeholders, see the chapter *Evaluation of pilot projects and methodology*.

the same location as the care providers. There were also many joint meetings, so in these environments the single entry points were not completely separate from the care providing team. The long-term care coordinator and the care team also faced certain challenges in the organisation of work in Dravograd, due to the single entry point being dislocated. Although it is important that the single entry point and the care providing team are separate and that the assessors do their work completely autonomously, positive aspects of cooperation between all employees were perceived in the environments. Sharing of information about users proved to be useful, so they participated in some meetings.

The pilot environments faced various challenges in employing the envisaged number of staff, as for example they failed to employ certain profiles (e.g. in Dravograd) or faced a significant turnover of employees (e.g. in Celje). The challenges of employment in long-term care are not specific to this project alone. These challenges have been increasingly noted by long-term care providers at the national level, which is why problems in this field must be addressed strategically, on the one hand in terms of incentives to increase recruiting power, and on the other hand by reflecting on whether staff in Slovenia can be secured from the domestic labour force alone or if the labour force for this work will have to be imported. What also contributed to the challenges related to employment was the fact that it was employment on a project for a definite period. This problem is particularly pronounced in such projects towards the end of projects, when employees are looking for new jobs, while it is difficult to recruit new employees for this shorter period at the end of projects. Staff turnover is also a challenge from the aspect of appropriate training of employees, as it is necessary to continuously implement the training provided to employees at the beginning of the project throughout the project for all new employees who enter the project at different times.

With the aim of evaluating whether organisational forms of cooperation and

networking in the field of long-term care have developed in the environments, the project monitored how the pilot environments were more broadly connected with the local environment and key stakeholders and how they were included in the project. The leading organisations of the pilot projects were those that in the existing system of long-term care operate as part of healthcare or social care and provide various services – community nursing, institutional care and home help. All pilot environments had a health care centre, a care home and a centre for social work in the consortium, which is crucial from the point of view of providing integrated care, as it includes key organisations from both healthcare and social care. An event at which the project was presented to local stakeholders in the field of long-term care was held in all environments in the first months of the project. Local project councils were also established in all pilot environments, in which all project partners were involved; other stakeholders (12) were later involved in it at a later stage. Both the introductory events at which the project was presented to local stakeholders and the local project council were mostly organised or established later than envisaged in the indicators, which indicates that it takes more time than envisaged for cooperation between stakeholders to be established, i.e. at least a few months. There were not many meetings of local project councils, with one of the reasons for this being the Covid-19 epidemic, as meetings in person were not possible most of the time in 2020, and decisions to adopt virtual ones were not made except in Krško. From the aspect of overcoming the difficulties of involving a large number of participants in meetings, the use of technology should also be considered, as this proved to be an effective mechanism for cooperation in certain cases during the Covid-19 epidemic.

The purpose of local project councils in the environment was mainly to acquaint all partners with the activities in the project, and it was noted in Krško that the purpose of the

local project council was to coordinate and determine professional guidelines for long-term care development strategy at the local level, which probably also contributed to the project activities being partially maintained even after the end of the project. Regular communication and cooperation in the pilot environments of Celje and Dravograd took place mainly with obligatory partners, while in Krško a broad range of other stakeholders from various fields were involved in various activities, although fewer stakeholders than in other environments were involved in the project. Protocols on the participation of all stakeholders in a pilot environment were established in the pilot environments. In Krško in particular, protocols were recognised as an important element in the organisation and implementation of long-term care, while little

attention was paid to protocols in the other two environments.

As part of the project, stakeholders were connected into consortia and partnerships, and they also created local project councils and cooperation protocols; however, at the end of the project, in a survey involving not only partners included in the project, they nevertheless assessed that stakeholder participation in the environment is not yet at the appropriate level. This means that efforts should be made to improve stakeholder cooperation that has also been established within projects. This is also an indicator that probably reaffirms at a broader level in the country that coordination between services providing long-term care services is not good in Slovenia and that a considerable amount of attention should be paid to this in light of the transition to more integrated care.

## BIBLIOGRAPHY

- Črnak Meglič, A., Drole, J., Kobal Tomc, B., Koprivnikar, B., Lebar, L., Nagode, M., Peternelj, A., ... Toth, M. (2014). *Podpora samostojnemu bivanju v domačem okolju in dolgotrajne oskrbe*. Analitsko poročilo DP5 projekta AHA.SI. Retrieved from [http://www.staranje.si/files/upload/images/aha.si\\_dolgotrajna\\_oskrba\\_porocilo\\_vl.pdf](http://www.staranje.si/files/upload/images/aha.si_dolgotrajna_oskrba_porocilo_vl.pdf)
- Dominkuš, D., & Peternelj, A. (2006). *Dolgotrajna oskrba v Sloveniji, Seminar ob pripravi Nacionalnega poročila o strategijah za socialno zaščito in socialno vključevanje 2006 – 2008*. Ministrstvo za delo, družino in enake možnosti.
- Dominkuš, D., Zver, E., Trbanc M., & Nagode, M. (2014). *Long-term care – the problem of sustainable financing. Host country paper*. Peer review on financing of long term care. Ljubljana, 18-19 November 2014.
- Džananič Zavrl, D. (2021). *Patronažno zdravstveno varstvo Slovenije*. Zaposleni in analiza opravljenega dela. Letna publikacija, 2020/2019. Ljubljana: Nacionalni inštitut za javno zdravje. Retrieved from [https://www.nijz.si/sites/www.nijz.si/files/uploaded/podatki/podatkovne\\_zbirke\\_raziskave/patronaza\\_patronazno\\_zdravstveno\\_varstvo\\_slovenije\\_2020.pdf](https://www.nijz.si/sites/www.nijz.si/files/uploaded/podatki/podatkovne_zbirke_raziskave/patronaza_patronazno_zdravstveno_varstvo_slovenije_2020.pdf)
- Flaker, V., Nagode, M., Rafaelič, A., & Udovič N. (2011). *Nastajanje dolgotrajne oskrbe: Ljudje in procesi – eksperiment in sistem*. Ljubljana: Fakulteta za socialno delo.
- Flaker, V., Cigoj-Kuzma, N., Grebenc, V., Kodele, T., Kranjc, B., Pirnat, T., ... Žnidarec Demšar, S. (2007). *Krepitev moči v teoriji in praksi*. Ljubljana: Fakulteta za socialno delo
- Goodwin, N., Sonola, L., Thiel, V., & Kodner, D. (2013). *Co-ordinated care for people with complex chronic conditions. Key lessons and markers for success*. The King's Fund 11–13 Cavendish Square London W1G 0AN.
- Kovač, N., Orehek, Š., in Černič, M. (2020). *Analiza izvajanja pomoči na domu v letu 2019, končno poročilo*. Ljubljana: Inštitut RS za socialno varstvo. Retrieved from: [https://www.irssv.si/upload2/Analiza%20izvajanja%20PND%20za%20leta%202019\\_30.9.2020\\_pop2.pdf](https://www.irssv.si/upload2/Analiza%20izvajanja%20PND%20za%20leta%202019_30.9.2020_pop2.pdf)
- Lebar, L., Dremelj, P., Flaker, V., Rode, N., Mali, J., Peternelj, A., Smolej Jež, S., ... Kobal Tomc, B. (2017). *Priprava podlag za izvedbo pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi*. Aktivnost 1: Priprava orodij za ugotavljanje potreb uporabnikov, metodika postopka ter ugotavljanje upravičenosti do storitev dolgotrajne oskrbe. Ljubljana: Inštitut RS za socialno varstvo.
- Ministrstvo za delo, družino socialne zadeve in enake možnosti. (2008). *Nacionalno poročilo o strategijah socialne zaščite in socialnega vključevanja za obdobje 2008-2010*.
- Ministrstvo za zdravje. (2018). Javni razpis »Izvedba pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi«. Retrieved from <https://www.uradni-list.si/glasilo-uradni-list-rs/vsebina/2018002400003/javni-razpis-za-izbor-operacij-izvedba-pilotnih-projektov-ki-bodo-podpirali-prehod-v-izvajanje-sistemskega-zakona-o-dolgotrajni-oskrbi-st-303-1201816-ob-198618>
- Nagode, M., Zver, E., Marn, S., Jacovič, A., & Dominkuš, D. (2014). *Dolgotrajna oskrba – uporaba mednarodne definicije v Sloveniji*. Urad RS za makroekonomske analize in razvoj. Retrieved from [https://www.umar.gov.si/fileadmin/user\\_upload/publikacije/dz/2014/DZ\\_02\\_14.pdf](https://www.umar.gov.si/fileadmin/user_upload/publikacije/dz/2014/DZ_02_14.pdf)
- Nagode, M., Kovač, N., Lebar, L., & Rafaelič, A. (2019). *Razvoj socialne oskrbe na domu: od besed k dejanjem*. Ljubljana: Fakulteta za socialno delo.
- Pan, G. P. (1995). *Long-term care: A single entry point for three populations*. Retrieved from [https://lrp.hawaii.gov/wp-content/uploads/1995\\_LongTermCare.pdf](https://lrp.hawaii.gov/wp-content/uploads/1995_LongTermCare.pdf)
- Smolej, Jež, S., Nagode, M., Jacovič, A., & Dominkuš, D. (2016). *Analiza kadra v dolgotrajni oskrbi*. Ljubljana, Inštitut RS za socialno varstvo. Retrieved from [https://irssv.si/upload2/analiza\\_kadra\\_v\\_do.pdf](https://irssv.si/upload2/analiza_kadra_v_do.pdf)
- WHO. (2016). *Integrated care models: an overview*. Working document. Retrieved from [https://www.euro.who.int/\\_data/assets/pdf\\_file/0005/322475/Integrated-care-models-overview.pdf](https://www.euro.who.int/_data/assets/pdf_file/0005/322475/Integrated-care-models-overview.pdf)
- Vlada Republike Slovenije. (2021). Predlog Zakona o dolgotrajni oskrbi. Retrieved from [https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Dolgotrajna/ZDO\\_parafa.pdf](https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Dolgotrajna/ZDO_parafa.pdf)

**FROM APPLICATION TO SERVICE:  
EXPERIENCE OF PROCEDURES IN  
PILOT PROJECTS**

Magdalena Žakelj  
Social Protection Institute of the Republic of Slovenia

Mateja Nagode  
Social Protection Institute of the Republic of Slovenia

*FROM APPLICATION TO SERVICE:  
EXPERIENCE OF PROCEDURES IN  
PILOT PROJECTS*

## KEY MESSAGES

- ▶ We believe that the procedures as part of the implementation of the pilot project were appropriate and that the activities ran mostly undisrupted.
- ▶ Forms used in long-term care procedures should be as adapted as possible to the understanding and abilities of all groups of users of long-term care services (Braille, easy-to-read format, audio recording).
- ▶ Assessing eligibility at home is a practice that needs to be maintained and encouraged.
- ▶ What needs to be ensured in a future long-term care system is that waiting lists are generated as rarely as possible.
- ▶ Users should be acquainted with the complaint procedures and be provided with support in the event that they wish to lodge a complaint.

## Introduction

Today, long-term care in Slovenia is regulated within the framework of various regulations and is provided through several separate social security (protection) systems that are regulated by various laws. The methods for exercise of rights and provision of services thus do not follow the same criteria and are therefore diverse and inconsistent with each other. Systematic regulation of long-term care would ensure a uniform and comprehensive procedure for exercising rights in the field of long-term care, from submitting an application to inclusion in long-term care and receiving services. Coordination of procedures is recognised as one of twelve key components in the Scirocco Maturity Model for Integrated Care (Scirocco, 2021). In addition to the methods and provision of services, the uniform procedure is precisely what was tested by pilot environments as part of long-term care pilot projects. Coordination and unification of the numerous procedures is necessary if we want to ensure quality, safe and effective long-term care.

Procedures are a key element in establishing long-term care, in fact they are the framework that regulates long-term care, determines the access and right to care, methods for exercising this right and providing and monitoring long-term care. Procedures are important because they determine the framework within which the needs for long-term care are met and services are provided, and they are also important because they determine the manner in which individual parts of the procedure are implemented and in which care is provided. Therefore, it is not only important that a person receives care, it is also important how, when and in what way they receive it. In this regard, both general rights and long-term care rights, as set out in national and international guidelines, must be respected in long-term care procedures.

The European Quality Framework for long-term care services (2012) clearly stipulates that quality long-term care must respect human rights and dignity, be individual-centred, preventive and rehabilitative, available, accessible, affordable,

comprehensive, integrated and continuous, outcome oriented and evidence based, and transparent, while being gender and culture sensitive. The Charter of Fundamental Rights of the European Union (2010) recognises and respects the right to live in dignity and independence and to be included in social and cultural life. It is therefore necessary to ensure that people in need of care receive support and assistance in a way that preserves their dignity and prevents their abuse - so all of this is the subject of the procedure.

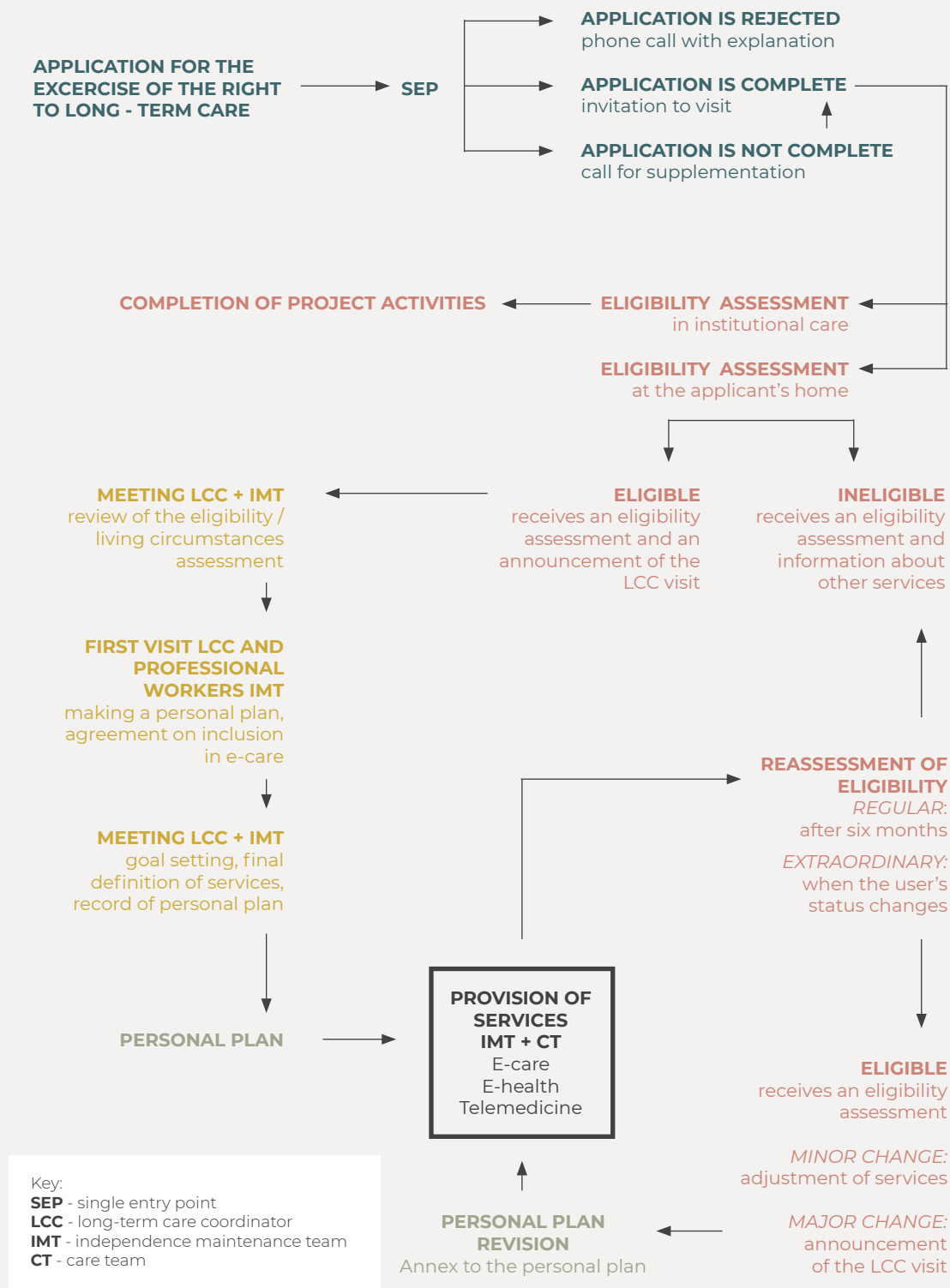
The process must, to the greatest possible extent, enable people to become active, to be provided a basis for achieving their goals and become subjects and contractual partners in long-term care processes. In establishing the procedure, old patterns of behaviour that make people passive, objectify them, blame them for their condition and discredit them as contractual individuals, thus excluding them from decision-making, should be avoided (Lebar et al., 2017; Flaker, 2017).

When creating the procedure, it is important to clearly define and coordinate all individual parts of the procedure: submission of an application for the right to services and other rights as part of long-term care, determining eligibility, procedures for defining assistance and support and, consequently, services to be received, and procedures that determine the provision of long-term care itself. Included in these main parts of the procedure are various actions and procedures that should contribute to the quality provision of services and thus user satisfaction, and through which the various mechanisms of the entire long-term care procedure could be measured and improved (Seys et al., 2019).

At the same time, the procedures should be conducted in such a way that the user understands them, can follow them and implement them, and so that they receive support if they need it. Throughout the process, from the first contact with the services to exiting the care system, the user must be at the centre of the planning and provision of care, and the task of the experts is to focus on respecting their rights for the entire duration of the process



Figure 1: Procedure for exercising long-term care rights in pilot projects



(European Network of National Human Rights Institutions, 2017).

This article describes the course of the entire procedure of the exercise and use of long-term care rights, which was tested in pilot projects, with a greater emphasis being placed on the main parts of the procedure as part of pilot projects (exercising the right, assessing eligibility, personal planning and coordination of long-term care, provision of services, e-care and e-health, waiting lists and complaint channels). Certainly, in the pilot environments, the various details of the procedure were also implemented in ways that we will not be able to cover in this article - on the one hand due to limited space, and on the other due to the lack of accurate data, as we were unable to delve into obtaining such data due to the large scale of the entire evaluation.

## Methodology

The objective of the evaluation was to evaluate both the procedure for assessing eligibility for long-term care and the entire long-term care procedure, from the submission of the application to the provision of services. With the evaluation, we wanted to evaluate whether the procedure tested in the pilot projects is suitable for the transition to the systematic implementation of long-term care. Two process indicators were also monitored at all times during the evaluation of the procedure:

- ▷ the proportion of persons assessed within three working days of the submission of the application, and
- ▷ the proportion of persons eligible for long-term care who met with the long-term care coordinator within three working days after the eligibility assessment was performed.

In order to evaluate both indicators, and in order to assess the duration of procedures in general, we used data from the information

system of the pilot environments for updated recording of data from the application, eligibility assessment, personal plan and monitoring of the implementation of the service. In order to obtain better insight and better understand the entire procedure, different types of information, data and documents were used. We systematically reviewed the entire documentation and forms related to the procedure provided by all three pilot environments and reviewed the minutes of 13 meetings between the contracting authority, pilot project coordinators and long-term care coordinators. Based on this documentation and discussions with the long-term care coordinators, a description of all phases of the procedure was prepared for each pilot environment separately, and the long-term care coordinators were asked to review, elaborate on and supplement the description. In addition, the evaluation of the procedure also took into account the opinions of employees, users and informal carers about the entire process and its individual phases. We reviewed employee reports on activities as part of the pilot projects, interviews with users and informal carers, interviews with long-term care coordinators and the minutes with the conclusions of the democratic forum of assessors. Univariate and bivariate statistical methods were used in the analysis of quantitative data from the information system, in which the days between individual parts of the procedure were calculated (for more detailed information about these measuring instruments and data, see Chapter *Evaluation of pilot projects and methodology*).

## Results

The pilot environments described the procedures for the promotion and implementation and the method of termination of the provision of long-term care as part of the pilot project in the protocol<sup>25</sup>. The draft protocol was prepared by

<sup>25</sup> Protocol on the promotion and implementation and the method of termination of the provision of long-term care service as part of the implementation of pilot projects that will support the transition to the implementation of the systemic law on long-term care (hereinafter referred to as: protocol).

Table 1: Number of working days from the submission of the application to the first visit by the assessor (left) and from the preparation of the first eligibility assessment to the first visit by the long-term care coordinator

| Working days       | Submission of the application - first visit by the assessor |       |       |           | First eligibility assessment – first visit by the long-term care coordinator |       |       |           |
|--------------------|-------------------------------------------------------------|-------|-------|-----------|------------------------------------------------------------------------------|-------|-------|-----------|
| Environment        | Total                                                       | Celje | Krško | Dravograd | Total                                                                        | Celje | Krško | Dravograd |
| N                  | 1887                                                        | 815   | 461   | 611       | 512                                                                          | 158   | 208   | 146       |
| Average            | 7.1                                                         | 4.2   | 1.8   | 14.9      | 24                                                                           | 41    | 11    | 23        |
| Median             | 2                                                           | 0     | 0     | 9         | 12                                                                           | 15    | 9     | 18        |
| Modus              | 0                                                           | 0     | 0     | 0         | 7                                                                            | 10    | 7     | 8         |
| Standard deviation | 13.7                                                        | 7     | 4.8   | 20.1      | 40                                                                           | 60    | 11    | 31        |
| Minimum            | 0                                                           | 0     | 0     | 0         | 0                                                                            | 0     | 0     | 0         |
| Maximum            | 250                                                         | 71    | 48    | 250       | 311                                                                          | 311   | 105   | 307       |
| First quarter (Q1) | 0                                                           | 0     | 0     | 4         | 7                                                                            | 8     | 5     | 8         |
| Third quarter (Q3) | 9                                                           | 7     | 1     | 20        | 25                                                                           | 44    | 14    | 29        |

the contracting authority of the pilot projects, and in agreement between the contracting authority, project coordinators and long-term care coordinators, it was supplemented and changed during the implementation of the pilot projects. The course of the entire procedure during the pilot projects is shown in Figure 1 and described in the remainder of this article.

## Exercising the right to long-term care

Eligible for long-term care services in the pilot projects were persons aged 18 or older who, due to the consequences of an illness, weakness related to old age, injury, disability, lack or loss of intellectual ability, were dependent on the assistance of other persons in activities of daily living and instrumental activities of daily living for a longer period of time, and not shorter than three months, and persons who were not included in personal assistance and who were classified in one of the five categories of eligibility for long-term care as part of the eligibility assessment (Ministrstvo za zdravje, 2018).

The key document in exercising the right to long-term care in pilot projects was the application<sup>26</sup> that interested persons could obtain in various ways: on the websites of leading pilot project organisations, from pensioners' associations, from home help providers and community nursing, from centres for social work and, above all, from the single entry point. Always enclosed with the application was the *Consent for the collection and processing of personal information* form, which was signed and submitted by the applicant together with the application.

At the request of the applicants, the assessors sent or brought the application to their home, and they were also able to complete and submit it at the single entry point. The pilot projects showed that the applicants mostly submitted

their applications in person or by mail directly to the single entry point. They were often assisted in completing the applications by home help employees or community nursing, who could deliver the application to the single entry point. It could be concluded from the interviews that the application procedure seemed easy enough for the users and their relatives, and that they received sufficient support from the employees in this part of the procedure.

The following outcomes were possible in processing the application: the application was complete, incomplete or rejected. The application was complete if it contained all the information required and the applicant met all the aforementioned criteria, which were a condition for the eligibility assessment to be performed. In the Dravograd pilot environment, all applications received were first discussed by the application team, except those for which the eligibility assessment had to be performed as soon as possible. After the team discussion, they were sent back to the single entry point, and the assessor then began the process of making an eligibility assessment. In the Celje and Krško pilot environments, applications were reviewed directly by the assessors and, in cases where these were complete, an appointment was agreed for the first eligibility assessment.

An application was incomplete if it did not contain all the required information, and in these cases the assessor called the applicant and obtained the missing information, or the application was taken to be supplemented by home help or community nursing employees. In many cases, the application was completed together with the applicant by the assessors themselves during the eligibility assessment visit.

There were very few cases where applications were rejected - only in Dravograd, where some applications were received from applicants from municipalities where the pilot project was not implemented, or the applicant

26 Application for exercising the right to long-term care as part of the project »Implementation of pilot projects that will support the transition to the implementation of the systemic law on long-term care« (hereinafter referred to as: application).

was already in possession of a decision on the right to personal assistance. In such cases, the applicant was called by the assessor, the reasons for the rejection were explained and other options for services that could be used were suggested.

## Eligibility assessment

After the application was received, the applicant and their carer or relative were visited by an assessor, who initiated the eligibility assessment procedure. A visit by the assessors should take place as soon as possible, and practice has shown that half of the applicants were visited by the assessor on the second working day after receiving the application ( $Me=2$ ) (Table 1). In the Celje and Krško pilot environments, half of the applicants were visited on the same working day ( $Me=0$ ), and in the Dravograd pilot environment within nine working days ( $Me=9$ ). Within three working days, which was the criterion followed in the evaluation, 51.9% of applicants were assessed in pilot projects: most of them in Krško (79.9%), followed by Celje (58.5%), the least in Dravograd (20.6%). The longer period in Dravograd is likely and mostly a consequence of the application processing team extending the application processing procedure by a few days.

The assessors made multiple visits within a short period of time to applicants from institutional care in order to make an eligibility assessment; to more than 60.0% as soon as the first working day, and only a quarter of applicants were visited at home ( $Q1=0$ ). The difference is statistically significant ( $U=308258$ ,  $p=0.000^{27}$ ). In Celje, about 90.0% of applicants from institutional care and about 10.0% of those living at home were visited on the same working day. The span is also relatively large in Krško (over 80.0% of visits on the same day in institutional care and just under 60.0% at home). This is attributed to the fact that the assessors took on many applications

in the care homes on the day of the eligibility assessment and both were dated on the same day. Meanwhile, in Dravograd, this span is the smallest and even reversed, as slightly less than a tenth of applicants from institutional care, and more than a tenth of applicants who lived at home were visited the same day. This balance is also a result of the work of the application processing team, which treated all applications received equally. In addition, for applicants in institutional care, assessors usually made eligibility assessments when there were not many applications from domestic environments in the single entry point.

The assessment of eligibility for long-term care had two possible outcomes: the applicant was either eligible for long-term care services or not eligible. They were informed about the results with the Eligibility Assessment form<sup>28</sup>, which, in addition to the eligibility category and other information, contained a description of the applicant's living circumstances. In Celje, in agreement with the contracting authority, this practice was terminated after a few complaints were received regarding the written content of living circumstances of applicants who were not eligible for services. In general, according to the long-term care coordinators, the assessors decided how much content regarding living circumstances to record at their own discretion, in particular when this included content to which the applicant could react negatively (e.g. excessive alcohol consumption, causes of violence, descriptions of the applicant or their living environment being unkempt, etc.). The assessors kept such statements separately, and they could be accessed by the long-term care coordinator and, if necessary, by others who worked with a specific user.

The applicant was not eligible for long-term care services if, on the basis of the eligibility assessment, they did not reach the threshold for inclusion in any of the five categories of long-term care eligibility. In such a case, the assessors in the Dravograd pilot environment usually revisited the

27 Due to the large dispersion of data, non-parametric bivariate tests were used to calculate statistically significant differences.

28 Assessment of eligibility for long-term care as part of the project »Implementation of pilot projects that will support the transition to the implementation of the systemic law on long-term care« (hereinafter referred to as: eligibility assessment).

applicant at home, handed them a letter with an eligibility assessment and forms for regulating the rights under existing regulations or documents with information on what kind of assistance, depending on their needs, they can turn to in the local environment. In such cases in the Krško pilot environment, the assessors sent a letter to the applicants with an eligibility assessment and a copy of the signed Consent for the collection and processing of personal data form. The letter was accompanied by leaflets with information about other services and services for which it was assessed, based on an interview with the applicant during the assessment, were of potential benefit to them. In the Celje pilot environment, the ineligible applicants were sent a letter with an eligibility assessment at the beginning of the project, and later only a letter informing them of their ineligibility and listing the organisations they can still turn to for help.

An applicant was entitled to long-term care services if they were placed in one of the five eligibility categories. The assessors sent the eligibility assessment to the long-term care coordinator, and a letter with the eligibility assessment to the applicants; in Krško this included a photocopy of the Consent for the collection and processing of personal data form, and in Celje they were sent, in addition to the eligibility assessment, a letter informing them of their inclusion on a waiting list once a waiting list was compiled, and they were also informed about the possibility of being included in e-care services and presented with a list of organisations they can still turn to for help. Resulting from the Dravograd pilot environment, cases were cited in which the beneficiaries did not want to receive services immediately after the assessment, as they submitted applications “as a reserve”. Some joined later, and some did not do so at all.

Applicants from institutional care did not receive the forms with the final eligibility

assessment directly, but the employees filed them in their personal files in the institutions where they lived or also in the file in the single entry point. For them, their involvement in the pilot project ended here<sup>29</sup>.

After they acquired the right to long-term care services, those who resided at home were re-assessed at regular, six-month intervals (regular assessment) or in the case of a change in the ability of self-care due to, for example, improvement or deterioration of the health or functional condition of the user, immediately after the change occurred, i.e. before the expiration of six months (extraordinary assessment). The change was communicated to the long-term care coordinator either by the service providers or by the user themselves or their relatives, and the long-term care coordinator further communicated it to the assessors in the single entry point.

When the user's condition improved and they were no longer entitled to long-term care services after a repeated, regular or extraordinary assessment, the assessor informed them of the outcome as in the first assessment. At the same time, they also informed the long-term care coordinator, who closed the user file. In the event that the user continued to be eligible for long-term care services, the assessor also informed them in the same way as in the first eligibility assessment. The provision of services continued, and the scope of services was adjusted to the increased/decreased needs. The long-term care coordinator was also informed about everything.

In the interviews, users expressed different opinions about the assessment procedure, and an analysis of the interviews shows that users were generally aware of the procedure: they said how many assessments they had and who conducted them, how long the interview lasted and what the outcome was of the assessment. On the other hand, some users were not able to say anything

<sup>29</sup> The participation of users of institutional care services was limited to the preparation of the eligibility assessment, as the purpose was to test the assessment tool and categorisation, which otherwise had no effect on their eligibility for institutional care services under current regulations.

about the assessment and did not remember this part of the procedure, or did not name it as such. After conducting the eligibility assessment with the applicant, in cases in which the assessors did not receive enough information from them, they also turned to the present relatives or informal carers.

Assessors and other staff in the pilot projects were generally of the opinion that the eligibility assessment procedure was designed in a way that allows them to obtain sufficient information on the applicant's condition relevant to long-term care planning.

## Personal planning and coordination of long-term care

After receiving the eligibility assessment, the long-term care coordinator agreed on the date of the first home visit with the beneficiary by telephone. The purpose of this visit was mainly to discuss the needs of the beneficiary, to obtain information for the preparation of the personal plan<sup>30</sup> and to agree on the implementation plan as part of the personal plan. Usually, the long-term care coordinators dedicated one visit to this, rarely more, as they were instructed by the contracting authority to obtain information for the personal plan in one visit.

In the first visit, the long-term care coordinator informed the beneficiary about the manner in which services are provided and the provisions of the protocol. If the beneficiary decided to use e-care and e-health services, they were given all the forms related to the inclusion to be signed and informed about further procedures related to these services.

In cases where the personal plan provided for the implementation of the "monitoring of prescribed therapy" service or the "measuring of vital functions" service, or when the beneficiary's health condition was of more complex nature,

it was necessary to obtain an opinion of the personal physician at this stage of the procedure<sup>31</sup>. In all three pilot environments, personal physicians were asked to provide such opinions by the long-term care coordinators themselves.

In cases where this was absolutely necessary (discharge from hospital, sudden change in the provision of services by other providers in the local environment), long-term care coordinators ensured that the provision of services began immediately, before the personal plan was finalised.

On average, the long-term care coordinator visited the beneficiary within 24 working days after making the eligibility assessment, with individual cases ranging from the same day to over 311 working days (Table 1). Most visits were made within seven days ( $M_0=7$ ), and half of them were made within 12 days ( $Me=12$ ). There are statistically significant differences between the pilot environments ( $K-W=8.199$ ,  $p=0.0177$ ): in Krško, the long-term care coordinator visited half of the beneficiaries within nine working days ( $Me=9$ ), in Celje within 15 ( $Me=15$ ) and in Dravograd within 18 days ( $Me=18$ ). We find that 11.7% of the beneficiaries met with the long-term care coordinator within three working days after the eligibility assessment: 13.9% in Krško, 11.0% in Dravograd and 9.5% in Celje.

According to the long-term care coordinators, various activities (e.g. telephone conversations, home visits) had already taken place with the beneficiary after the eligibility assessment, although they could not be recorded in the information system because the user was not yet active in terms of receiving services, or they could not be recorded because employees did not have this option in the selection of services or in the code list. In some cases, these services were not entered retroactively after the information system was established and upgraded, so there may be a discrepancy between the data from the

<sup>30</sup> Personal plan for the provision of long-term care as part of the pilot activities »Implementation of pilot projects that will support the transition to the implementation of the systemic law on long-term care« (hereinafter referred to as: personal plan).

<sup>31</sup> Opinion of the personal physician or treating specialist on the relevant health condition of the insured person (hereinafter referred to as: opinion of the personal physician).

information system and the actual situation in the pilot environments. The large gap in the number of days between the eligibility assessment and the visit by the long-term care coordinator was mainly due to the fact that, as already mentioned, applicants also submitted applications “as a reserve”, just in case they happen to need services in the future, while they currently have support ensured by relatives and/or informal carers. Some simply changed their minds after the assessment and did not yet want to receive services.

The personal plan was signed by the long-term care coordinator and the beneficiary, with each keeping their own copy. By doing so, they confirmed that they had been acquainted with and that they agreed with the content and would take their share of responsibility, while and at the same time the signing of the personal plan formed the basis for the start of the provision of services.

If the eligibility category was changed after the re-assessment and it transpired that a major change in the scope of services was needed, the long-term care coordinator prepared an annex to the personal plan<sup>32</sup> in which they recorded the change, new goals and services to achieve the goals. In these cases, they visited the user, and in cases of minor changes in the scope of services, they only informed the user about them by phone. When the annex to the personal plan was made, the user received two copies to sign and kept one for their personal records.

The long-term care coordinator visited the user for the first time to create a personal plan. In Dravograd and Krško they were usually joined by an employee from the maintenance independence unit, who also discussed the user's needs and goals from their point of view. Later, on the first visit at the beginning of the provision of services, the long-term care coordinator accompanied the employee from the care unit, introduced them and gave the user a personal plan to sign. After that, they visited the users in cases when the personal plan was revised, if there were problems

with the provision of services or in other cases when personal intervention of the long-term care coordinator was necessary (for example, intervention in a certain case where, despite growing problems due to dementia and the risk brought about by their health condition, the user still wanted to continue driving their car and disregarded warnings from their carer).

In order to have the personal plan signed, the pilot environments resorted to other practices in addition to the above-mentioned: the first employee who visited the user gave them the personal plan to sign it, or the personal plan was sent by mail, and the employees who provided services brought it back signed.

Otherwise, the long-term care coordinator communicated with the user or their relatives by telephone, most often in cases of a change (temporary or permanent) in the provision of services, which is also stated by users in interviews: *“She also keeps me informed of when she's coming”, “Yes, she calls if there is any change. For instance, if someone who visits, say a physiotherapist, goes on an annual leave. She comes on Thursdays, for instance, and if she couldn't, then she would come on a specific day, if I agree”*. The long-term care coordinator kept the schedule of the provision of service for the care unit, and the employees of the independence maintenance unit agreed themselves on the dates of the visits with the users.

## Provision of long-term care services

Long-term care services started to be implemented immediately after the personal plan was signed. Long-term care coordinators from all three environments said that they tried to organise the provision of long-term care services in such a way that as few different people as possible would come to the users' homes.

<sup>32</sup> Annex to the personal plan for the provision of long-term care as part of the pilot activities *»Implementation of pilot projects that will support the transition to the implementation of the systemic law on long-term care«* (hereinafter referred to as: annex),



Employees and deadlines for the provision of services were changed mainly during annual leaves and sick leaves. In these cases, users were notified of the changes in advance.

The services provided were initially recorded by the service providers manually in the service log, and later via a mobile app and an NFC tag. What some relatives missed was real-time insight into the content of the services provided: *“I would like, for example, when the girls come, that they have a notebook like they have in care homes, where they would write down what they have done, because we are at work and when we come home, the parents are not really sure and they are not able to tell what has been done”*.

As for the complete procedure, almost all interviewed users and informal carers assess that the procedure from the submission of the application to the moment when the service started to be provided was fast enough (*“For me it was fast, they came really fast to assess me, and all, and then you get a decision and a provider came just like that.”*) and, what is more, most users stated that they did not deal with excessive paperwork as part of the procedure. The assessors at the democratic forum agreed that the entire procedure that they followed in the pilot projects is suitable for transfer to other environments or for a systemic solution.

## E-care and e-health

Beneficiaries of long-term care were also able to enjoy various forms of assistive technologies, which differed slightly between environments (more about this in Chapter *Perception of the use of assistive technologies*). They were primarily informed about these options by the assessors.

The Dravograd and Krško pilot environments assisted those interested in all steps, from the submission of the application for inclusion to signing a contract with the provider. If necessary, an employee from the pilot project was present

when the support service equipment was being installed. At the end, if necessary, they also arranged for the equipment to be returned to the provider. In Dravograd, everything necessary related to e-health was arranged by a coordinator of long-term care with working position placed in a hospital, while a doctor from the Slovenj Gradec General Hospital also informed the users about the options for inclusion.

In Celje, beneficiaries from the waiting list who expressed the wish to be included in support services were sent an application for inclusion. The beneficiaries completed the application and sent it to the single entry point, which in turn sent it to the service provider. From there onwards, the provider arranged everything directly with service users.

In Krško, 24-hour on-call duty service was provided for users who lived alone and did not have anyone to respond in the event of an emergency. It was carried out by an employee from the independence maintenance unit, who in the event of an emergency checked what had happened and reacted accordingly. Due to difficulties in providing financial resources for the implementation of the 24-hour duty service, this practice was discontinued after some time.

## Waiting list

How to act in the event that it is not possible to provide services to beneficiaries due to the limited capacity of the long-term care provider was defined in the protocol, which envisaged that the waiting list is kept by the long-term care coordinator who, in addition to the name and surname of the beneficiary, also keep the date of receipt of the assessment report for the exercise of long-term care rights. Later, the pilot environments agreed the following with the contracting authority: *“Beneficiaries are included in the project in the order in which their applications were submitted, and in the event of a different choice of inclusion (e.g.*

*inclusion of a person who only needs the services of the independence maintenance unit which are available), an official note is written.”*<sup>33</sup> In Celje, where the waiting list was kept, the latter instruction was considered. Some employees also pointed to the importance of the degree of urgency of the need for services when placing people on the waiting list: *“The priority aspect has not been taken into account. Those users who do not receive home help and have no other organised assistance should be treated as a priority”*. They argued that there were situations in which immediate assistance was unavoidable and that in such exceptional cases the criterion of urgency should be taken into account.

Otherwise, the pilot environment in Celje was the only pilot environment<sup>34</sup> that kept a waiting list practically for the entire duration of the project. The waiting list in Celje started to fill up as early as February 2019 and was kept until the end of the pilot project. The inclusion of a user from the waiting list in the provision of services was possible only with the departure or cessation of the provision of care to another user. Many people on the waiting list were thus left without project services as the project concluded. In part, the situation was resolved by providing only independence maintenance services, meaning that the user received only those services that could be provided as part of the project, and not all the services they needed.

The need to be included in the project in Celje was therefore significantly greater than the pilot project was able to satisfy with its resources. In addition to the disadvantage for beneficiaries, the waiting lists also caused distress to employees, especially assessors, who reported in employee reports that the waiting lists were one of the negative aspects of their work: *“The work of an assessor in the field is interesting, but at the same time difficult, especially when you are making an assessment with a person who urgently*

*needs assistance, and you have to tell them that unfortunately we cannot help them at the moment as there is a waiting list”*.

## Complaint procedure

Complaints or objections expressed by service users are an important part of the provision of services, with the right to object being provided to applicants, beneficiaries and users of the pilot project. The course of the objection was briefly defined in Article 20 of the protocol, which was used in Dravograd and Krško: *“In the event of unprofessional conduct of formal care providers, the user is acquainted with the official complaint channels under the applicable law”*. In Krško, added to the basic protocol was a protocol for the case of a complaint against the assessment of eligibility for long-term care services, where the complaint channel was described and the Appeal Note form was added. The option of complaint in the protocol that was prepared on the basis of the draft protocol of the contracting authority and which the evaluators received for inspection was not mentioned in Celje.

According to the information from the environments, we find that the long-term care coordinator acquainted the users with the content of the protocol during their first visit, while in none of the environments the users said that they were specifically acquainted with the option and method of complaint; in one of the environments they said the long-term care coordinator did not specifically explain to users the right to complain during their first visit. According to our data, the pilot environments did not present the option of complaint to users in any other way (for example: they did not receive the full or at least the draft protocol, the information about the option of complaint was not included in any other document, e.g. in the

<sup>33</sup> Meeting on 17 September 2019.

<sup>34</sup> In Krško, this was avoided with the employment of two additional healthcare technicians when there was an increase in the number of users.

eligibility assessment or personal plan). Thus, we did not receive information about what exactly, as far as the complaint procedure is concerned, the long-term care coordinators told the beneficiaries and whether they presented both internal and external complaint channels to them.

Upon our inquiry, the long-term care coordinators said they did not report on complaints from applicants or users received in the formal way defined in the protocol or in any other way. The contracting authority did not warn us of any complaints received during the evaluation, either.

Nevertheless, in reviewing the data, we detected cases of complaints and, consequently, measures being taken. For example, it was reported from the Dravograd pilot environment that they had received a letter from a lady who did not agree with being included in a specific category of eligibility for long-term care. The eligibility was re-assessed, with the same result. According to the statement by the user (possibly the same one) in the interview, it is evident that she complained twice and both times unsuccessfully: *“It came in writing that I was not eligible for the second category. It is important that I get at least something, even though I had thought I was entitled to the second one. I was waiting for their reply for one month. Then my daughter-in-law wrote to them again, but the request to put me in the second category was rejected again. I told them that I could not believe it. At first I kept persisting, but then I left it alone.”* We also noticed in the interviews that users may not have been aware that they have the option of complaint (*“No, no, you have nowhere to complain to”*).

As we already mentioned in the section on the assessment of eligibility for long-term care, the Celje pilot environment received complaints from some ineligible users about the content of the summary of living circumstances in the eligibility assessment.

We did not systematically cover the channels for objection and the option of complaint in the evaluation, while we noticed during various

activities, research instruments and conversations with users or their relatives that the option of complaint was not sufficiently explained to users and that, despite the pilot environments having received no formal complaints, they dealt with quite a few complaints received in other ways (telephone, through service providers), on the basis of which they took action. However, to our knowledge, these have not been systematically recorded in the pilot environments. What is more, the complaint channel was not defined in sufficient detail in the protocol to clearly present to users all the steps of the complaint procedure.

## Discussion with key messages

As part of the pilot activities, the pilot projects tested the entire long-term care procedure - from the submission of an application for exercising the right to long-term care to the use of long-term care services. The procedure was tentatively determined by the contracting authority through a public tender, and the pilot environments supplemented and upgraded it during the pilot activities. Such a procedure, which has been tested on such a comprehensive scale in Slovenia for the first time, also brings quite a few new features.

An important new feature is the transfer of a large part of activities from various organisations to the home of (potential) users. For example, the assessment of eligibility for long-term care in the pilot projects was mostly carried out at the applicant's homes. By doing so, the professionals came significantly closer to their living space, which is something that had not thus far been applied in the field of social and health care in Slovenia to such a large extent. The eligibility assessment at the applicant's home allowed the assessor to observe how the applicant functions in the environment where they felt the most comfortable. This is the practice that needs to be maintained and encouraged. The same

applies to personal planning, which also took place in the home environment as the centre of the user's daily life, and where professionals find it easiest to identify their needs together with them and find answers to these needs. The evaluation showed that it is important to transfer as much of the procedure as possible to the home environment, and also that the professionals are flexible in all parts of the procedure and that they adapt to the circumstances and needs of (potential) users (e.g. flexibility and assistance in completing and supplementing applications, assessing eligibility at home, at a single entry point, in an institution or elsewhere, and similar).

It was important for the evaluation to evaluate the time frame of the long-term care procedure, in particular the two key steps (speed of the creation of the eligibility assessment and the first visit of the long-term care coordinator); in doing so, we relied on two process indicators. The practice in Dravograd, where applications for eligibility assessments were initially processed twice a month by a team specially appointed for this purpose (it later held meetings if necessary), has shown that such an arrangement significantly prolongs this part of the procedure. Compared to Krško (79.9%) and Celje (58.5%), the lowest number of applicants was assessed within three days of reception of the application, which was the criterion of the first process indicator, in Dravograd (20.6%). Translating this practice to the system would not be effective, as it would prevent applicants from acquiring rights as soon as possible, while depriving assessors of autonomy in processing applications. The medium-sized proportion of assessments performed within three days of reception of the application in Celje is most likely due to the waiting list, as it was not possible to immediately include beneficiaries in services, so speeding up this part of the procedure was probably not such a priority. The experience of Krško is the one that is the most representative for planning the system procedure. This shows that assessors can make the vast majority of assessments within three days of reception of the application.

We monitored how quickly the pilot environments managed to secure the first visit of the long-term care coordinator after the eligibility assessment was carried out as part of the second process indicator. The indicator criterion envisaged three working days for this step, with the results showing that in this time span the coordinators of long-term care in all pilot environments visited only slightly more than a tenth of beneficiaries, the most in Krško and the least in Celje. The reasons for this result are attributed to various factors. The main one is that there were several assessors, and they were able to prepare several eligibility assessments at once, while there was one long-term care coordinator and, consequently, they were not able to carry out such a large number of visits in a comparable period of time. The second reason was related to the submission of applications "as a reserve", which was a practice that was also detected in the environments, so the visit of the long-term care coordinator also depended on the readiness and will of the beneficiaries. Not insignificant is the fact that the information system, in which the data on visits was recorded as the basis for our analysis, was still under development and was being upgraded during the project; in the part related to personal planning in particular it was upgraded quite late, so the coordinators of long-term care were not able to record all the data in the information system on time, nor did they necessarily enter and correct all of them retroactively.

From the point of view of the procedure, the results of the evaluation showed that it is important for the time span of personal plan preparation and related visits of the long-term care coordinator that the coordinator is flexible and adapted to the user's more or less complex needs and specific situations.

Although the article does not pay particular attention to the structure and content of the forms used by employees in their work in the pilot projects, we must emphasise that it is important that these be made easier and not

more difficult for them to edit, monitor and store data; it is therefore necessary to computerise data management, transparency and optimisation of the quantity of data collected at the highest possible level. One piece of information should therefore be collected only once and in one place. This can be ensured by having the employees review the entire documentation on the applicant before the interview, or by determining the central document in which the most information about the user is collected, e.g. the eligibility assessment or personal plan, and which, with the user's knowledge, can be viewed by different employees. It is important that users communicate each piece of information only once, and that forms are sufficiently understandable and adaptable to people with different needs (e.g. Braille, easy-to-read format, audio recording).

We recorded the different ways in which documents created as part of the pilot projects were handled. For example, in one pilot environment, eligibility assessments were not sent to those assessed as ineligible, and in all environments, the notes on living circumstances were adjusted in accordance with the judgement of the assessors. This was not a good practice nor is it in accordance with the social model of the view of the user, which should be the guidance in modern long-term care systems (Flaker, Nagode, Rafaelič, & Udovič, 2011). Violations of the user's right to access information about themselves must be prevented and they must be acquainted with all steps as part of the long-term care procedure. In order to avoid uncomfortable situations and to adjust records on users, it would be good if assessors and other professionals who cooperate with the applicant check what information they want to have included in the description of living conditions and discuss what is important in the context of long-term care to have written down and in what way.

As a good practice, we can certainly point out the great involvement of the pilot environments in arranging support services,

as otherwise users would be left to their own devices and, in many cases, they would not be able to use these services. The contribution of pilot projects in this regard was exceptionally important, and the practice should be singled out in the Krško pilot environment in which the lack of a family member of a user was compensated for in a certain period of the implementation of pilot projects with a 24-hour duty service of an employee on the project. This was a practice that also requires understanding and support at the systemic level.

We can also welcome the practice that in emergency cases, the long-term care coordinators made sure that services started to be provided immediately, even if the personal plan had not yet been finalised. All the described examples show that flexibility as part of procedures and in the provision of services is possible, and this can further prevent the distress of users and of their relatives as well as employees. Obtaining an opinion of the personal physician, which took place through the long-term care coordinator, also proved to be effective.

Waiting lists, which of course are not a specific feature of the pilot project, but a constant in various long-term care services, pose a general challenge for political policy makers. It is necessary to anticipate any possible pitfalls of these challenges (preparation of appropriate staffing standards, detailed planning of procedures, etc.) and to develop criteria for the inclusion of beneficiaries from the waiting list in the provision of services. The experience of pilot projects has shown that it was more sensible to put people on a waiting list based on the date of receipt of the application and not on the date of the assessment of the eligibility of long-term care, while at the same time the results of the evaluation show that the principle of the need for services must also be reconsidered.

The complaint procedure is also an important part of any procedure. As part of the evaluation, we have covered this part only to a lesser extent, but we can nevertheless say that in the future it

will be necessary to define the user complaint procedure in more detail and transparently. The user must be acquainted with all internal and external complaint channels, provided with information and complaint forms, and empowered to lodge a complaint and be provided support. It transpired during the evaluation that the pilot environments did not detect or at least did not report on user complaints. This can be most likely attributed to the fact that, in most cases, users were not sufficiently acquainted with the complaint channels. Complaints are not necessarily only an indication of poor performance of the long-term care providers. Employees should understand complaints as user feedback on their work.

We highlighted the main deviations and recommendations that we observed in relation to the course of procedures as part of the evaluation. Despite all the above-mentioned, we recognise the entire procedure of the provision of long-term care as suitable for being translated into the systematic implementation of long-term care, as it allowed the employees in the pilot projects, from first to last contact, to greatly support the user in all acts as part of the procedure, so that they felt safe and respected.

As part of the implementation of the pilot projects, the principles that keep the user at the centre and encourage the defining of their needs in cooperation with them, as they see them themselves, were thus used in the methods for eligibility assessment and personal planning as well as from the procedural aspect. The extent to which employees actually succeeded in this as part of the pilot project is difficult to assess unambiguously; given the different data that we obtained during the evaluation, we find that there is still room for strengthening such an approach and placing the user at the centre of integrated long-term care. However, we must also take into account the fact that such changes, which require a completely different view of one's work and of the user, take more time and such effects would probably be more visible if the pilot projects lasted longer.

Finally, we can conclude that procedures in the future long-term care system, if carried out in the same manner as in the pilot project and taking into account the mentioned restrictions and proposals, could be sufficiently fast and efficient.

## BIBLIOGRAPHY

- AGE Platform Europe. (2012). *Evropski okvir kakovosti storitev dolgotrajne oskrbe Načela in smernice za dobro počutje in dostojanstvo starejših, potrebnih oskrbe in podpore*. Retrieved from [https://www.age-platform.eu/sites/default/files/24171\\_WeDo\\_brochure\\_A4\\_48p\\_SL\\_WEB.pdf](https://www.age-platform.eu/sites/default/files/24171_WeDo_brochure_A4_48p_SL_WEB.pdf)
- European Network of National Human Rights Institutions. (2017). *Applying a Human Rights-Based Approach to Long-term Care for Older Persons: A toolkit for Care Providers*. Retrieved from [http://ennhri.org/IMG/pdf/respect\\_my\\_rights\\_hrba\\_in\\_ltc\\_care\\_providers.pdf](http://ennhri.org/IMG/pdf/respect_my_rights_hrba_in_ltc_care_providers.pdf)
- European Parliament, European Council and European Commission. (2010). *Charter of fundamental rights of the European Union*. (2010)C 83/389.
- Flaker, V. (2017). *Teze ob diskusiji o zakonu o dolgotrajni oskrbi in ob vzpostavljanju sistema dolgotrajne oskrbe*. *Kakovostna starost, revija za gerontologijo in medgeneracijsko sožitje*, 20, 38-42.
- Flaker, V., Nagode, M., Rafaelič, A., & Udovič, N. (2011). *Nastajanje dolgotrajne oskrbe: Ljudje in procesi – eksperiment in system*. Ljubljana: Fakulteta za socialno delo.
- Lebar, L., Dremelj, P., Flaker, V., Rode, N., Mali, J., Peternelj, A., Smolej Jež, S., ... Kobal Tomc, B. (2017). *Priprava podlag za izvedbo pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi* Aktivnost 1: Priprava orodij za ugotavljanje potreb uporabnikov, metodika postopka ter ugotavljanje upravičenosti do storitev dolgotrajne oskrbe. Ljubljana: Inštitut RS za socialno varstvo.
- Ministrstvo za zdravje. (2018). Javni razpis »Izvedba pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi«. Retrieved from <https://www.uradni-list.si/glasilo-uradni-list-rs/vsebina/2018002400003/javni-razpis-za-izbor-operacij-izvedba-pilotnih-projektov-ki-bodo-podpirali-prehod-v-izvajanje-sistemskega-zakona-o-dolgotrajni-oskrbi-st--303-1201816-ob-198618>
- Scirocco exchange, *Maturity model* (2021). Retrieved from <https://www.sciroccoexchange.com/digital-infrastructure>
- Seys, D., Panella, M., VanZelm, R., Sermus, W., Aeyels, D., Bruyneel, L., Coeckelberghs, E., & Vanhaecht, K. (2019). *Care pathways are complex interventions in complex systems: New European Pathway Association framework*. doi: <https://doi.org/10.1177/2053434519839195>

# **ASSESSMENT OF ELIGIBILITY FOR LONG-TERM CARE**

Polona Dremelj  
Social Protection Institute of the Republic of Slovenia

Boris Majcen  
Institute for Economic Research

Mateja Nagode  
Social Protection Institute of the Republic of Slovenia

Lea Lebar  
University of Ljubljana, Faculty of Social Sciences



## KEY MESSAGES

- ▶ The assessment of eligibility for long-term care is a novelty in Slovenia and was tested for the first time within the framework of pilot projects. The experience and results of the pilot projects based on the assessment of eligibility are thus exceptionally important.
- ▶ Statistical analyses showed that the assessment scale was suitable and the statistical adequacy of proposed adjustments for scoring the modules was also approved.
- ▶ The findings that the structure of applicants as regards the category of eligibility was very similar irrespective of the type of the environment and that various profiles of assessors did not affect the classification of applicants in certain categories were also important.
- ▶ The assessors also confirmed that the assessment scale was suitable, as they recognised the concept of assessing people's independence as an appropriate method for assessing applicant eligibility.
- ▶ The eligibility assessment must take place in the same manner irrespective of where it is being implemented. The assessor must consider the fact that a person lives alone and assesses on this basis how much assistance they require for implementing individual activities. In the event of a significant change in their living circumstances which may affect the amount of assistance the person requires, it can be proposed that the eligibility assessment is carried out again.
- ▶ The assessor's educational profile may encompass healthcare or social care; it is also desirable that both of these profiles possess prior or additional knowledge of the other profile. It is advisable that teams at single entry points should be as heterogeneous as possible regarding the assessors' education.
- ▶ When introducing new profiles, such as the assessor, continuous theoretical and practical training is important.
- ▶ The assessors working on pilot projects can form an important learning basis for further training in eligibility assessment.

## Introduction

One of the most important challenges in the systemic arrangement of long-term care is the introduction of a new or uniform practice of establishing eligibility for long-term care, i.e. a procedure with which it would be possible to determine which social groups are eligible for rights regarding long-term care and to what extent. A lack of a uniform procedure for determining eligibility in Slovenia is highlighted in numerous policy documents at the EU level (i.e. Rodrigues, 2014; Social Protection Committee and European Commission, 2014). Carrino and Orso (2014) define the procedure of implementing the eligibility assessment as a preparation of a “vulnerability profile” which must be compared to the “requirements for objective vulnerability” determined by legislation in each country (Carrino & Orso, 2014). The result of preparing such a profile is the classification of applicants in groups of beneficiaries in which beneficiaries with a smaller scope of needs are usually included in lower categories and thus entitled to fewer services and benefits, while the beneficiaries with a larger scope of needs are in higher categories.

Various approaches and tools for determining eligibility are used in the European area. The tools are roughly divided into two groups; the first group includes those intended only for the assessment of a person’s functional abilities, which include tools for the assessment of activities of daily living (ADL) and instrumental activities of daily living (IADL), while the second group includes more complex tools which enable a comprehensive needs assessment, i.e. assessment of functional abilities, cognitive and psychological aspect, and also the social aspect. The latter capture more aspects of a person’s life and are thus more extensive (Nagode, Lebar, & Dremelj, 2018; Nagode, Lebar, & Kovač, 2014). In recent years, European countries have

been increasingly recognising the importance of incorporating a broader selection of aspects of a person’s life, especially the cognitive and psychological aspect, which is being incorporated, for example, in Germany, France and Spain, but not yet in Great Britain and Austria (Ranci, Österle, Arlotti, & Parma, 2019).

The selection of a tool for assessing eligibility for long-term care, which was used in pilot projects, took place in 2016 when Slovenia became engaged in the preparation of a tool for eligibility assessment for long-term care.<sup>35</sup> Based on the examination of various tools and results of an international workshop on needs assessment and due to its good testing results, comprehensiveness and methodological justification, the working group selected the German tool, NBA. The choice of tools was based on the criteria that the ideal tool should meet, i.e.: high-level of tool standardisation, simple assessment procedure, which is not time-consuming, suitability for use in the domestic environment and in institutions, flexibility and orientation towards an individual in the process of personal planning, the observance of all aspects of a person’s life and a focus on the person’s wishes and needs when planning care. The proposal of the tool thus consisted of two sections: an assessment scale for eligibility assessment (hereinafter: assessment scale) and the proposal for implementing personal planning, which is analysed in more detail in Chapter *Personal planning and coordination in long-term care: identifying needs and planning care together with the user*. Members of the working group translated and adjusted the tool in a way to suit the Slovenian context and verified it in the field from the viewpoint of comprehensibility and applicability (Lebar et al., 2017).

The assessment scale focuses on person’s activities in everyday life in which they may need other people’s assistance. It comprises eight

<sup>35</sup> Within the operation (project) of Preparation of bases for the implementation of pilot projects that will support the transition to the implementation of the systemic act on long-term care. The developer or beneficiary was the Social Protection Institute of the Republic of Slovenia (IRSSV), which set up a working group that included experts from all fields of long-term care in order to ensure an integrated approach to the preparation of the tool. When drafting their proposal, the working group also cooperated with expert Monika Gabanyi (Lebar et al., 2017).

**Table 1: Variants of scoring adjustments in Slovenia (NBA-SLO (V1) and NBA-SLO (V2))**

| <b>FIELDS OF LIFE (MODULES)</b>                                                                  | <b>NBA ORIGINAL<sup>36</sup><br/>(proportion of a total score)</b> | <b>NBA-SLO (V1)<br/>REDUCTION of Module 4</b> | <b>NBA-SLO (V2):<br/>REDUCTION of Module 5</b> |
|--------------------------------------------------------------------------------------------------|--------------------------------------------------------------------|-----------------------------------------------|------------------------------------------------|
| <b>Module 1</b><br>Mobility                                                                      | 10%                                                                | 10%                                           | 10%                                            |
| <b>Module 2 + 3</b><br>Cognitive and communication abilities + Behaviour and mental health       | 15%                                                                | 15%                                           | 15%                                            |
| <b>Module 4</b><br>Self-care                                                                     | 40%                                                                | 35%                                           | 40%                                            |
| <b>Module 5</b><br>Ability to deal with illness-/therapy-related demands and burden              | 20%                                                                | 20%                                           | 15%                                            |
| <b>Module 6 + 7</b><br>Managing everyday life and social contacts + Activities outside the house | 15%<br>(only M6)                                                   | 10%                                           | 10%                                            |
| <b>Module 8</b><br>Household maintenance                                                         | 0%                                                                 | 10%                                           | 10%                                            |

modules (fields of life, see Table 1) and each module consists of several items (questions). The assessor assesses the user's degree of independence in everyday life. In doing so, it is presumed that the person wishes to implement these activities. Eligibility (for services, benefits) is established on the basis of the assessment results. For each field (module), points are added up in accordance with the prescribed calculation rules (Lebar et al., 2017; Wingenfeld, Büscher, & Gansweid, 2008).

The assessment scale changes the paradigm in Slovenia, as it diverts from the "dependency profile" (Carrino & Orso, 2014) and establishes the paradigm of "self-dependency" as the basis for evaluating eligibility for long-term care services and benefits. The need for long-term care is thus defined on the basis of providing assistance to ensure independence and the maximum utilisation of the person's abilities.

As part of the pre-pilot project, the participants proposed that, in addition to the original, two additional variants of scoring (NBA-SLO) would be tested in the pilot projects. The original scale for eligibility assessment (Buescher, Wingenfeld, & Schaeffer, 2011; Wingenfeld et al., 2008) does not include modules 7 and 8 in the scoring, but because Slovenia has a strong tradition of social care and an already existing infrastructure or developed network of home help providers and as the activities of these modules maintain a person's higher quality of life, it is sensible that its significance is highlighted by adjusting the assessment scale, i.e. by including modules 7 and 8 in the scoring (Lebar et al., 2017).

The proposed method of scoring anticipates that activities outside the house (module 7) are combined with managing everyday life and social contacts (module 6), in a similar manner as the modules cognitive and communication abilities (module 2) and behaviour and mental health (module 3) are combined in the German system (NBA ORIGINAL). Accordingly, the combination of modules 6 and 7 makes up 10% of the total score and module 8 an additional 10%. Due to the

<sup>36</sup> Buescher, Wingenfeld, & Schaeffer (2011), Wingenfeld et al. (2008).

resulting five per cent surplus, one of the strong modules is reduced, i.e. module 4 (M4): Self-care – (NBA-SLO (V1)) or module 5 (M5): Ability to deal with illness-/therapy-related demands and burden – (NBA-SLO (V2)) (Lebar et al., 2017).

Based on the drafted eligibility assessment, the applicant is classified in one of the five categories of eligibility for long-term care as per the score they receive.<sup>37</sup> An adult eligible for long-term care must receive at least 12.5 weighted points in the eligibility assessment procedure and must have been dependant on a third person's assistance for at least three months or permanently when performing the activities of daily living and instrumental activities of daily living over a longer period of time. Classification in category "0" means that the applicant failed to exceed the set threshold – their established degree of independence and thus their need for assistance is not sufficient to be eligible for long-term care.

As part of the pilot projects in the field of long-term care, the eligibility assessment was implemented by specifically trained assessors. The latter thus form a foundation for creating a new professional profile in Slovenia.

## Methodology

One of the objectives of the pilot project evaluation regarding long-term care was to assess the suitability of the selected assessment scale. The latter was assessed from the viewpoint of time needed for assessment (time consumption of assessment), the method of scoring individual modules of the assessment scale (proposal of adjustment for Slovenia) and the suitability of classifying applicants in eligibility categories, assessors' subjective assessments regarding the suitability of the assessment scale, the objectivity of assessment and assessors' qualifications for assessing.

As part of determining the suitability of the assessment scale, the following indicators were further assessed:

- ▷ 70% of the existing beneficiaries in pilot environments are assessed by means of the assessment scale in the first nine months;
- ▷ at least 80% of all LTC beneficiaries are assessed again after six months if they are still part of the pilot activities;
- ▷ proportion of users who were grouped into a different eligibility category after the second assessment;
- ▷ proportion of users who transferred to institutional care;
- ▷ proportion of persons who fail to meet the eligibility threshold but are informed about the existing rights or care options regarding social and health care and about participation in the evaluation procedure.

Data from the information system of pilot environments was used to determine the suitability of the assessment scale, which mostly referred to the data from the application, the eligibility assessment and the recording of certain HR data.

A special section of the questionnaire for employees (under points M0 and M18) was intended for assessors, in which we asked about the course of the assessment of applicants and the suitability of the assessment scale and the instructions for assessment in order to obtain a subjective opinion about the suitability of the eligibility assessment. We also used certain findings or results of a deliberative discussion at the democratic forum. See more on individual measuring instruments in Chapter *Evaluation of pilot projects and methodology*.

When analysing quantitative data, univariate, bivariate and multivariate statistical methods were used. The ordered logit model was used among the latter. This is also known as an ordered logistic regression or proportional odds model, which is a regression model for the ordinal dependent variable.<sup>38</sup>

<sup>37</sup> In the latest proposal of the act on long-term care (2021), the eligibility categories are defined on the basis of the applicant's degree of independence and their abilities, i.e. category 1 denotes minor limitation of independence and abilities, category 2 moderate limitation, category 3 severe limitation, category 4 more severe limitation and category 5 the most severe limitation of independence and abilities.

<sup>38</sup> McCullagh (1980).

## Results

The results referring to the eligibility assessment for long-term care (hereinafter: the eligibility assessment) are displayed in three sets. Initially, we highlight the characteristics of eligibility assessment from different aspects. Then, we present the experience of assessors with the eligibility assessment, and we complete the chapter with an assessment of the suitability of classification into eligibility categories.

### Characteristics of eligibility assessment

In all three pilot environments, a total of 2,031 applications were recorded in the information system. Some 1,972 persons were assessed by means of the assessment scale, i.e. 885 in Celje, 475 in Krško and 612 in Dravograd. The discrepancies between the number of applications and the number of assessments occurred for various reasons, e.g. applicant's death, inclusion in a service within the existing legislation, rights and other reasons (e.g. the applicant changed their mind after completing the application). Applications for eligibility assessment were completed by 834 persons from institutional care (41.1%) and 1,197 persons who lived at home (58.9%). Of all the applicants living at home, almost everyone was assessed (95.8%).

The proportion of beneficiaries among all assessed applicants amounted to 81.1% in all pilot environments. Although it was somewhat lower in Dravograd (76.1%) and somewhat higher in Celje (84.0%), the differences between environments are not very great.

The eligibility threshold was not attained by 18.9% of persons; among those living at home, this proportion amounted to 21.8%. The

latter were thus not incorporated in the service implementation.

Following the first assessment at home, 378 of the assessed applicants were eligible in Celje. The second assessment was carried out for 192 beneficiaries, which is 51.8% of all beneficiaries after the first assessment.<sup>39</sup> The data on the date of the first assessment is available for 370 beneficiaries and the date of the second assessment for 148 beneficiaries. Data on both dates is available for a total of 148 beneficiaries, which is 39.2% of those eligible at the first assessment. Among these, only 29.7% received the second assessment within five to seven months, while the remaining ones received the assessment before (35.8%) or later (34.5%). The objective of at least 80% of all beneficiaries of long-term care being assessed again in six months was achieved in eight months in the pilot environment among those assessed twice.

Following the first assessment at home, 289 of the assessed applicants were eligible in Krško. The second assessment was carried out for 128 beneficiaries, which is 44.3% of all beneficiaries after the first assessment.<sup>40</sup> The number of units of analysis regarding date equals the number of assessment units. Among 128 of the assessed at both time points, the second assessment was made within five to seven months for 61.7% of the assessed ones. Prior to five months, the assessment was made for 27.3% of beneficiaries and for 10.9% of beneficiaries the assessment was repeated after seven months. The objective of at least 80% of all beneficiaries of long-term care being assessed again in six months was achieved in seven months in the pilot environment among those assessed twice.

Following the first assessment at home, 230 of the assessed applicants were eligible in Dravograd. The second assessment was carried out for 96 beneficiaries, which is 41.7% of all beneficiaries

<sup>39</sup> For 70 users lacking the second assessment, there is information of an early termination of participation in the project, i.e. more than half of them died (51.4%) and one third (32.9%) were admitted to institutional care. The remaining ones no longer wanted to receive services (4.3%), obtained personal assistants (2.9%) or left for other reasons (8.5%). It is impossible to determine reasons for the lack of the second assessment for 116 users.

<sup>40</sup> For 142 users who lack the second assessment, we have information on early termination of cooperation in the project, i.e. less than one third died (29.6%), one quarter (25.4%) no longer wanted to receive services, some 14.8% were admitted to institutional care, 7.7% no longer required relevant care, 4.2% received a personal assistant, and other reasons were provided for the remaining ones. For 19 users, the reason for the missing values is unknown.

**Table 2: All applicants, assessed, beneficiaries of long-term care as per the first assessment, total and by individual environments – number and proportion**

|                                                                 | <b>Total</b> | Celje | Krško | Dravograd |
|-----------------------------------------------------------------|--------------|-------|-------|-----------|
| <b>Applicants (N)</b>                                           | <b>2031</b>  | 899   | 501   | 631       |
| <b>Applicants in institutional care (N)</b>                     | <b>834</b>   | 452   | 114   | 268       |
| <b>Applicants living at home (N)</b>                            | <b>1197</b>  | 447   | 387   | 363       |
| <b>Assessed (N)</b>                                             | <b>1972</b>  | 885   | 475   | 612       |
| <b>Assessed living at home (N)</b>                              | <b>1147</b>  | 434   | 361   | 352       |
| <b>Beneficiaries among the assessed (N)</b>                     | <b>1599</b>  | 743   | 390   | 466       |
| <b>Beneficiaries among the assessed living at home (N)</b>      | <b>897</b>   | 378   | 289   | 230       |
| <b>Applicants from institutional care (%)</b>                   | <b>41.1</b>  | 50.3  | 22.8  | 42.5      |
| <b>Applicants from home environment (%)</b>                     | <b>58.9</b>  | 49.7  | 77.2  | 57.5      |
| <b>Assessed (in %)</b>                                          | <b>97.1</b>  | 98.4  | 94.8  | 97.0      |
| <b>Assessed from home environment (%)</b>                       | <b>95.8</b>  | 97.1  | 93.3  | 97.0      |
| <b>Beneficiaries among the assessed (in %)</b>                  | <b>81.1</b>  | 84.0  | 82.1  | 76.1      |
| <b>Beneficiaries among the assessed in home environment (%)</b> | <b>78.2</b>  | 87.1  | 80.1  | 65.3      |
| <b>Ineligible among the assessed (in %)</b>                     | <b>18.9</b>  | 16.0  | 17.9  | 23.9      |
| <b>Ineligible among the assessed in home environment (in %)</b> | <b>21.8</b>  | 12.9  | 19.9  | 34.7      |

after the first assessment.<sup>41</sup> The number of units of analysis regarding date equals the number of assessment units. Among 96 assessed at both time points, 42.7% received the second assessment within five to seven months. The assessment was done for 20.8% of beneficiaries before five months and after seven months for 36.5% of beneficiaries. The objective of at least 80% of all beneficiaries of long-term care being assessed again in six months was achieved in eight months in the pilot environment among those assessed twice.

The average time of evaluation during the first assessment in all pilot environments totalled 67.9 minutes or approximately one hour and eight minutes and it was shortened to a little over an hour during the second and third assessments. During the first and second assessments, half of these were performed in less than one hour and half of them in more than one hour; the shortest time of assessment was 20 minutes and the longest 480 minutes (8 hours). The latter refers to the assessment in two cases and it most likely includes the entire duration of the assessment procedure and not just the assessment. In one case, the assessment lasted 240 minutes (4 hours) and 210 minutes (3 hours and a half) in three cases, which was the longest time of assessment. The latter took place in the applicant's home environment.

Similar time frames were also recorded regarding second assessments; the average, minimum and maximum time of assessment were somewhat reduced upon each subsequent assessment.

The assessment of applicants in their home environment was on average (74.7 minutes or one hour and some 15 minutes) longer than the assessment of users in institutional care (less than one hour). The median value was also higher when the assessment took place in the home environment (70 minutes) than in the institutional care (60 minutes). The average time of the second assessment reduced in the applicant's home

environment (little over an hour) and in the institution (one hour and more than two minutes); the median value was lower for the assessment in the home environment.

Indicative total time used for preparing the eligibility assessment amounted to five hours and included transport, visit to a home and interview with the applicant, consultation with other assessors and draft of the assessment, preparation of the report, completion of the assessment scale and entry of data in the table template for the calculation of the eligibility category. The drafting of the assessment is extended when assessors are still in training (time shortens with gained experience), when arranging documentation, when only one person is assessing, when the applicant experiences mental health problems and when assessing an applicant who lives at home (assessments in an institution are usually shorter).

## Assessors' experience with eligibility assessing

Opinions about the suitability of the assessment scale for assessing eligibility were collected from the assessors by means of a survey questionnaire. The assessor in all pilot environments agreed for the most part (average assessment in M0 was 3.75 and 3.81 in M18)<sup>42</sup> with the concept of assessing a person's independence as being a suitable method for assessing eligibility. In both survey points, overall, the assessors also indicated their agreement with the fact that the assessment scale encompasses all fields relevant for the eligibility assessment. A similar trend can be seen in the statements that the assessment scale enables the provision of a realistic assessment (regarding this statement, most assessors at both time points agreed: AS = 4) and that the modules of the assessment scale are appropriately weighted (average value in the M0 point is somewhat lower than in M12, but the

41 For 67 users who lacked the second assessment, we have information on early termination of cooperation in the project, i.e. more than one third died (37.3 %), one quarter (25.4%) no longer wanted to receive services, less than one quarter (23.9%) were admitted to institutional care, and other reasons were provided for the remaining ones. For 67 users, the reason for the missing values is unknown.

42 On the scale from 1 (I do not agree at all) to 5 (I completely agree).



median value and the mode value increased at the second assessment, i.e. from 3 to 3.5 and from 3 to 4, respectively.

Certain assessors claimed problems when assessing persons with disabilities or health issues, especially when dealing with persons with sensory disabilities and dementia patients. Irrespective of the above, they assessed that they were relatively well trained to assess persons with disabilities or health issues. During the first survey, they felt competent to assess persons with sensory disabilities to a lesser extent, while the average self-assessment of competence for assessing this target group increased or improved (from 2.9 to 3.4) during the second survey.<sup>43</sup> The difference is statistically significant ( $t = 1.743$ ,  $p = 0.093$ ). The increase in self-assessment of competence at the second survey is also revealed in the increase of minimum assessment provided by the assessors, i.e. from 1 to 3, which means that no assessor felt incompetent to assess persons with sensory disabilities after a year and a half of implementing pilot projects.

The majority of assessors stated upon the first survey that it would be better if an individual applicant was assessed by two assessors (in a pair). At the democratic forum, the assessors also agreed that assessment in a pair has more advantages. These are also shown in the assessor's safety (in cases of violence in the applicant's family, emotional blackmail, cognitive impairments and difficult relatives) and also in the technical sense of assessment implementation (prompt taking of notes, interview with the applicant, separate interview with relatives, etc.). As necessary training which they should receive, the assessors state: training in the field of healthcare and social care, workshops and training regarding communication, training on dementia, mental disabilities, addiction, use of assistive devices, etc. Furthermore, they highlighted the need for the implementation of joint assessments with expert assessors (at least ten joint assessments), regular evaluation and supervisory meetings and the option of peer and additional expert consulting.

As per their educational profile, the assessors in the pilot project were either registered nurses, registered physiotherapists, occupational therapists or social workers. Which profile is suitable for an assessor was also one of the important discussion topics at the democratic forum at which the participants agreed that all of the educational profiles stated above can be independent assessors, but it is vital that the team of assessors at the single entry point is heterogeneous. Previous or additional healthcare education for profiles coming from social care and prior or additional social education for profiles in healthcare are advised.

## Suitability of classification in eligibility categories

Regarding the results of eligibility assessment according to three scoring variants, we found that some 76% of assessed persons would be eligible for long-term care as per the method of scoring adopted from the German assessment model (NBA-original), which does not include modules 7 and 8 in the scoring. According to both scoring variants proposed for Slovenia, some 79% of persons (reduced M4) or a little less than 79% of persons (reduced M5) would be eligible for long-term care. The results are also similar at the level of the individual pilot environment.

We also observed changes in the categories of eligibility assessed during the implementation of the pilot project. The objective was to determine what changes occurred in the category of eligibility during the second assessment. For 61.9% of beneficiaries, the category of eligibility did not change during the second assessment; the situation worsened for more than one fifth (21.2%) and improved for 16.8% of beneficiaries. If comparing the category of eligibility of the first assessment with the latest one, similar conclusions can be drawn: the category has not changed for 58.1% of users, 24.1% were classified in a higher

<sup>43</sup> On the scale from 1 (I do not agree at all) to 5 (I completely agree).



**Table 3: Results of assessing applicants by three scoring variants (total of all pilot environments)**

#### **NBA – original**

|   | CATEGORY OF ELIGIBILITY |          |          |          |          |          |
|---|-------------------------|----------|----------|----------|----------|----------|
|   | <b>0</b>                | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> |
| N | 445                     | 328      | 356      | 353      | 258      | 152      |
| % | 23.52                   | 17.34    | 18.82    | 18.66    | 13.64    | 8.03     |

**TOTAL NBA – original: 1892**

#### **Reduced M4**

|   | CATEGORY OF ELIGIBILITY |          |          |          |          |          |
|---|-------------------------|----------|----------|----------|----------|----------|
|   | <b>0</b>                | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> |
| N | 384                     | 307      | 362      | 388      | 298      | 153      |
| % | 20.30                   | 16.23    | 19.13    | 20.51    | 15.75    | 8.09     |

**TOTAL Reduced M4: 1892**

#### **Reduced M5**

|   | CATEGORY OF ELIGIBILITY |          |          |          |          |          |
|---|-------------------------|----------|----------|----------|----------|----------|
|   | <b>0</b>                | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> |
| N | 399                     | 297      | 358      | 364      | 314      | 160      |
| % | 21.09                   | 15.70    | 18.92    | 19.24    | 16.60    | 8.46     |

**TOTAL Reduced M5: 1892**

category and 17.7% in a lower category, i.e. their condition improved.

Differences in the changes of categories of eligibility were seen among the pilot environments. The category of eligibility did not change from the first to the latest assessment for 64% of users in Celje, 49% of users in Krško and 58% of users in Dravograd. The largest proportion of transitions to a higher category was recorded in Dravograd (32%) and the largest proportions of transitions to a lower category in Krško (31%). With regard to transitions, the data on the users' transition to institutional care and subsequent termination of pilot activities is also important. A total of 11.1% of such transitions was recorded: 12.1% in the Celje pilot environment, 10% in Krško and 10.8% in Dravograd.

Below, we analyse the suitability of applicants' classification in certain categories of eligibility and also which factors impact the classification. The dependent variable, "category of eligibility", is the ordinal variable. Classification of applicants in categories 0, 1, 2, 3, 4 and 5 represents the assessment of preserved abilities to carry out the activities of daily living and instrumental activities of daily living, and healthcare services in long-term care. The ordered logit model was used for the analysis. We first present basic information about the dependent and explanatory variables. In the continuation, our objective was to determine the net effect of an individual explanatory variable on the dependent one.

Table 6 displays results of the ordered logit model, whereby it is possible to interpret the direction and characteristic, but not the size of the coefficients obtained for each explanatory variable. The number of observations used in the model totalled 1,385. The model chi-square distribution with 24 degrees of freedom amounts to 371.29 and is highly significant, which means that the used explanatory variables significantly affect the classification in the categories of eligibility for long-term care.

A negative, but only lowly significant coefficient ( $P > |z| = 0.095$ ) for the "gender" variable means that if a person is a woman, the probability of classification

in a higher eligibility category almost does not change on average with regard to a person who is a man. It may be determined for the “age” variable that with the increase of age the probability of being classified in a higher eligibility category also increases on average (positive and highly significant coefficient,  $P > |z| = 0.000$ ). The result obtained for the “education” variable was also expected as the transfer from lower to higher education decreases on average the probability of being placed in the higher eligibility category (negative and significant coefficients,  $P > |z| = 0.023$  in  $P > |z| = 0.000$ , for the second or third level of education).

An interesting result can be seen for the “marital status” variable in which we determined whether the probability of being classified in a higher eligibility category changes significantly for persons who are widowed, single or separated in comparison to persons who are married. The results revealed that the coefficients obtained for all three marital statuses were significantly negative, i.e. if a person is not married and has a different status, the probability of their classification in a higher category is on average reduced (negative and highly significant coefficients,  $P > |z| = 0.000$ ,  $P > |z| = 0.003$  in  $P > |z| = 0.000$ ).

The expected result of the “assistance and attendance allowance” variable (persons receiving this allowance have serious problems with carrying out basic activities of daily living and require suitable care) is that these persons would be classified in higher eligibility categories. The results and the positive and significant coefficient confirmed this ( $P > |z| = 0.000$ ).

We further wanted to know if the probability of being placed in eligibility categories also differs between pilot environments as they have different content and represent urban, semi-rural and rural environments (pilot environment variable). The Celje urban pilot environment served as the basis for comparison. The results showed that the probability of being classified in a higher category of eligibility for people living in a semi-rural or rural environment does not on average differ

**Table 4: Changes in the category of eligibility for users in the community**

#### WORSE SITUATION

|           | First assessment –<br>second assessment |      | First assessment –<br>latest assessment |      |
|-----------|-----------------------------------------|------|-----------------------------------------|------|
|           | N                                       | %    | N                                       | %    |
| <b>+3</b> | 4                                       | 1.0  | 4                                       | 1.0  |
| <b>+2</b> | 10                                      | 2.4  | 20                                      | 4.8  |
| <b>+1</b> | 74                                      | 17.8 | 76                                      | 18.3 |

#### UNCHANGED SITUATION

|          | First assessment –<br>second assessment |      | First assessment –<br>latest assessment |      |
|----------|-----------------------------------------|------|-----------------------------------------|------|
|          | N                                       | %    | N                                       | %    |
| <b>0</b> | 257                                     | 61.9 | 241                                     | 58.1 |

#### BETTER SITUATION

|           | First assessment –<br>second assessment |      | First assessment –<br>latest assessment |      |
|-----------|-----------------------------------------|------|-----------------------------------------|------|
|           | N                                       | %    | N                                       | %    |
| <b>-1</b> | 59                                      | 14.2 | 62                                      | 14.9 |
| <b>-2</b> | 4                                       | 1.0  | 5                                       | 1.2  |
| <b>-3</b> | 6                                       | 1.4  | 6                                       | 1.4  |
| <b>-4</b> | 1                                       | 0.2  | 1                                       | 0.2  |

#### TOTAL

|  | First assessment –<br>second assessment |              | First assessment –<br>latest assessment |              |
|--|-----------------------------------------|--------------|-----------------------------------------|--------------|
|  | N                                       | %            | N                                       | %            |
|  | <b>415</b>                              | <b>100.0</b> | <b>415</b>                              | <b>100.0</b> |

Table 5: Explanatory variables and their effect on the dependent variable

| Name                                       | Effect on the dependent variable                                                                                                                                                                                       | Value domain of variable                                                                                                                                                                          |
|--------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Gender</b>                              | Does gender affect the probability of classification in a higher category of eligibility?                                                                                                                              | 0 = man, 1 = woman                                                                                                                                                                                |
| <b>Age</b>                                 | Does an increase in age affect the probability of classification in a higher category of eligibility?                                                                                                                  | 0 = primary school or secondary vocational education<br>1 = secondary school education<br>2 = higher or more                                                                                      |
| <b>Marital status</b>                      | Does a marital status different to the "married" status affect the probability of classification in a higher category of eligibility?                                                                                  | 0 = married or cohabitation<br>1 = widowed<br>2 = single<br>3 = separated                                                                                                                         |
| <b>Assistance and attendance allowance</b> | Does the receipt of assistance and attendance allowance affect the probability of classification in a higher category of eligibility?                                                                                  | 0 = does not receive assistance and attendance allowance<br>1 = receives assistance and attendance allowance                                                                                      |
| <b>Pilot environment</b>                   | Does another pilot environment, in comparison to the Celje pilot environment, affect the probability of classification in a higher category of eligibility?                                                            | 0 = Celje pilot environment<br>1 = Krško pilot environment<br>3 = Dravograd pilot environment                                                                                                     |
| <b>NEED</b>                                | Do other reasons in comparison to old age affect the probability of classification in a higher category of eligibility?                                                                                                | 0 = Old age<br>1 = Disease<br>2 = Disease, old age<br>3 = Dementia and disease or old age<br>4 = Mental disabilities<br>5 = Injury<br>6 = Other reasons, usually a combination of several reasons |
| <b>TYPE</b>                                | Does classification in the group of applicants in institutional care in comparison to the group of other applicants affect the probability of classification in a higher category of eligibility?                      | 0 = Others<br>1 = In institutional care                                                                                                                                                           |
| <b>PROFILE-2</b>                           | Does a different profile of the assessor in comparison to the "social worker" profile affect the probability of classification in a higher category of eligibility?                                                    | 0 = Social worker<br>1 = Occupational therapist<br>2 = Physiotherapist<br>3 = Nurse<br>4 = Two assessors                                                                                          |
| <b>Experience</b>                          | Does a period of preparing the eligibility assessment in comparison to the starting period affect the probability of classification in a higher category of eligibility?                                               | 0 = period of assessment until the end of April 2019<br>1 = period of assessment between 1 May 2019 and 28 February 2020<br>2 = period of assessment starting on 1 March 2020                     |
| <b>OCI</b>                                 | Does the extension of time (measured in minutes) used for the preparation of the eligibility assessment by means of the assessment scale affect the probability of classification in a higher category of eligibility? |                                                                                                                                                                                                   |

significantly from the probability of classification in an urban environment (highly insignificant coefficients in both pilot environments,  $P > |z| = 0.544$ ,  $P > |z| = 0.453$ ).

The structure of applicants differed as per the individual pilot environment; the applicants had different characteristics as per the services and benefits which they had already received before completing the application. All applicants were thus divided into two groups; a group which consisted of applicants in institutional care and a group which consisted of the remaining applicants (the “type” variable). We wanted to know whether there were significant differences in the probability of being classified in higher categories of eligibility for applicants in institutional care if compared to the group with the remaining applicants. Highly significant and positive coefficients ( $P > |z| = 0.000$ ) confirmed the expected result that the probability of being placed in higher eligibility categories increased on average for people in institutional care. Similar results were revealed when classifying applicants into four groups (0: does not receive any form of long-term care; 1: receives only informal assistance; 2: receives assistance and attendance allowance and services at home; 3: is in institutional care). Group 0 was a control group and the coefficients obtained for the remaining three groups were significant and positive, i.e. the probability of classification in a higher eligibility category was thus higher in all three groups if compared to the control group.

We also wished to know whether the reason written in the filed application affects the probability of classification in a higher category of eligibility (the “need” variable). The enumerated reasons were divided into seven groups and the “old age” reason was set as the control group. Do other reasons, which reflect more concrete problems (disease, injury, dementia or a combination of several problems), on average affect the probability of being classified in a higher eligibility category more than old age? The expected positive response was confirmed in all groups by means of calculations.

Various profiles of assessors participated in the implementation of the assessment of eligibility for long-term care. For the most part, the assessment was carried out by one assessor and two assessors performed the assessment in certain cases (the “profile\_2” variable). For the purpose of ensuring a suitable quality of assessment and the establishment of possible differences in assessing as per the preliminary education of assessors, it was necessary to determine whether the different profiles of assessors within the pilot projects made for variations in assessments regarding individual applicants and whether the assessments thus made were also the result of the assessor’s profile. The assessments were made by four different profiles or two assessors of identical or different profiles. The “social worker” profile was used as the control profile, to which a possible significant change in probability due to various other profiles was compared.

Average values of the assessed eligibility categories indicated lower assessments in the assessor’s “nurse” profile, which was also confirmed with the application of the ordered logit model and the observance of the relevant variable (significant and negative coefficient for the “nurse” profile, ( $P > |z| = 0.004$ ) and highly insignificant coefficients for other profiles), which could have been a result of the characteristics of applicants assessed by a nurse (they could have been younger, women, with lower education, etc.; see the results of the model below). By incorporating this variable in a broader model and thus controlling numerous other characteristics, we tried to obtain the actual, net effect of this variable. The results thus obtained reveal that the probability of classification in a higher category of eligibility for all other profiles, including the “nurse” profile in comparison to the “social worker” profile was not significantly different (highly insignificant coefficients for all profiles).

In the initial phase of project implementation and eligibility assessment, it could have been expected that the assessors were still adjusting to the assessment scale and perhaps the assessments

Table 6: Results of the ordered logit model

```
. ologit OC1_kategorija_DO Spol Starost i.izobrazba i.Stan i.DPP i.PO i.VRSTA i.potreba i.profil_2 i.izkušnje
> OC1_čas_ocenjevanja
```

```
Iteration 0: log likelihood = -2400.9186
Iteration 1: log likelihood = -2218.8111
Iteration 2: log likelihood = -2215.2813
Iteration 3: log likelihood = -2215.272
Iteration 4: log likelihood = -2215.272
```

```
Ordered logistic regression      Number of obs      =      1,385
                                LR chi2(24)              =      371.29
                                Prob > chi2               =      0.0000
                                Pseudo R2                 =      0.0773

Log likelihood = -2215.272
```

| OC1_kategorija_DO   | Coef.     | Std. Err. | z     | P> z  | [95% Conf. Interval] |           |
|---------------------|-----------|-----------|-------|-------|----------------------|-----------|
| Spol                | -.1884232 | .1129297  | -1.67 | 0.095 | -.4097615            | .032915   |
| Starost             | .0352718  | .0051448  | 6.86  | 0.000 | .0251882             | .0453554  |
| izobrazba_          |           |           |       |       |                      |           |
| 1                   | -.2902599 | .1281312  | -2.27 | 0.023 | -.5413925            | -.0391274 |
| 2                   | -.7711371 | .1756283  | -4.39 | 0.000 | -1.115362            | -.426912  |
| Stan                |           |           |       |       |                      |           |
| 1                   | -.6820874 | .1312902  | -5.20 | 0.000 | -.9394115            | -.4247634 |
| 2                   | -.5093391 | .169343   | -3.01 | 0.003 | -.8412453            | -.1774328 |
| 3                   | -1.030398 | .2247163  | -4.59 | 0.000 | -1.470834            | -.5899623 |
| 1.DPP               | 1.216315  | .1116495  | 10.89 | 0.000 | .9974858             | 1.435144  |
| PO                  |           |           |       |       |                      |           |
| 2                   | .0867509  | .1431066  | 0.61  | 0.544 | -.193733             | .3672347  |
| 3                   | -.1464224 | .1949796  | -0.75 | 0.453 | -.5285755            | .2357306  |
| 1.VRSTA             | .6498138  | .1262629  | 5.15  | 0.000 | .4023431             | .8972845  |
| potreba             |           |           |       |       |                      |           |
| 1                   | .7683257  | .1462868  | 5.25  | 0.000 | .4816089             | 1.055043  |
| 2                   | .7248868  | .1963824  | 3.69  | 0.000 | .3399844             | 1.109789  |
| 3                   | 1.609708  | .1994415  | 8.07  | 0.000 | 1.218809             | 2.000606  |
| 4                   | 1.102631  | .3755098  | 2.94  | 0.003 | .3666458             | 1.838617  |
| 5                   | .7112682  | .2646336  | 2.69  | 0.007 | .192596              | 1.229941  |
| 6                   | .4802526  | .1810519  | 2.65  | 0.008 | .1253973             | .8351079  |
| profil_2            |           |           |       |       |                      |           |
| 1                   | -.0824612 | .1858285  | -0.44 | 0.657 | -.4466784            | .281756   |
| 2                   | -.1472282 | .1488697  | -0.99 | 0.323 | -.4390074            | .144551   |
| 3                   | -.0092546 | .1709711  | -0.05 | 0.957 | -.3443517            | .3258425  |
| 4                   | .3474452  | .2165988  | 1.60  | 0.109 | -.0770806            | .771971   |
| izkušnje            |           |           |       |       |                      |           |
| 1                   | -.0953201 | .1251892  | -0.76 | 0.446 | -.3406865            | .1500464  |
| 2                   | .628374   | .1993406  | 3.15  | 0.002 | .2376735             | 1.019074  |
| OC1_čas_ocenjevanja | .0030683  | .0023226  | 1.32  | 0.186 | -.0014839            | .0076205  |
| /cut1               | 1.483294  | .5025244  |       |       | .4983642             | 2.468224  |
| /cut2               | 2.62461   | .5066274  |       |       | 1.631638             | 3.617581  |
| /cut3               | 3.634571  | .5106343  |       |       | 2.633746             | 4.635396  |
| /cut4               | 4.807773  | .515695   |       |       | 3.797029             | 5.818517  |
| /cut5               | 6.474411  | .5282482  |       |       | 5.439064             | 7.509759  |

Table 7: Ordered logit model – results for the “profile\_2” variable

```
. ologit OC1_kategorija_DO i.profil_2
```

```
Iteration 0: log likelihood = -3350.2766
Iteration 1: log likelihood = -3344.5654
Iteration 2: log likelihood = -3344.5637
Iteration 3: log likelihood = -3344.5637
```

```
Ordered logistic regression
```

```
Number of obs      =      1,912
LR chi2(4)         =      11.43
Prob > chi2        =      0.0222
Pseudo R2         =      0.0017
```

```
Log likelihood = -3344.5637
```

| OC1_kategorija_DO | Coef.     | Std. Err. | z     | P> z  | [95% Conf. Interval] |           |
|-------------------|-----------|-----------|-------|-------|----------------------|-----------|
| profil_2          |           |           |       |       |                      |           |
| 1                 | .0232458  | .1469809  | 0.16  | 0.874 | -.2648314            | .311323   |
| 2                 | .0136793  | .1179163  | 0.12  | 0.908 | -.2174323            | .244791   |
| 3                 | -.2861816 | .099953   | -2.86 | 0.004 | -.4820859            | -.0902774 |
| 4                 | -.0112911 | .1662928  | -0.07 | 0.946 | -.3372191            | .3146368  |
| /cut1             | -1.588555 | .0829219  |       |       | -1.751079            | -1.426031 |
| /cut2             | -.6382385 | .0744036  |       |       | -.7840669            | -.4924101 |
| /cut3             | .168004   | .0732423  |       |       | .0244518             | .3115562  |
| /cut4             | 1.092054  | .0780261  |       |       | .9391254             | 1.244982  |
| /cut5             | 2.435225  | .103474   |       |       | 2.232419             | 2.63803   |

from this period on average varied from the assessments in the continuation. Furthermore, the first wave of the Covid-19 epidemic was experienced in 2020, which could have also affected the assessing itself. Therefore, the duration of the entire period of assessment was divided into three sub-periods (the “experience” variable): a) from the project start to the end of April 2019; b) from May 2019 to the end of February 2020, and c) from March 2020 onwards. The results obtained show no statistically significant differences in the probability of classification in a higher category of eligibility for the group of assessments implemented in another period. However, the highly significant and positive coefficient for the third period (period after the outbreak of the epidemic) means that the probability of being placed in higher eligibility categories was on average increased for people being assessed in this period ( $P > |z| = 0.002$ ).

Finally, we tested the possible effect of the length of the eligibility assessment, which proved to be insignificant ( $P > |z| = 0.186$ ). More time spent on the assessment apparently has no effect on changing the probability of classification in higher categories of eligibility.

## Discussion with key messages

The assessment of eligibility for long-term care is a method which was tested for the first time in the field of long-term care within pilot projects in Slovenia. This was thus a novelty, which is why the experience and results of the pilot projects for the evaluation of suitability of the assessment scale for assessing eligibility for long-term care are of exceptional importance.

To monitor the assessment of eligibility, we formed several indicators (provided in the introduction of this contribution), and their

attainment was established on the basis of data collected in the information system.

The indicator, which stipulated that at least 70% of the existing users of long-term care services above the age of 18 must be included by the pilot environment in the assessment procedure, was somewhat changed during the evaluation. Because no prescribed method for preparing the assessment of the existing population of long-term care users was in place for the pilot environments (as Slovenia has no validly applicable definition of long-term care, the environments could have approached the assessment in various ways), we pursued the realisation or the attainment of the criterion as per the call for project evaluation within the implementation of pilot projects, i.e. at least 600 people assessed in the Celje pilot environment and 300 people assessed in the Krško and Dravograd pilot environments each).

The results showed that the target indicator was attained in all pilot environments and also exceeded (before schedule), i.e. some 885 applicants were assessed in the Celje pilot environment by the end of the project and 612 in Dravograd and 475 in Krško. We find that the target values of the indicator were set too low, which had already been established at the start of implementing pilot projects. This was revealed by the estimate of the number of potential long-term care users prepared by the pilot environments despite insufficient existing data in this field and also the assessment drafted by the Social Protection Institute of the Republic of Slovenia based on the collected and calculated data. We assessed that some 2,145 users of long-term care (of services and cash benefits) were found in the Celje pilot environment in 2016, 1,050 in the Dravograd pilot environment and 841 in the Krško pilot environment.<sup>44</sup> In their bids to the public call, the pilot environments themselves stated that there were many more long-term care users in their environments than anticipated by the criterion

<sup>44</sup> To assess the number of long-term care users in pilot environments, the methodology prepared by the working group at the Statistical Office of the Republic of Slovenia in 2014 was used (Nagode et al., 2014). We proceeded on the basis of the data at the national level for 2016 (latest published data), which is collected and published annually by the Statistical Office of the Republic of Slovenia.



set in the public call for individual types of environments: “The anticipated number of existing and potential users of the project concerned considerably exceeds the minimum indicators set...” (Celje Health Care Centre, 2018); “We understand that we by far exceed the condition of providing 70%...” (Residential Home for the Elderly Koroška in Dravograd, 2018).

The evaluation results support the proposal for the adjustment of the assessment scale from the pre-pilot project (Lebar et al., 2017) to include in the scoring all eight modules and not just the first six as was seen in the German model (Wingenfeld et al., 2008). It was specifically revealed that the adjustment of scoring did not have a significant impact on the proportion of people eligible for long-term care as only 76% of applicants were entitled to long-term care if only the first six modules were observed, and 79% if we observed all modules. As stated initially, the activities defined in modules 7 and 8 maintain a higher quality of life.

From the viewpoint of time consumption when completing the assessment scale, it was determined that the scale was suitable for assessing eligibility for long-term care. The results revealed that the average time of assessment at the applicant's home amounts to little over one hour and does thus not present a great time load for the assessor or the applicant.

The results obtained through the ordered probit model confirm the expected effects of individual explanatory variables and simultaneously reveal the suitability of classifying applicants in eligibility categories. We can thus conclude that the assessment scale is suitable for assessing eligibility for long-term care, and different profiles of assessors do not make a difference when classifying applicants in eligibility categories. The results further show that the probability of being classified in a higher category of eligibility in semi-rural and rural environments does not on average differ significantly from the probability of classification in an urban environment.

The assessors also think that the scale is suitable for assessing eligibility for long-term care and consider the concept of assessing people's independence, on which the assessment scale is based, as a suitable method of evaluation. When assessing eligibility, the assessor must assess the person with regard to their current condition, whereby they do not observe the broader context of receiving assistance (e.g. assistance by informal carers in their home environment and assistance by formal carers in an institution). They must consider the fact that a person lives alone and assess on this basis how much assistance they require for implementing individual activities. The starting point for assessment is the person's needs, so if they do not wish to carry out a certain activity this is noted in the assessment. In the event of a significant change in the user's living circumstances which may affect the amount of assistance the user needs, it is necessary to implement the eligibility assessment again.

The assessors perform the eligibility assessment on their own, which is why we were unable to determine the level of compliance of several assessments (compliance of scoring and classification in the eligibility category) and thus the objectivity of the assessment scale from the viewpoint of a multiple assessment of the same user.

Improved objectivity of the assessment scale was only one of the reasons why the assessors proposed that the eligibility assessment should be implemented by two assessors. The advantage of two assessors lies in the technical aspect of the assessment implementation (decreased use of service vehicles, less time required to draft the assessment), improved professionalism when assessing (if assessors represent different expert profiles, there is no need for additional consultation with colleagues at the single entry point) and improved safety of assessors. They further claimed that when assessing on their own, they seldom use a computer for prompt taking of notes or even entering of assessments. When assessing they have to focus on the applicant



(“aspect of humanity”) and avoid practices which would lead them to become “insurance agents”, as one assessor expressed themselves vividly at the democratic forum. If the assessors implement the eligibility assessment in a pair, they could produce two to a maximum of three assessments a day, while one assessor completes one to two eligibility assessments in a day and visits one to two applicants at their homes. The proposed standard is the result of a deliberative discussion at the democratic forum.

In addition to the method, the eligibility assessment also resulted in another novelty, i.e. the proposal of a new professional profile in Slovenia – the assessor. The assessors trained for their work during the pilot project. They acquired good assessment skills. Problems arose when assessing persons with sensory disabilities,

dementia patients and persons with mental disorders. When introducing new profiles such as the assessor, continuous theoretical and practical training is important in addition to initial training. Joint assessments with expert assessors proved to be exceptionally useful among practical training courses, and so were the peer and inter-professional consultations. Together with expert assessors, the assessors from the pilot environments represent an important professional group which obtained valuable practical experience during the project through this new method being introduced in Slovenia, and thus present an indispensable learning base for further steps in the systematic introduction of the eligibility assessment in the Slovenian long-term care system.

## BIBLIOGRAPHY

- Büscher, A., Wingefeld, K., & Schaeffer, D. (2011) *Determining eligibility for long-term care – lessons from Germany*. International Journal of Integrated Care. 11(2).
- Carrino, L., & Orso, C. E. (2014) *Eligibility and Inclusiveness of Long-term Care Institutional Frameworks in Europe: a cross-country comparison*. Ca' Foscari University of Venice, Dept. of Economics Research Paper Series No. 28/WP/2014.
- Lebar, L., Dremelj, P., Flaker, V., Rode, N., Mali, J., Peternelj, A., Smolej Jež, S., ... Kobal Tomc, B. (2017). *Priprava podlag za izvedbo pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi* Aktivnost 1: Priprava orodij za ugotavljanje potreb uporabnikov, metodika postopka ter ugotavljanje upravičenosti do storitev dolgotrajne oskrbe. Ljubljana: Inštitut RS za socialno varstvo.
- McCullagh, P. (1980). *Regression Models for Ordinal Data*. Journal of the Royal Statistical Society. Series B (Methodological). 42 (2): 109–142.
- Nagode, M., Lebar, L., & Dremelj, P. (2018). Orodja za ocenjevanje potreb po dolgotrajni oskrbi v evropskem prostoru: izkušnje in izzivi za Slovenijo. Socialni izziv, 23(39), 46–54.
- Nagode, M., Lebar, L., & Kovač, N. (2014). Pregled izvajanja socialne oskrbe na domu po evropskih državah s poudarkom na ocenjevanju potreb uporabnikov, Končno poročilo. Ljubljana: Inštitut RS za socialno varstvo.
- Nagode, M., Zver, E., Marn, S., Jacović, A., & Dominkuš, D. (2014). Dolgotrajna oskrba – uporaba mednarodne definicije v Sloveniji. Urad RS za makroekonomske analize in razvoj. Retrieved from [https://www.umar.gov.si/fileadmin/user\\_upload/publikacije/dz/2014/DZ\\_02\\_14.pdf](https://www.umar.gov.si/fileadmin/user_upload/publikacije/dz/2014/DZ_02_14.pdf)
- Ranci, C., Österle, A., Arlotti, M., & Parma, A. (2019) 'Coverage versus generosity: Comparing eligibility and need assessment in six cash-for care programmes', Social Policy & Administration, vol. 53, pp. 551–566.
- Rodrigues, R. (2014). *Long-term care: the problem of sustainable financing*, Discussion paper, Peer Review on financing of long-term care, Slovenia.
- Social Protection Committee & the European Commission. (2014). *Adequate social protection against long-term care needs in an ageing society*.
- Wingefeld K., Büscher A., & Gansweid B. (2008). *Das neue Begutachtungsassessment zur Feststellung von Pflegebedürftigkeit*. [The new assessment tool for determining the need for nursing care], Bielefeld, Institut für Pflegewissenschaft an der Universität Bielefeld.

**PERSONAL PLANNING AND COORDINATION  
IN LONG-TERM CARE: IDENTIFYING NEEDS  
AND PLANNING CARE TOGETHER WITH  
THE USER**

Magdalena Žakelj  
Inštitut RS za socialno varstvo

Mateja Nagode  
Inštitut RS za socialno varstvo

## KEY MESSAGES

- ▶ The personal plan should be a central document in which the user's data is covered broadly enough to avoid the practice of the user answering the same questions asked by several different experts.
- ▶ The use of the personal planning method would require multiple training sessions and continuous monitoring of the development of personal plans in order to provide support to long-term care coordinators in even more user-oriented and broad-based personal plans.
- ▶ Personal plans should record the user's life story, which provides a wide awareness of their context and clearly reflects their desires and goals, from which the necessary services are derived.
- ▶ In order to avoid fragmentation of individual care, we propose that all goals from the life story should be written in a personal plan with an arrangement about who will implement them, or which other services/organisations will be involved in their implementation.
- ▶ Annexes ("changes" or "revisions") of the personal plan should show changes in the scope of services, as they follow chronologically.
- ▶ For the future use of the personal planning method in long-term care, it should be defined as to what form of personal plan

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and life story writing should be used - a broad-based personal plan or a personal plan focused on long-term care services. Depending on the decision, it will be necessary to adapt the forms and instructions and train the employees.

- The pilot projects have confirmed that the long-term care coordinator is the central profile of long-term care, and their work is highly team-based.
- The role of long-term care coordinator has proven to be meaningful and crucial for further work with users. We propose that the norm of the number of users with whom an individual long-term care coordinator should cooperate be set low enough that they are able to follow the concepts of the personal planning method and coordination of services in their work.
- Considering the warnings of long-term care coordinators from pilot environments, we propose that the possibility be introduced in the future of providing a “transitional service package” or “initial service package” that the user would receive after the assessment of eligibility, during the creation and adaptation of the personal and, with it, the implementation plan regarding their needs.
- We propose that long-term care coordinators be systematically acquainted with the social model of cooperation with the user, as included in the principles of the personal planning method.

## Introduction

The personal planning method used in pilot projects of long-term care is one of the methods that began to develop in the world in the mid-1980s. In Canada, it was known as case management, and in the United Kingdom, care management (planning and implementation of care) was used in addition to this term. This personal planning method is not new in Slovenia either, as it started to be introduced in social care in the mid-1990s, after it was first presented by David Brandon in 1993 (Brandon, D. & Brandon, A., 1994; Videmšek & Mali, 2018).

In Slovenia, the method had different names in different periods. Initially, it was the care plan as a direct translation of care planning (*ibid.*), then the individual plan for independent living (Zaviršek, Zorn, & Videmšek, 2002), followed by individual planning with realisation of goals (Škerjanc, 2006; Škerjanc, 2010) and then individual planning and service provision (Flaker, Nagode, Rafaelič, & Udovič, 2011). Today the most broadly used term is individual planning and implementation of services (Flaker, Mali, Rafaelič, & Ratajc, 2013).

Despite the fact that personal planning is not new in Slovenia, the method is still considered innovative. For example, “in institutional care for older people, it is mentioned as a condition for innovation, because according to Mali et al. (2017), the needs of residents, sustainable changes in institutional care cannot be ensured without individual planning and monitoring.” (Videmšek & Mali, 2018).

In Slovenia, the described personal planning method was developed, adapted and used mainly by professionals in the field of social work, and the key new feature that it brought was the shift in the treatment of the user, from the user as an object of treatment to the user as the central subject in defining their needs and creating solutions to satisfy them. The key tool of personal planning is thus the personal plan, which consists of a life story, goals and a plan for the implementation of goals (implementation plan).

In the practice of creation of personal plans, and otherwise, we often or exclusively focus on the health condition or deficits of the older people and people who need support, which we see as the main source of their problems – in this respect we speak about acting within the medical model of disability or cooperation with the user. Consequently, this leads to the creation of a personal plan that contains mainly medical and corrective measures. In order to avoid medicalisation, as the Common European Guidelines on the Transition from Institutional to Community-based Care call the manner in which a person is perceived as part of the medical model, personal plans must be comprehensive, based on the social model of disability or cooperation with the user, or on the theory of social exclusion (Škerjanc, 2004; Škerjanc, 2006). This includes identifying barriers in the environment that are the main factor that restricts people, as well as recognising that people with disabilities are eligible for full and equal participation in all aspects of society (Common European Guidelines on the Transition from Institutional to Community-based Care, 2012). As with the mentioned models of disability or cooperation, the aspect of health is also approached from a medical or social model.

From the aspect of the use of nursing diagnoses in healthcare, Ščavničar (1998: 32) notes that “pre-prepared models for nursing diagnoses are only a guideline that is complemented by those special features that are obvious in the client as a unique being”. She also emphasised that these should be based on health and should not be exclusively focused on disease, and that they should be developed and supplemented (*ibid.*). Roper, Logan and Tierney (2001) have created a model for assessing needs and planning care in nursing care that should enable the assessment of all human needs based on the life cycle of a person. The purpose of this model is to plan the greatest possible independence and quality of life of the user or patient; when planning it is necessary to cooperate with them at all times. In assessing needs and planning care, it is first necessary to get

to know the person and their needs, plan how to compensate for deficits and advance human health and other areas of life (Roper et al., 2001).

In the document Preparation of bases for the implementation of pilot projects that will support the transition to the implementation of the systemic act on long-term care (Lebar et al., 2017), drafted by a group of professionals in social and health care and commissioned by the Ministry of Labour, Family, Social Affairs and Equal Opportunities, guidelines are provided on how to prepare a personal plan in accordance with the “method of personal planning of long-term care based on life-world research” and how to set goals and plan the use of both the resources already available to a person and those that are still to be gained in order to achieve their goals.

The creators of the bases for the implementation of pilot projects in the field of long-term care have proposed a personal planning method for use in pilot environments that, in their opinion, best encompasses a person's life in a way that enables their needs to be identified and the services required to satisfy them to be selected. Of course, this method is not the only possible method, as we could use another one that would meet the criteria from the Common European Guidelines on the Transition from Institutional to Community-based Care (2012). These state that there is no uniform answer as to what methodology should be used for determining needs and for personal planning, as long as it follows the following principles:

- ▷ involving users or their relatives or advocates, where appropriate, in deciding on their future and support services. The assessment cannot be made solely by viewing the file and talking to the user's carers or professionals;
- ▷ true involvement of the family or advocates throughout the entire process (depending on needs);
- ▷ an integrated approach that takes into account the person as a whole, not only their disability;
- ▷ taking into account the advantages and resources

of the individual, in addition to their needs and the problems they face.

Modern trends and legislation in the field of long-term care (e.g. AGE Strategy 2022-2025, Care Act 2014, Common European Guidelines on the Transition from Institutional to Community-based Care, 2012) show that tailored care and personal planning should be focused on a person's life as a whole. The goals arising from the personal plan or life story of the user, therefore, concern not only the healthcare and social care services or goals that are expected to be implemented as part of long-term care services, but also other goals of this person. The purpose of a personal plan is to achieve the user's goals with the help of a personal story. In the implementation plan, the goals are then “broken down” into tasks that lead to their realisation or implementation. Goals are thus an important part of the personal plan, as “goal-oriented” care is a response to the limitations of care that is oriented towards problem-solving, especially when facing the growing complex needs of people with numerous chronic conditions and challenges in the socio-economic situation.” (Boeckxstaens, Boeykens, Macq, & Vandenbroeck, 2020).

## Methodology

The goal of the evaluation was to evaluate the implementation of the personal planning method and the work of the long-term care coordinator in pilot projects, and to prepare proposals for amendments that would be important in the transition to the systemic provision of long-term care. To this end, we focused on reviewing personal plans<sup>45</sup>, with special emphasis on monitoring the result indicator *‘proportion of users with personal plans that are being implemented’*. In reviewing personal plans, we focused on the recorded living conditions, goals and implementation plans, and at the same time on the observance of the principles of the personal

<sup>45</sup> Personal plan for the provision of long-term care as part of the pilot activities »Implementation of pilot projects that will support the transition to the implementation of the systemic law on long-term care« (hereinafter referred to as: personal plan).

planning method both in the mentioned records and in the work of the long-term care coordinator as part of personal planning. At the same time, our goal was to evaluate the role of the long-term care coordinator both in light of cooperation with the user and other stakeholders as part of the provision of services, as well as in the field of coordinating the provision of services.

In order to be able to evaluate the set goals and indicator, we used several types of data and information.

One of the richer sources of information is the personal plans of users. We have received a total of 576 such plans: 181 from Celje, 159 from Dravograd and 236 from Krško. We included 60 in the random sample for the systematic analysis of personal plans<sup>46</sup> - 20 from each pilot environment. We reviewed and included in the analysis all 71 received revisions of the plan or annexes to the personal plan: 35 from Celje, 9 from Dravograd and 27 from Krško. We analysed the records of all elements of both documents.

In order to be able to evaluate the user experience with personal planning and coordination of services, we included the users in surveys and interviews. After six months of involvement in the project activities, they responded to a questionnaire on the experience of care, with an emphasis on coordination and the central role of users. We received a total of 259 responses (101 from Celje, 87 from Krško, 71 from Dravograd), which represents 59.5% of all of those assessed for the second time<sup>47</sup>: The quantitative data was then enhanced with the qualitative data, with interviews with users and informal carers being conducted for this purpose. We were interested in their experience of being involved in the pilot projects. The guidelines for the interview were adjusted to the aspect of an individual target group, while they otherwise covered the same key topics, including the experience of personal planning and coordination.

To gain insight into the work and role of the long-term care coordinator, we conducted several semi-structured interviews with the long-term care coordinators at two points of time. We first conducted four interviews between April and June 2019 (one each in Krško and Dravograd and two in Celje), and an additional seven as the project was being concluded: three in Celje, three in Krško and one in Dravograd. In the second interview, in addition to the experience of the role of long-term care coordinator, we were also interested in their reflection on the experience in the pilot project and the vision of the long-term care coordinator's profile in the future. Those who assumed the role of long-term care coordinator later or while the project was already being implemented were asked in more detail about their experience of the commencement and conclusion of the role and transfer of knowledge and work. In Dravograd, we conducted an additional interview with the long-term care coordinator who performed their work at the general hospital, focusing on the experience of coordinating discharges from the hospital. We also reviewed the reports of employees on activities as part of the pilot projects and relied on some of the findings or results of deliberative discussion in the democratic forum and reviewed the minutes of 13 meetings between the contracting authority, pilot project coordinators and long-term care coordinators. More on individual measuring instruments in Chapter *Evaluation of pilot projects and methodology*.

## Results

In the remainder of the article, we will focus first on the profile of the long-term care coordinator and their role in the project from the aspect of coordination of long-term care services, and then on the field of personal planning and in more detail on the personal plan and its individual

<sup>46</sup> We first included in the selection the fourteenth in order from the list of all plans (they followed in the order of user codes - first the Celje pilot environment, then Krško and Dravograd), and then included in the sample every fifth one that contained all the data that was the subject of analysis.

<sup>47</sup> The questionnaire was conducted by the assessors when making the second eligibility assessment with the user.



elements, which are compared with the concepts of the method used.

## Long-term care coordinator and long-term care coordination

According to the public call for applications (2018), the post of a long-term care coordinator could be assumed by a graduate social worker or a registered nurse. In the pilot projects, the structure was dominated by the social worker profile: five were social workers and two were registered nurses. The experience of pilot projects has confirmed that this role can be performed by both profession profiles, although, as the long-term care coordinators pointed out themselves, it is essential that they have knowledge of both professions - healthcare and social care. What leads us to such a conclusion is also the following statement from an interview with a long-term care coordinator: *"It is good that a long-term care coordinator comes from both the healthcare and social care staff. Because the medical staff, as I said earlier, are focused on the implementing service, while the social staff are more the ones who listen and, I would say, have a little bit broader social sensitivity than the health staff, but it's not that healthcare workers don't have it. In order to cover this field comprehensively, it would also be good to ensure that these two professions really complement each other in the future."*

As new methods and approaches were used in the pilot projects of long-term care, the long-term care coordinators participated at the beginning of their implementation in special education and training sessions specifically intended for their role in the project – implementation of personal planning and coordination of pilot activities. The training sessions were carried out by experts in the field of health and social work, authorised by the contracting authority of the pilot projects. The training sessions empowered them to work with users and other stakeholders. Of key importance for their work was knowledge of the principles of personal planning, establishing a work

relationship, knowledge of the structure of the personal plan, researching the user's life-world, recording the personal plan and the importance of revising the personal plan.

The long-term care coordinators who started working on pilot projects at a later date did not receive this type of training, and where this was possible, they were taught how to perform the work by their predecessor. The transfer of work and knowledge took place in different ways, from a few hours to a few days, depending on when the new long-term care coordinator started working and whether the previous long-term care coordinator was still employed in the pilot project. Some long-term care coordinators handed over their notes with detailed instructions to their successors and showed and explained all the main and most important elements. One long-term care coordinator noted in an interview that they went through one role and personal plan with the predecessor, and one mentioned that they handed over to the new long-term care coordinator material and literature from the initial training for long-term care coordinators.

In the Krško and Celje pilot environments, three different employees held the position of long-term care coordinator during the pilot project, which meant significant fluctuation for the project, multiple interventions in the group dynamics and, last but not least, an impact on knowledge transfer between long-term care coordinators. In the Dravograd pilot environment, this role was performed for the duration of the project by two long-term care coordinators employed for half of the full time.

As part of the pilot projects of long-term care, the first task of the long-term care coordinator in cooperation with the user was to create a personal plan (more in the next sub-chapter). In addition to this role, the role of connecting and coordinating all stakeholders involved in care, with the common goal of ensuring good and safe integrated long-term care for users, was also important. The long-term care coordinator thus led the care unit and the independence maintenance unit and worked

closely with the single entry point. They also connected and cooperated with other stakeholders from the environment: centres for social work, home help providers, community nursing and others. The long-term care coordinators also agreed in the interviews that their work was highly team-based and that they played a strong role in connecting with all employees within and outside the project (more on this in Chapter *Teamwork and integration of stakeholders as the foundations for ensuring integrated long-term care*). As part of the coordination, the long-term care coordinator compiled care provision schedules and coordinated the providers and thus took care of the organisation of care. They were available for phone calls from employees who had various questions related to care or reported absence, as well as from users when they cancelled the implementation of services for a certain day, even outside working hours – in the afternoons and at weekends. This meant that when receiving a call from an employee reporting absence, they had to arrange a substitute and inform users of any changes in the provision of services and vice versa.

It follows from the monitoring of the work of the long-term care coordinator that, in addition to personal planning and coordination of long-term care, they performed many other tasks as part of their job description, including (optionally) participating in establishing a pilot project in a pilot environment and contributing to creating teams by selecting staff and working with the contracting authority and other pilot environments in creating the forms used in the procedures for exercising and implementing the right to long-term care. They also participated in the creation of the procedures themselves and establishing methods of cooperation with the teams as part of the pilot environment. They were in charge of involving and coordinating informal carers and volunteers. This meant that they organised various education and training sessions for them, which they attended themselves. For the duration of the entire pilot project, and especially at the beginning, in some cases the long-term care coordinator

arranged presentations of the pilot project and also implemented them in various organisations in the pilot environment. Throughout the pilot project, they were the central person and also collaborated with the evaluator.

The following statement from an interview indicates that the work of the long-term care coordinator in the pilot projects was very broad: *“The coordinator has a lot, a lot of work to do. This is perhaps also because the work of formal providers who are on the project needs to be coordinated, to adapt to them in some way, and of course to adapt to the user and their relatives, who had their own expectations and wishes, who required time for conversations, so there were many telephone conversations. There was considerable coordination of schedules, even after the implementation plan was signed. In short, much coordination, and adjustments of sorts to this person and that person. There is a lot of work.”*

Even when the pilot projects were coming to an end, when the activities stabilised and ran more smoothly, there was still a considerable amount of work for long-term care coordinators, as one of them said in an interview:

*»... the work is still totally varied, even strenuous, because you have to be ready to communicate every day; both with users on the one hand and with representatives of the system/mayors on the other ... Because you fight for their rights, organise training, sessions, and for employees; if their car breaks down, you arrange a new car or a company car ... So, it is precisely because of this different/diverse work and the 24-hour presence that it is, well, demanding.”*

We ascertained that all these activities did not leave the long-term care coordinator much time left for direct contact with users. Given the number of those involved in the provision of services, one can imagine how small the amount of contact with an individual user actually was. This is also confirmed by the following statements by interviewed long-term care coordinators:

*“I basically embarked on this with an idea of being a long-term care coordinator, and I*

*imagined it to be more teamwork, work with users, and coordinating work in the field; that the user essentially gets the services they require .... However, it was actually also promotion, and informing, and municipalities/partners ....”*

*“I may have had a distorted idea. I badly wanted to do more social work. And I did, but it was mostly those first visits, contacts in the family, when you get to know the situation and see what they need.”*

During the evaluation, we noticed in several different places that the scope of work of the long-term care coordinator was in fact set very broadly. They were also the only ones to carry out personal planning, as opposed to the eligibility assessment, which was carried out by several assessors. These were able to assess a large number of applicants in a short period of time, of whom all eligible ones then had to be visited by the (sole employed) long-term care coordinator. For this reason, in the Dravograd pilot environment, two social workers from the independence maintenance unit assisted the long-term care coordinator in preparing personal plans and establishing and managing services, in agreement with the contracting authority of the project.

The scope of work for the post of a long-term care coordinator was set too broadly in the pilot project and therefore resulted in coordinators being overburdened, and for some this was the reason why they left the post. One of the employees wrote in the evaluation report that:

*“I assess that there is simply too much work for a single coordinator, with the number of people being so large.”*

In interviews, long-term care coordinators expressed their reservations and concerns in the following way:

*“...it always seems to me that there should be more coordinators given the number of assessors. But this is how the public call for tenders was set up”.*

*“It seemed to me that I couldn’t make it, that I’m not able to. It was such a large burden on me, even outside work. It was difficult, I don’t know.”*

One pointed out that the work of the long-term care coordinator was “multifunctional”, as in addition to social work (for example, personal planning), it also required a lot of organisational knowledge and skills (networking and coordination). However, the nature of the work of long-term care coordinators changed during the pilot project, as they initially spent more time educating employees, setting up the project itself (e.g. preparing documentation) and focusing on planning of work (e.g. establishing procedures and protocols), and only later were they able to focus more on the work with users, in the field. Only one long-term care coordinator had such a comprehensive experience - the one who performed this work throughout the entire pilot project.

## Personal planning and personal plan

Following the eligibility assessment carried out by the assessors with the applicants, the long-term care coordinators started personal planning with those beneficiaries who wanted to be included in the services. The basic document of the personal planning method was the personal plan<sup>48</sup>, which in the introduction contained personal and contact information of the user<sup>49</sup> and their guardian, legal representative or informal carer, followed by elements that we focus on in this sub-chapter: living conditions, short-term and long-term goals and an implementation plan with services defined as the user is expected to receive them. The form for the personal plan also envisaged the following items: additional proposals for professional goals and measures, required connection or inclusion of other services/providers or desired involvement of organised volunteers, and the method of inclusion of other healthcare and social care services, volunteers or informal carers, and the item of possible

<sup>48</sup> The template of the personal plan form was prepared by the contracting authority and coordinated for use with the pilot environments.

<sup>49</sup> In this part, the term user is also used for a person who has been assessed as eligible and for whom a personal plan was prepared.

additional comments relevant for consideration in long-term care. At the bottom of the form was a space for the signature of the user and coordinator of long-term care and a space for entering the place and date of the created plan.

Before paying a visit at home, the long-term care coordinators were able to obtain information relevant to the personal plan from the eligibility assessment and, in many cases, from conversations with employees from the independence maintenance team, who provided their opinions on the basis of a review of the eligibility assessment even before the scope of their services was determined as part of the personal plan. The long-term care coordinator then obtained other important information at the first visit to the user. These visits were usually attended by relatives or other informal carers who could participate in the discussion and development of the personal plan. In a conversation with the user and their relatives, the long-term care coordinator further anticipated which services would be appropriate for their situation and presented these services to them. After the visit, they made a final agreement with the employees of the independence maintenance unit regarding all the services they are supposed to receive. After that, the long-term care coordinator wrote down the personal plan with the implementation plan and sent it or brought it to the user for their signature. They entered the new services in the service implementation schedule and provided all information to the employees from the care unit and reminded them of any possible special features.

In the Krško pilot environment, where the rate of created personal plans was the highest (81.7%)<sup>50</sup>, personal plans were not made mainly in cases where beneficiaries did not want to use the service, and often the reason was also the death of the beneficiary. The situation was similar in Dravograd (69.1%)<sup>51</sup>. In the Celje pilot environment, where the rate of created personal plans was the

lowest (47.9%), the situation was somewhat more specific - the problem of long waiting lists soon emerged, as not all beneficiaries could be covered by the available staff, so personal plans have not been drawn up for these beneficiaries. In general, the “proportion of users with personal plans that are being implemented” for all environments combined was 64.2%.

### **LIVING CONDITIONS – A SUFFICIENT FRAMEWORK FOR COMPREHENSIVE IDENTIFICATION OF USER NEEDS?**

In accordance with the personal planning method, the long-term care coordinator, in collaboration with the beneficiary, records their life story, from which they identify together the beneficiary's needs and determine the goals on the basis of which the services will be determined. In the personal plan, the life story was renamed “living conditions” in the pilot projects, and in the created personal plans these are usually represented as an abbreviated version of the record of “living circumstances”, as recorded by the assessors in the Eligibility Assessment form. The same instruction for recording was provided in both forms – *“living conditions and housing conditions, daily life and care, assessment of the condition (physical and psychosocial).”* The long-term care coordinators therefore made similar notes to those of the assessors, only in an abbreviated way, and in some cases, they directly copied the record from life circumstances, as one of the interviewees pointed out: *“I was told the following: here you make it out of this assessment, which is a biography of that person, it's basically copy-paste, you copy it and make it shorter. That is, what is not important for care you take out, you copy the services that were proposed by the assessor, and then you can make additions. But it's not quite like that. [...] For future use, I set it out*

<sup>50</sup> Calculated as a proportion of personal plans created for those applicants who were eligible for long-term care in the first assessment.

<sup>51</sup> In the Dravograd and Celje pilot environments, the reasons for the interruption of pilot activities were not recorded in the information system in all cases.

*differently, more broadly and more in line with what I talked about with the user.”.*

A comparison of the records made by the assessors and coordinators of long-term care, i.e. “living circumstances” and “living conditions”, shows that there were almost no substantive differences between the records. The content in both records included data describing the user’s status that intertwined with a description of the help the user needed and the information on who provided it, and it was also indicated what else they were able to do on their own. The record placed an emphasis on the health condition of the user and the help they needed relative to the health condition. Interviews with long-term care coordinators showed why there were no major differences between the records made by assessors and long-term care coordinators:

*“I always got a life story from our assessors, in fact you let them (users) know already that you know the situation, that they don’t need to talk about such painful things, because there are many different things that may have already been established by assessors and we basically focused more on the services that they receive. Because you could basically see in the eligibility assessment what he can do, where he is still independent, where his strengths are, and where he needs help. So, we focused more on that – their feeling of what they would accept and where they feel they need help”.*

It transpired that there were no major substantive differences between the records made by individual long-term care coordinators from different pilot environments. In addition, the long-term care coordinators consulted with other persons participating in the project before making the final record of the user’s living conditions and the content of their eligibility assessment, and added their observations to the description of the living conditions.

In various discussions, as evidenced by the minutes of meetings of various teams, long-term care coordinators and the contracting authority, interviews with long-term care coordinators and the discussion in the democratic forum, the question

emerged of the user’s access to records about their living conditions or circumstances: should these records be shown to the user at all, or whether it is more appropriate to create two types of records - one to be given to the user and the other to be used only by employees. For example, one environment has adopted the practice of not sending a description of life circumstances in the Eligibility Assessment form to applicants who were not eligible for long-term care services. In the other two environments, according to the long-term care coordinators, the assessors recorded the content regarding living circumstances that was sent to the applicant in the scope and content at their own discretion, in particular when this included content to which the applicant could react negatively (e.g. excessive alcohol consumption, causing violence, descriptions of the applicant or their living environment being unkempt, etc.). The assessors kept such statements separately, and they could be accessed by the long-term care coordinator and, if necessary, by others who worked with a specific user.

Here are examples of records from personal plans that, according to the principles of the personal planning method, should not appear in personal plans or other user records:

*“Speech is difficult to understand.”, “She is obtrusive for other residents”, “Does not look good”, “Participates appropriately in a conversation”, “He is oriented”, “Cognitive abilities are intact”, “The person has motivation”, “The lady does not know what month it is, whether she has taken her therapy or not.”.*

Such sentences are problematic or ethically questionable, regardless of whether they are written in a positive or negative sense, as they devalue and confuse the person. These are sensitive topics, and such notes can hurt a person because they do not understand on what basis they were created. The following example, in which a user who pointed out in an interview that he was affected when he received a personal plan in which the long-term care coordinator wrote that he had no motivation, shows the negative impact of such recording:

*Interviewer: The gentleman helped you or you did that on your own? User: No, I did it on my own. After she wrote that I have no motivation or anything. Maybe I was in such a mood that day, so ...*

*Interviewer: [...]*

*User: Yes, it affected me a little bit, because motivation is one thing and you thinking about the meaning of life is another, let's say.*

## GOALS AND IMPLEMENTATION PLAN HAND IN HAND

Long-term care coordinators wrote down goals in personal plans in a variety of ways. As already stated, the long-term care coordinators in all three pilot environments usually made the record of living circumstances with a strong emphasis on the health condition of the individual and on what help the user needed, and less often they recorded actual, specific preferences of the user (what a life story, for example, should contain), which is why it is noticed that the goals in personal plans are quite structured: very short, written in a similar way for different users, tied to help from the point of view of the user's health condition.

In most personal plans, the goals follow well the story written in the living conditions and relate to it. For example, if a person needs any form of care, help with physical tasks or company, this is reflected in the goals:

*"The lady would like to socialise, as she feels lonely. GOAL: Socialising".*

In rare cases, when the user, or relatives on their behalf, expresses a specific wish, this is consistently stated in the goals:

*"Last autumn, they were able to accompany him up/down the (steep) stairs so that he could go for a walk in a wheelchair, outside the house. He would like this to be so this year. GOAL: Improving the physical condition, ability of transportation - while being helped up/down the stairs, on the wheelchair and outside the house."*

In some examples, it is clear from the description that the goal represents exactly what

the user needs, while it is not clear from what is written that he would have said during the conversation that this is exactly what he wants:

*"[...] has suffered a stroke, [...]. His speech remained the most affected, which he cites as very annoying, as conversations and socialising have always meant a lot to him. GOAL: Improving communication skills".*

It also happens that the long-term care coordinators fail to record the set goal in the form as it was written in the living conditions, or that it is not evident from the record on the living conditions at all or it may have been set by the user's relatives:

*"The relatives and the user want the transfer to the wheelchair to be carried out safely so that they can bring him to the car and go on a trip together. GOAL: Establishing basic motor functions that would enable him to be independent in performing as many basic daily activities as possible."*

*"The lady lives [...]. The diagnosis is dementia,[...] The lady's blood pressure fluctuates greatly, [...]. The lady does not want to be cared for by her relatives, she does not refuse the help of strangers [...]. The lady is tiny and of medium height. GOAL: The relatives want morning care and physiotherapy."*

The long-term care coordinators created the objectives of the implementation plan primarily as descriptions of services: *"Preservation of motor functions, strength, mobility", "Obtaining physiotherapy/occupational therapy," "Measuring blood sugar and controlling medication", "Assistance in the provision of personal care".*

In the personal plans, the long-term care coordinators in all three pilot environments mostly recorded the short-term goals of users, while long-term ones were recorded less often. For many users, it was evident from the records of living conditions that, due to their health condition, certain services need to be arranged for them immediately. Services recorded in personal plans, e.g.: physiotherapy, personal care, assistance in nutrition, were therefore usually listed as short-term goals. Under the long-term goals, the long-



**Table 1: An example of an implementation plan with goals and an implementation plan****Goal 1: Assistance in care**

| Service code | Name of service                             | Provider | Start date | End date | Date of implementation of service (what days, from – to)                                                          | Possible special features in implementation of service |
|--------------|---------------------------------------------|----------|------------|----------|-------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|
| <b>O3</b>    | Dressing and undressing                     | SO       | 17/05/2019 |          | Mon: 1:30 p.m. – 2:30 p.m.<br>Tue: 1:30 p.m. – 2:30 p.m.<br>Wed: 7:15 p.m. – 8:15 p.m.<br>Thu: 1 p.m. – 2:30 p.m. |                                                        |
| <b>O5</b>    | Hair washing                                | SO       | 17/05/2019 |          | Mon: 1:30 p.m. – 2:30 p.m.<br>Tue: 1:30 p.m. – 2:30 p.m.<br>Wed: 7:15 p.m. – 8:15 p.m.<br>Thu: 1 p.m. – 2:30 p.m. |                                                        |
| <b>O6</b>    | Healthy nail care/fingernail trimming       | SO       | 17/05/2019 |          | Mon: 1:30 p.m. – 2:30 p.m.<br>Tue: 1:30 p.m. – 2:30 p.m.<br>Wed: 7:15 p.m. – 8:15 p.m.<br>Thu: 1 p.m. – 2:30 p.m. |                                                        |
| <b>O7</b>    | Healthy nail care/toenail trimming          | SO       | 17/05/2019 |          | Mon: 1:30 p.m. – 2:30 p.m.<br>Tue: 1:30 p.m. – 2:30 p.m.<br>Wed: 7:15 p.m. – 8:15 p.m.<br>Thu: 1 p.m. – 2:30 p.m. |                                                        |
| <b>O8</b>    | Skin care                                   | SO       | 17/05/2019 |          | Mon: 1:30 p.m. – 2:30 p.m.<br>Tue: 1:30 p.m. – 2:30 p.m.<br>Wed: 7:15 p.m. – 8:15 p.m.<br>Thu: 1 p.m. – 2:30 p.m. |                                                        |
| <b>O11</b>   | Morning full body wash, bed bath or bathing | SO       | 17/05/2019 |          | Mon: 1:30 p.m. – 2:30 p.m.<br>Tue: 1:30 p.m. – 2:30 p.m.<br>Wed: 7:15 p.m. – 8:15 p.m.<br>Thu: 1 p.m. – 2:30 p.m. |                                                        |

**Goal 2: Care for maintaining health**

| Service code | Name of service                                                                                                     | Provider | Start date | End date | Date of implementation of service (what days, from – to)                                                          | Possible special features in implementation of service |
|--------------|---------------------------------------------------------------------------------------------------------------------|----------|------------|----------|-------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|
| <b>Z14</b>   | Monitoring of vital functions in a stable chronic disease                                                           | BN       | 17/05/2019 |          | Mon: 1:30 p.m. – 2:30 p.m.<br>Tue: 1:30 p.m. – 2:30 p.m.<br>Wed: 7:15 p.m. – 8:15 p.m.<br>Thu: 1 p.m. – 2:30 p.m. |                                                        |
| <b>O12</b>   | Assistance in eating and drinking by mouth, including serving food and drink to people without swallowing disorders | SO       | 17/05/2019 |          | Mon: 1:30 p.m. – 2:30 p.m.<br>Tue: 1:30 p.m. – 2:30 p.m.<br>Wed: 7:15 p.m. – 8:15 p.m.<br>Thu: 1 p.m. – 2:30 p.m. |                                                        |

**Goal 3: Assistance in household**

| Service code | Name of service                 | Provider | Start date | End date | Date of implementation of service (what days, from – to)                                                          | Possible special features in implementation of service         |
|--------------|---------------------------------|----------|------------|----------|-------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------|
| <b>P4</b>    | Assistance in running household | SO       | 17/05/2019 |          | Mon: 1:30 p.m. – 2:30 p.m.<br>Tue: 1:30 p.m. – 2:30 p.m.<br>Wed: 7:15 p.m. – 8:15 p.m.<br>Thu: 1 p.m. – 2:30 p.m. | Only cleaning of floors and cleaning of windows, if necessary. |



**Goal 4: Maintenance of independence and greater mobility**

| Service code | Name of service                                                                                                    | Provider | Start date | End date | Date of implementation of service (what days, from – to) | Possible special features in implementation of service |
|--------------|--------------------------------------------------------------------------------------------------------------------|----------|------------|----------|----------------------------------------------------------|--------------------------------------------------------|
| <b>S1</b>    | Assessment and evaluation of the state of the user – initial and final                                             | FT/K     | 17/05/2019 |          |                                                          |                                                        |
| <b>S3</b>    | Advice for environment adaptation                                                                                  | FT/K     | 17/05/2019 |          |                                                          |                                                        |
| <b>S5</b>    | Prevention, counselling and empowerment of the user for independent living                                         | FT/K     | 17/05/2019 |          |                                                          |                                                        |
| <b>S6</b>    | Services to maintain motor independence: flexibility, strength, stability, mobility, endurance and fall prevention | FT/K     | 17/05/2019 |          |                                                          |                                                        |

term care coordinators mentioned, for example: improving and maintaining health condition, maintaining independence, maintaining social skills, i.e. conditions that are expected in the long run with all the services provided. Also recorded among the long-term goals were e.g.: home care, staying in the home environment, helping to obtain a device such as a hearing aid/denture - in short, goals that cannot be achieved in the short term, as they take some time and/or funding to be achieved. It can be observed from an analysis of goals that the use of short-term goals was of primary importance, i.e. that most of the recorded goals were short-term.

It can be concluded from the statement of the long-term care coordinator that it was not easy to set goals as part of personal planning: *“Some users know exactly what they want, what their goals are, and some get lost in this process because they have never thought about it”, “They looked at me bemusedly when I asked them about short-term and long-term goals, about what I’m doing here”. The following statement, which touches on the boundary between objectives and services, tells a similar story: “For example, regular help in personal care or that the person will have regular control over medications. This is where I was getting lost. It is important that these terms are clarified; that you know what the goal is and what the service is.”.*

The implementation plan is that part of the personal plan that contains an inventory of all services that the user receives, and states who, when and for how long they are provided. In all three pilot environments, the long-term care coordinators recorded in the implementation plan only the long-term care services that they provided as part of the pilot project. It was evident from the rare living conditions in the personal plans that the user also receives some services from other persons or providers, outside the consortia of pilot projects – for example: *“The occupational therapist got connected with Tačke pomagačke and together they go on visits to the user. Tačke pomagačke is a volunteer association that performs therapeutic work with the help of dogs.”.* Such services, as well

as services that the long-term care coordinators listed in the living conditions or under other items of the personal plan, were not systematically recorded in the implementation plan itself, as this exclusively recorded the services provided by employees in pilot projects.

The implementation plan was written in the form of a table, above which the goal was clearly addressed, and a code (e.g. O11, S5, S6) and the name of the service in question and which provider visited the user recorded in the table – in some cases with the name and surname and the professional profile, and in most cases only with the job or only with abbreviations of the job (FT, SO, etc.) or with abbreviations of the unit (EO, EOS). The start date, the end date of the service, which most of the long-term care coordinators did not enter, and the date of the service (from - to) were also stated, and the note “by agreement” was also found. It was therefore usually recorded from which date the service would be provided, on which days and at what time. Possible special features were added at the end (e.g. *“the lady wants instructions and advice for exercises that she can later perform on her own”*).

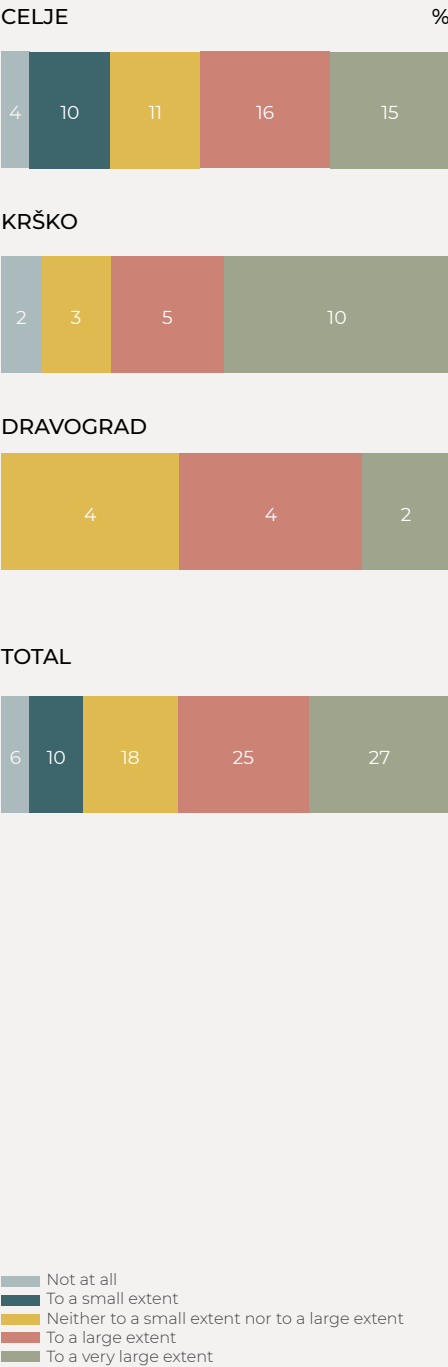
It was evident from the records and stories that regarding some users, it became clear only after the services were determined in the implementation plan and the first home visits, especially by professional workers from the independence maintenance unit, exactly which services the individual needed and to what degree and how much they actually used them. This was often due to the fact that users needed time to accept and become accustomed to receiving services and the new dynamic brought by new people entering their homes.

If, in addition to the content of the described main parts of the personal plan, we also look at the other items of the personal plan listed at the beginning of this chapter, we notice that in the item on the manner of inclusion of other healthcare and social care services, volunteers or providers of informal care, the long-term care coordinators of all three pilot environments

recorded all types of services that the person also received outside the pilot project. They mentioned the inclusion of assistance to the family at home, community nursing care, delivery of meals, information on whether the person received various cash benefits, whether they were included in a special social care and employment centre, day or intergenerational centres and whether they received any other service outside the pilot project; physiotherapy, cleaning, delivery of meals; information on the frequency of the service per week and the tasks performed by the contractor was also entered in some places. The long-term care coordinators also recorded informal care in this space, i.e. whether help was provided by a son, daughter, partner, etc. They did not record, however, what these informal carers do. A special section, “informal assistance”, was dedicated to this, although the long-term care coordinators did not mention its scope to any great extent there because they had already provided a description of the assistance given by relatives in the previous section on other services. The scope of informal care is an important piece of information about how burdened relatives are by care, i.e. how much they are involved in it. It could be seen from the personal plans that contained this information that the number of hours of informal care ranged from four to 140 hours per week. It was evident in the personal plans in the spaces where the long-term care coordinator recorded data on informal care tasks that these were mainly tasks and services such as shopping, hygiene care, household chores, meal preparation (the role of informal carers was also observed with additional measuring instruments, which are presented in more detail in Chapter *Care for those who care: studying the quality of life of informal carers*).

As part of personal planning, the long-term care coordinators also performed a revision of the personal plan. The revision was regular, at six monthly intervals or, in extraordinary circumstances, before six months had elapsed, if a major change to the scope of long-term care services was needed. The long-term care

Figure 1: To what extent does a personal plan for long-term care make your life easier? (N=86)



coordinator performed both on the basis of a reassessment of the user's eligibility for long-term care. In the event of a change in the scope of services, an annex was thus concluded with the user<sup>52</sup>. At the beginning of the pilot project, the form was identical in content to the personal plan, while the contracting authority later prescribed a special form for the annex. In the annex, the long-term care coordinators briefly described the circumstances that led to the need to increase or decrease the scope of services and entered additions or changes to the implementation plan on this basis. In some cases, the long-term care coordinators only entered the service that had been changed or added, and not the service that the user received unchanged, which is why the difference in the scope of services received and the full range of services that the user received was not evident from the annex. In addition, there was also space in the annex for information on the assistance the user was still receiving and for any other relevant comments.

In addition to the described findings of an analysis of personal plans, an analysis of various minutes of meetings has also shown that instead of "personal plan", the term "agreement" appeared in some places, which significantly changes its actual meaning.

Considering the experience of their work, the long-term care coordinators from all three pilot environments noted that it would be necessary to introduce in the future the option of providing a "transitional service package" or "initial service package" that the user would receive after the eligibility assessment, during the creation and adaptation of the personal plan to their needs. This should be especially true for beneficiaries to whom the provision of services should be ensured as soon as possible in order to enable them to stay at home or who have no other care options, e.g. in the event of discharge from hospital, in the event of a sudden significant deterioration in health and functional

condition, in the event of the sudden absence of an informal carer and in similar situations.

Finally, we shall look at how users have assessed the role of a personal plan in their lives<sup>53</sup>. In the questionnaire, they were asked to what extent a personal plan for long-term care makes their life easier. Almost a third of the surveyed users (31.4%) said that it makes their life easier to a very large extent, 29.1% said to a large extent, a fifth (20.9%) said neither to a small nor to a large extent, a tenth (11.6%) said to a small extent, and 7% said not at all. It could be said that, in general or on average (average=3.7), that users perceive the personal plan as a means of making their life easier, although there were also those among the respondents who do not attribute a special role to the personal plan in terms of making their life easier. Perhaps this information can be connected to the fact that the personal plan should cover the whole life of a person and thus all the services they need, and not just the services of the pilot project. This means that they could manage their entire lives with it.

## Discussion with key messages

Personal planning in long-term care is highly oriented towards the user and their empowerment, which for professionals in the field of long-term care can represent a new perspective and a different way of working with users than they may be used to from the existing healthcare and social care systems.

The personal planning method used in the pilot projects therefore places the user into social life and does not focus solely on their body. The long-term care coordinator therefore makes sure that the services required are coordinated between the different providers. In doing so, they follow the content of the personal plan that they

<sup>52</sup> Annex to the personal plan for the provision of long-term care as part of the pilot activities »Implementation of pilot projects that will support the transition to the implementation of the systemic law on long-term care« (hereinafter referred to as: annex).

<sup>53</sup> In the survey presented in the chapter on methodology, we asked the respondents who had previously said that they had a personal plan about this. They were asked to rate this on a scale from 1 (not at all) to 5 (very much).

have prepared together with the user. The user thus takes an active role in deciding on the type and scope of services and activities they want to receive, and the professional becomes a co-creator and recorder and is no longer in the role of someone who, from their position, independently determines the needs of the user and the services they believe the user needs. It is a collaboration between the user and the professional in building solid, sufficiently flexible and personally selected support for the user. In order to strengthen such an attitude, in addition to new methods and approaches in long-term care it is necessary to acquaint the long-term care coordinators and all others who cooperate with users with the social model of cooperation with the user.

Practice in pilot projects has shown that even someone who has no past experience with this method can be trained for personal planning. However, as the personal planning method in the field of long-term care in the form as used in the pilot projects has been implemented to a lesser extent, it is still considered a new feature, despite the fact that it has been known and developed in Slovenia since the 1990s. Therefore, in the future it will be necessary to provide long-term and in-depth training sessions on personal planning, and above all to provide the long-term care coordinators with continuous support and supervision in personal planning. It also transpires that long-term care coordinators can be both social workers and registered nurses, while it would be good if these profiles were to complement each other and combine the principles of operation of both professions. The long-term care coordinator needs knowledge from both the healthcare and social care systems, as this enables them to perform their role more comprehensively and cohesively.

In order for the personal plan to encompass the entire life context of the user, it is important that the life story that is the foundation of the personal plan is broadly captured and that it reflects the individual's life and their own storytelling. It is also important that it is written

from the perspective of power, in a friendly, positively evaluated and user-friendly way, with as much information as possible provided by the users themselves and contributing to the quality of their care. The life story is not just a place in which to describe an individual's health condition and, especially, to make judgements and impersonal observations. However, we notice that the method of personal planning in the pilot projects in this respect departed from the principles of the method and this is why all the content that the life story is supposed to cover in accordance with the method was not fulfilled as expected. In the given context of personal planning, the term "living conditions" in the personal plan itself dictated a narrower record and not a record in the sense of a life story, despite the fact that the long-term care coordinators had quite extensive conversations with users and therefore gained a considerable amount of information about their lives. Also, the focus on the health condition of the user in these interviews and records was probably more meaningful and important for planning the goals and services offered as part of the pilot projects.

The next important element of the personal plan are the goals, which are the "link between the narrative and the implementing part of the personal plan. They are an excerpt from the analysis of the situation and its conclusion, the consequence of the narrative and its projection into the future. At the same time, the goals are the basic framework for planning the implementation of the plan. In an operationalised form, they are actually the implementing part of the plan" (Lebar et al., 2017).

We have established that the goals recorded in the personal plans were usually short, written in a similar way for different users, regardless of the different problems they faced, and they were mainly related to help from the aspect of the user's health condition. The reason for this may have been in the structured record of living conditions. In accordance with the concept of the personal planning method, the goals should always be set in a descriptive form, in the user's words, in order to

find out from them what they are striving for, and what plans they have for the future.

By analysing personal plans, we have found that only the services provided by employees on the project were recorded in the implementation plan, while the services that the user received from other sources were recorded in the personal plan by different items. As it has already been noted, in order to ensure comprehensive care, it is important that all services received by the user are recorded in one place, in this case in the implementation plan. Although the pilot projects did not envisage this, we think that it would be sensible for the long-term care system that it is consistently recorded in the implementation plan what, when and to what extent assistance is provided by formal providers, informal carers and others (e.g. volunteers). This way, the personal plan could become a universal right of long-term care and a method of comprehensive care as proposed by the creators of the bases for the implementation of the pilot projects in the field of long-term care (Lebar et al. 2017)

It is also important to respect the principle of inclusion of users and their relatives in the entire process of personal planning. As was the practice in the pilot environments, the long-term care coordinators and staff in the care unit present the service options to the user and agree with them or their relatives on the choice of services. All those who work with the user must also ensure that the user is acquainted with everything related to their care and other activities and that they participate in deciding on the content and scope of services.

In addition, it is important that the long-term care coordinator ensures that the content of the entire personal plan, including the implementation plan, is written in a way that is understandable to the user and their relatives, without abbreviations and with clear information on persons and dates related to the provision of individual services.

Writing an in-depth life story together with the user, identifying and setting specific goals and operationalising them well requires a long-term care coordinator to possess many skills, which they

can acquire only through practice and with the support of an professional who is trained in this method and has experience in personal planning. It would therefore be unfair to simply conclude that the practice of setting goals or any other practice in the context of personal planning in pilot environments was not good enough, as the long-term care coordinators, after introductory training sessions on personal planning in the creation of personal plans, no longer received professional support in creating and reviewing personal plans.

When providing long-term care, users should also be provided with the option of being gradually integrated into services and their personal and implementation plans should be adapted accordingly, as some people may be distrustful of the new or unaware of their needs in full, and therefore need more time to become accustomed to new things, which personal planning has turned out to be. People, especially the older adults, are often not accustomed to the fact that the expert who visits them is interested in their entire life story, that they will explore with them their wishes and goals, and that they are able to participate in deciding on the content of the care provided to them. This is certainly a new practice for the users, and one with which, as the data presented as part of the implementation of personal planning in the pilot environments shows, they were generally satisfied and which they evaluated positively.

Also important for the planning and implementation of long-term care is information from relatives and foresight, observations and other aspects that may be noticed in the field by both the assessor and the long-term care coordinator, so it is important that all those who work with the user as part of the provision of long-term care are informed about them. The answer to the question of whether the user should have access to all the documentation and records that employees make about them is certainly not simple, as evidenced by the experience of the pilot projects, as this topic has been the subject of various discussions. From the point of view of the user's central role and their perspective

of power, it is essential that they receive the eligibility assessment and the personal plan as a whole. Especially where sensitive information is concerned, the user should be interviewed in regard to obtaining their permission about what to include in, and how to write, the personal plan, and be informed about what information is to be recorded and to whom it will be provided in order to ensure the good and safe provision of long-term care. As is well known, the user has the right to access their entire documentation, so from this point of view it is even more important that descriptions and notes about them are compiled in a respectful manner.

It is also worth mentioning at this point the naming of the personal plan and the annex itself, as we usually limit and determine its role and use by naming the document. It used to happen that, instead of “personal plan”, the term “agreement” appeared in some places, which implies a much narrower meaning of this document, and probably a different, more rigid relationship between the two “signatories”. A similar narrowness and rigidity also stems from the term “annex”, which is understood as a kind of addition to the “contract” (i.e. personal plan) that has already been concluded. The personal plan is, in fact, a product that can be revised appropriately and constantly to reflect changes in the condition of users.

The annex to the personal plan should contain a record of the entire context of changes in the provision of services and not be just a record of changes in the scope of services. For this reason, it would make sense to rename it from the annex to the personal plan to a “change of personal plan”, which is what the annex actually is. The term “revision of the personal plan” has already become established in social work, so this term could also be used.

The long-term care coordinators usually obtained information for the creation of a personal plan while having a conversation with the user during a home visit. Considering the concept of the personal planning method used, in which the life story and the resulting goals and needs

are expected to be gradually built, and their implementation and all the resources that can contribute to this are expected to be envisaged in terms of time and implementation, more visits and interviews with the user and their relatives are required to make a more widely applicable personal plan. In particular, more visits by the long-term care coordinator to the user’s home would be necessary in cases where users have complex life situations and particularly specific needs. It is equally important that the long-term care coordinator, together with the user, draws up a personal plan that provides sufficient basic information to every expert who comes into contact with the user and serves to avoid the user or their relatives repeatedly having to answer the same questions.

We also assess that it is sensible to establish a “transitional package of services” or an “initial package of services” for beneficiaries immediately after the eligibility assessment, as in this case an immediate response to the user’s needs would be ensured with long-term care services and the user would not have to wait for these services to begin, while at the same time a document written in this way could be a legal basis for services to start being provided and costs to be claimed until the personal plan is drawn up and signed.

It can be seen from the description of the main works and tasks of the long-term care coordinator that they performed a large number of different tasks. Among these tasks, cooperation with the user took up only a small part of the whole, although direct cooperation and care for the user is supposed to be its central task. One of the proposals in interviews with long-term care coordinators was “... that someone take over only matters such as schedules and paperwork”.

In order to perform quality work, the long-term care coordinator can only take over a certain number of users, as interventions and work are usually very extensive, and communication, visits and arranging various matters for the user take a lot of time. Given that the responsibilities of the long-term care coordinator are supposed to

encompass both work on the case of an individual and work related to services provided to them (case and care management), the range of tasks pertaining to an individual can be very extensive, especially when it comes to users with complex life situations. It is precisely because of this, and for the sake of quality work with the user, that attention should be paid to how low the number of users (and how complex their needs are) should be for the volume of work of an individual long-term care coordinator to be manageable. The long-term care coordinator should have enough time to explore additional resources to meet the needs of the user in the local environment or to identify shortcomings that must be addressed or advantages in the user's home environment that must be strengthened.

It could be concluded that it will be necessary to thoroughly consider and coordinate well with decision-makers the decision on what form of personal planning and what method for the

drafting of personal plans would be most suitable for systemic use. The evaluation has shown that a personal plan made in accordance with the described method could be the foundation for all persons involved in user care and support, even beyond long-term care, so that the personal plan could become a universal right of an individual. In this way, the user and the long-term care coordinator would become equal partners who together discover the possibilities and resources for building a flexible, albeit sufficiently strong, support system for the user, consisting of services and activities offered by various professions and other resources in the community. With such a work relationship and a wide range of services, a future long-term care system could even more consistently follow the user's needs and new approaches to the participation of users and all those who work in the field of long-term care would in this way be deeply rooted and consolidated.



## BIBLIOGRAPHY

- AGE Platform Europe . A Society for ALL Ages AGE Strategy, 2022-2025. Retrieved from [https://www.age-platform.eu/sites/default/files/AGE\\_Strategy\\_22-25\\_FINAL.pdf](https://www.age-platform.eu/sites/default/files/AGE_Strategy_22-25_FINAL.pdf)
- Boeckstaens, P., Boeykens, D., Macq J., & Vandenbroeck, P. (2020). *Goal-Oriented-Care*. Brussels: King Baudouin Foundation.
- Brandon, D., & Brandon, A. (1994). *Jin in jang načrtovanja psihosocialne skrbi*. Ljubljana: Visoka šola za socialno delo.
- Evropska skupina strokovnjakov in strokovnjakinj za prehod iz institucionalne v skupnostno oskrbo (2012). *Skupne evropske smernice za prehod iz institucionalne v skupnostno oskrbo (Smernice za uveljavitev in podporo trajnostnemu prehodu iz institucionalne v družinsko in skupnostno oskrbo otrok, ljudi z oviranostjo, ljudi s težavami z duševnim zdravjem in starih ljudi v Evropi)*. Brussels: Retrieved from <https://di.irssv.si/skupne-evropske-smernice>
- Flaker, V., Nagode, M., Rafaelič, A., & Udovič, N. (2011). *Nastajanje dolgotrajne oskrbe: Ljudje in procesi – eksperiment in sistem*. Ljubljana: Fakulteta za socialno delo.
- Flaker, V., Mali, J., Rafaelič, A., & Ratajc, S. (2013). *Osebnostno načrtovanje in izvajanje storitev*. Ljubljana: Fakulteta za socialno delo.
- Kahlert, R., Boehler, C., & Leichsenring, K. (2020). *Expert monitoring and evaluation of pilot projects to establish onestop shops and integrated LTC delivery in Slovenia, Final report*. Viena: European Centre for Social Welfare Policy and Research.
- Lebar, L., Dremelj, P., Flaker, V., Rode, N., Mali, J., Peternej, A., Smolej Jež, S., ... Kobal Tomc, B. (2017). *Priprava podlag za izvedbo pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemkega zakona o dolgotrajni oskrbi* Aktivnost 1: Priprava orodij za ugotavljanje potreb uporabnikov, metodika postopka ter ugotavljanje upravičenosti do storitev dolgotrajne oskrbe. Ljubljana: Inštitut RS za socialno varstvo.
- Mali, J., Flaker, V., Peršič, M. L., Rafaelič, A., Rode, N., Urek, M., & Žitek, N. (2017). *Inovativne oblike oskrbe v domovih starejših občanov: končno poročilo*. Ljubljana: Fakulteta za socialno delo.
- Ministrstvo za zdravje. (2018). Javni razpis »Izvedba pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemkega zakona o dolgotrajni oskrbi«. Retrieved from <https://www.uradni-list.si/glasilo-uradni-list-rs/vsebina/2018002400003/javni-razpis-za-izbor-operacij-izvedba-pilotnih-projektov-ki-bodo-podpirali-prehod-v-izvajanje-sistemkega-zakona-o-dolgotrajni-oskrbi-st-303-1201816-ob-198618>
- Roper, N., Logan, W., & Tierney, A. J. (2001). *The Roper-Logan-Tierney Model of Nursing*. Edinburgh: Churchill Livingstone.
- Ščavničar, E. (1998). *Negovalna diagnoza*. Obzornik zdravstvene nege, 32, 167-172.
- Škerjanc, J. (2004). *Individualizacija socialnovarstvenih storitev in njen vpliv na kakovost življenja uporabnikov*. Magistrsko delo. Ljubljana: Fakulteta za socialno delo.
- Škerjanc, J. (2006). *Individualno načrtovanje z udeležanjem ciljev Pomen uporabniškega vpliva pri zagotavljanju socialnovarstvene storitve*. Ljubljana: Center RS za poklicno izobraževanje.
- Škerjanc, J. (2010). *Prispevek uporabnikov socialnovarstvenih storitev k oblikovanju konceptov za praktični študij socialnega dela (doktorska disertacija)*. Ljubljana: Fakulteta za socialno delo
- UK Legislation. Care Act. (2014). Retrieved from <https://www.legislation.gov.uk/ukpga/2014/23/enacted>
- Videmšek, P., & Mali, J. (2018). *Od načrta skrbi in programa oskrbe do osebnega načrtovanja in izvajanja storitev*. Socialno delo, 56, 27 – 42.
- Zaviršek, D., Zorn, J., & Videmšek, P. (2002). *Inovativne metode v socialnem delu. Opolnomočenje ljudi, ki potrebujejo podporo za samostojno življenje*. Ljubljana: Študentska založba.

# **TEAMWORK AND INTEGRATION OF STAKEHOLDERS AS THE FOUNDATIONS FOR ENSURING INTEGRATED LONG-TERM CARE**

Polona Dremelj  
Social Protection Institute of the Republic of Slovenia

Aleš Istenič  
Social Protection Institute of the Republic of Slovenia

## KEY MESSAGES

- ▶ The employees in pilot environments were satisfied with individual aspects of their work life, but they were somewhat less satisfied with working conditions and their direct superiors. They are more satisfied with the work they did, working hours and their position in the project.
- ▶ They were particularly dissatisfied with the payment for the work performed. The pilot environments classified their employees in salary grades in different ways, usually in respect of whether they were employed within healthcare or social care. The latter had a poor effect on the motivation to work, including mutual cooperation and integration between the colleagues of various professions. The result revealed that dispersion of long-term care between various sub-systems (especially healthcare and social care) had a negative impact on cooperation and integration, and that service integration is also necessary from this point of view as joint competence of various sectors will thus be enhanced.
- ▶ The providers of social care at home expressed the greatest dissatisfaction with the payment for the work they do among all employees in the pilot environments.
- ▶ Supervision proved to be an important element of working life and a significant advantage for the employees in the pilot environments.
- ▶ The team functioning dynamics varied among the pilot environments. While mutual cooperation between the employees within individual teams and among the employees in different teams was noticed in the Dravograd and Krško pilot environments at the end of the project, such cooperation was not established in the Celje pilot environment. The reasons for that can also be sought in fewer formal meetings held between the employees in Celje in comparison to the other two pilot environments.
- ▶ The LTC coordinator has the central and connecting role in all three pilot environments when it comes to work-related information exchange, work process, and the provision of expert advice when resolving work challenges.

## Introduction

The well-being of employees, their cooperation, success and dedication to their work and how the organisation works as an entity is very important for the efficient functioning of organisations. By measuring organisational climate, it is possible to determine the functioning of an organisation or a work environment. The organisational climate is defined as a set of measurable characteristics of the work environment, as they are directly or indirectly perceived by people living and working in this environment and which affect the motivation and behaviour of employees. Payne et al. (in Berberoglu, 2018) defined organisational climate as the way in which employees perceive their organisation and its purposes, while Churchill et al. (in Berberoglu, 2018) defined it as the sum of the social factors which constitute the workplace environment for a worker.

Organisations ascribing great significance to the provision of good organisational climate are more efficient and successful. Good organisational climate also strengthens the feeling of satisfaction at work. Research shows that employee satisfaction contributes to attaining better productivity and dedication to work and reduces the level of absenteeism and intention to terminate the employment relationship (Hagmaier & Abele, 2012). High-performance organisations focus on bringing the best out of their human resources, and in so doing create an exceptional team capable of delivering outstanding results (McWinner, 2020).

Research carried out on a representative sample of retirement homes in Switzerland (Schwendimann, Dhaini, Ausserhofer, Engberg, & Zúñiga 2016) showed that the job satisfaction of employees involved in the healthcare of users is significantly related to supportive leadership<sup>54</sup>, teamwork and the resident safety climate,<sup>55</sup> responsive administrative staff and adequate staffing resources in the organisation. Employees

who express their job satisfaction view their superiors as supporting and appreciating their work, and employees who mutually trust and encourage each other evaluate teamwork as positive and simultaneously report job satisfaction.

The establishment of cooperation between employees is crucial for successful teamwork. Cooperation in healthcare, social care and long-term care is composed of two key elements, i.e. the generation of collective action, which responds to the complex needs of users and the creation of a team spirit, which combines the knowledge of the various members and through which each person feels respected and trusted (D'Amour & Oandasan, 2005). Unfortunately, it is revealed in practice that numerous countries experience a lack of integrated health and social care. Problems are particularly evident in coordination and cooperation between individual professions (interprofessionalism) and competent institutions in the fields of healthcare and social care. The results of a three-year project that took place in Sweden also showed the same; its objective was to improve social care and healthcare services for elderly people living at home. To attain this objective, multi-interprofessional teams were established whose knowledge was to fill the gap in cooperation between social care and healthcare. The results of the project were not encouraging as the organisation of multi-interprofessional teams (by competent institutions) failed. The care of elderly people did not improve, and coordination and cooperation between social care and healthcare were also not established because interprofessional competitiveness prevailed over the goal of mutual cooperation (Emilsson, Strid, & Söderberg, 2020).

Within the framework of pilot projects regarding long-term care, the pilot environments tried to establish foundations for teamwork in long-term care as a lack of integrated healthcare and social care is also a significant problem in Slovenia.

<sup>54</sup> The most important quality of supportive leadership is care for others and provision of help (Boštjančič, 2009).

<sup>55</sup> The terms safety climate or safety culture refer to the positions of the healthcare provider on matters pertaining to user safety.

## Methodology

As part of the evaluation, two general objectives were set regarding employee working life, i.e. to evaluate teamwork in long-term care (LTC) (whether the method of teamwork in LTC is suitable for the transition to the systematic implementation of LTC) and the quality of working life of formal care providers (whether the quality of (working) life of formal care providers improves during the implementation of pilot projects). From the aspect of monitoring the course of activities in pilot projects, we examined the attainment of the following process indicators by means of evaluation:

- regular meetings between LTC coordinators, care teams and assessors, at which information was exchanged about possible challenges at work, open issues, etc. (at least five times a year),
- regular supervision of formal care providers and employees at the single entry point.

The quality of employee working life in pilot environments was examined with an online questionnaire for employees. We wanted to determine how employees feel while working on the pilot project and what, in their opinion, are the advantages and disadvantages of the work they perform. The survey was implemented twice in order to determine how the employees' quality of life changed during their work on the project.

The questionnaire included questions to measure organisational climate and employee satisfaction with certain aspects of working conditions, work-family life balance, contacts with various stakeholders in the field, and positive and negative aspects of work within the project. To measure organisational climate and satisfaction with individual aspects of working conditions, we somewhat adjusted the questions from the SiOK questionnaire (Slovenian organisational climate), which was drafted within the project of research and monitoring organisational climate in Slovenian

organisations in 2001 by a group of consulting companies under the auspices of the Chamber of Commerce and Industry of Slovenia.<sup>56</sup>

The questionnaires were not necessarily completed by the same persons (considerable staff turnover) on both occasions, which is why the samples of surveyed persons are discussed independently. Thus, the changes in opinions cannot be monitored at the level of individual employees, but at the level of all employees together.

At the end of the pilot projects, we prepared an additional questionnaire for the employees by means of which we inquired how and in which cases do employees offer support to one another, connect and cooperate. Four questions were drafted for the respondents, inquiring about which colleague they turned to for help and support in relevant situations. For data analysis, we used the Pajek<sup>57</sup> programme, which is intended for the analysis and visualisation of large networks.

Cooperation between employees on the project or teams was also monitored with the help of minutes taken at meetings in the pilot environments, which were provided by the environments. To clarify certain results, data from the user satisfaction survey (M6) was also used. Descriptive (e.g. presentation of proportions) and bivariate (t-test) data analyses were also performed.

## Results

The results are presented in four separate sub-chapters, i.e. we first present the dynamics of the teams which were established in pilot environments, this is followed by the sub-chapter on organisational climate and employee satisfaction. In the next sub-chapter, we discuss cooperation between the employees from the aspect of providing mutual support, and the last sub-chapter focuses on cooperation with other important stakeholders in the local environment.

<sup>56</sup> We used the questionnaire for 2007 obtained from the diploma thesis by Gorše (2011).

<sup>57</sup> Mrvar & Batagelj, 1996–2020. Accessible at: <http://mrvar.fdv.uni-lj.si/pajek/>.

## Team dynamics in pilot environments

All three pilot environments established key teams important for the implementation of long-term care (more in Chapter *Transition to integrated long-term care by establishing a single entry point, integrated care team and connecting stakeholders*). In Krško, all teams were located at one location, while in the other two environments they were dispersed at various locations: three in Celje and six in Dravograd.

In all environments, the teams were connected and coordinated by the long-term care coordinator, who also participated in practically all of the meetings listed below. With the exception of three meetings of the assessors' team, no meetings were held in Celje, which would be divided by individual teams. Meetings of all teams were held 23 times. The integrated care team held the most meetings (47) in the Krško pilot environment. Meetings usually took place on a weekly basis. The assessors held 14 meetings, the care team held six and the independence maintenance team held five meetings. Numerous meetings were thus organised in this environment, which were divided by individual teams until July 2020. In the last months of the project, the employees held joint meetings. The assessors at the single entry point held the most meetings (27) in the Dravograd pilot environment. Some 14 meetings of the integrated care team with assessors were also organised. These meetings took place on a monthly basis, except in the period from April 2019 to September 2019. The integrated care team met eleven times during the project and the home help providers in the local environment were present at five meetings.

The Covid-19 epidemic significantly affected the implementation of meetings in all pilot environments between mid-March 2020 to mid-May 2020. There were no physical meetings in this period, instead the employees exchanged information by phone or e-mail.

## Organisational climate and employee satisfaction

Table 1 shows assessments of individual categories of organisational climate in the pilot environments. When reading the results of measuring organisational climate, we particularly focus on the comparison of results from two different times, i.e. at the start and the end of project implementation. The assessment results of individual categories of organisational climate represent a guideline indicating that the organisation of processes must be improved accordingly in the areas in which assessments are low.

Assessments reveal that respondents perceived their working environment as rather positive at the start of the project. "Attitude towards quality" was assessed highest, which means that the employees contribute to the quality of work to the best of their abilities and feel responsible for the quality of their work. Assessments in the "motivation and engagement" category were also very high, which means that the employees are committed to their work and prepared to invest additional effort. Their superiors appreciate work well done and good work results are duly noticed and commended. Attitude towards quality is an organisational advantage reported on by all three pilot environments. Motivation and engagement are organisational advantages of the Celje and Krško pilot environments, while this category received a lower score in the Dravograd pilot environment.

"Knowledge of objectives" of the pilot project received the lowest assessments (but still quite high) in the first measurement. In this area, all three pilot environments tackled the challenge of improving this aspect of organisation during project implementation. Poorer aspects of organisations or the aspects representing a challenge for the Dravograd pilot environment also included management, communication and information, and organisation. The latter is particularly attributed to the various locations at which employees perform their work. The LTC coordinator for Dravograd is, for example, located in Slovenj Gradec and the

**Figure 1: Location of individual teams in pilot environments****DRAVOGRAD****RESIDENTIAL HOME FOR THE ELDERLY SLOVENJ GRADEC**

- SEP assessors
- Team for activities of daily living and instrumental activities of daily living
- Independence maintenance team

**RESIDENTIAL HOME FOR THE ELDERLY KOROŠKA ČRNEČE**

- LTC coordinator
- Independence maintenance team

**SLOVENJ GRADEC GENERAL HOSPITAL**

- LTC coordinator

**CENTRE FOR SOCIAL WORK, RAVNE NA KOROŠKEM UNIT**

- SEP assessors

**KOROŠKA INTERGENERATIONAL CENTRE IN RAVNE NA KOROŠKEM**

- Team for activities of daily living and instrumental activities of daily living

**RAVNE HEALTH CARE CENTRE**

- SEP assessors

**CELJE****CELJE HEALTH CARE CENTRE**

- LTC coordinator
- SEP assessors
- Team for activities of daily living and instrumental activities of daily living
- Independence maintenance team

**PUBLIC INSTITUTION SOCIO**

- Team for activities of daily living and instrumental activities of daily living

**ST JOSEPH HOME**

- Team for activities of daily living and instrumental activities of daily living

**KRŠKO****CENTRE FOR SOCIAL WORK, KRŠKO UNIT**

- LTC coordinator
- SEP assessors
- Team for activities of daily living and instrumental activities of daily living
- tim za ohranjanje samostojnosti

single entry point had its head office in Ravne na Koroškem. This posed a great challenge for the organisation of work and impeded the ongoing communication and information transfer between the LTC coordinator and the single entry point.

At the end of the pilot project, the assessment of affiliation, internal relations, attitude towards work quality, and innovation and initiative somewhat improved in all project environments, but the differences between assessments are not statistically significant. The assessments of the knowledge of objectives, which was below average (3.4) during the first survey, scored 3.6 at the end of the project and the organisation category increased from 3.5 to 3.8. The difference in assessments of the latter was statistically significant between the first and second measurements ( $t = 0.646$ ,  $p = 0.09$ ).

If looking at individual pilot environments, the average assessments of organisational climate categories, except for organisation, decreased in Celje. The assessments in Celje were higher if compared to the remaining two pilot environments during the first survey, i.e. average scores were above 4 in eight out of ten categories. At the start of the project, the highest scores in Celje were received by attitude towards quality ( $AS = 4.9$ ) and motivation and engagement ( $AS = 4.5$ ), while at the end of the project, these two scores decreased the most, i.e.  $AS = 4.4$  and  $AS = 4.2$ , respectively. Differences in assessments are statistically significant ( $t = 2.564$ ,  $p = 0.015$  or  $t = 3.308$ ,  $p = 0.002$ ). At the end of the project, the assessment regarding the knowledge of objectives also decreased, i.e. from  $AS = 3.69$  to  $AS = 3.40$ , which could be related to a high staff turnover in the Celje pilot environment.

Differences between scores at the start and end of the project were not statistically significant in the Krško pilot environment; nevertheless, positive changes are seen in the categories affiliation, internal relations, organisation and knowledge of objectives.

In the Dravograd pilot environment, where the lowest scores in individual organisational climate categories were recorded at the start

of the project in comparison to the other two environments, the average assessments increased in all categories. The highest difference in the average assessment was in the category of knowledge of objectives, followed by affiliation, and innovation and initiative.

The respondents were also asked about satisfaction regarding individual aspects of their working life. Average satisfaction assessments are positive in all environments, which means that employees are (more or less) satisfied with individual aspects; they are less satisfied with working conditions and their direct superiors, and they are more satisfied with the work they do, working hours and their position in the project.

If looked at by individual pilot environments, differences between the observed points in time are found only in the Celje pilot environment, i.e. the score for work satisfaction somewhat decreased during the second survey ( $AS = 4.6$  (M0);  $AS = 4.1$  (M18)). The difference is statistically significant ( $t = 2.287$ ,  $p = 0.03$ ). Satisfaction with the work they do dropped statistically significantly ( $t = 1.934$ ,  $p = 0.09$ ), especially for the assessors in the Celje pilot environment, i.e. the assessors were less pleased with their work at the end of the project implementation than at its onset. Due to high staff turnover in the Celje pilot environment, the second survey was mostly completed by different assessors, which is why we can say that the group of assessors responding to the first survey were less satisfied with their work than the assessors responding to the second survey.

An important aspect of satisfaction with working conditions is also satisfaction with the payment for the work done. At the start of the project, 46.5% of the respondents were satisfied with the payment for their work and more than half of all respondents (52%) at the end of the project. If looked at from the viewpoint of individual pilot environments, the proportion of employees who are satisfied with the payment for their work increased in Celje (from 38.5% to 45%) and Dravograd (from little over 31% to little less than 47%), while this proportion somewhat



**Table 1: Differences in average assessments of organisational climate categories in total and by pilot environments during the survey in points M0 and M18**

|           |             | AFFILIATION | INTERNAL RELATIONS | MOTIVATION AND ENGAGEMENT | ATTITUDE TOWARDS QUALITY | PROFESSIONAL COMPETENCE | INNOVATION AND INITIATIVE | MANAGEMENT | COMMUNICATION AND INFORMATION | ORGANISATION | KNOWLEDGE OF OBJECTIVES |
|-----------|-------------|-------------|--------------------|---------------------------|--------------------------|-------------------------|---------------------------|------------|-------------------------------|--------------|-------------------------|
| TOTAL     | M0          | 3.83        | 3.93               | 4.11                      | 4.42                     | 3.90                    | 3.99                      | 3.77       | 3.63                          | 3.50         | 3.36                    |
|           | M18         | 4.04        | 4.07               | 3.96                      | 4.35                     | 3.83                    | 4.01                      | 3.75       | 3.72                          | 3.82         | 3.61                    |
|           |             | ↑           | ↑                  | ↓                         | ↓                        | ↓                       | ↑                         | ↓          | ↑                             | ↑            | ↑                       |
|           | difference* |             |                    |                           |                          |                         |                           |            | *                             |              |                         |
| CELJE     | M0          | 4.08        | 4.42               | 4.50                      | 4.88                     | 4.27                    | 4.34                      | 4.03       | 4.04                          | 3.69         | 3.69                    |
|           | M18         | 4.03        | 4.35               | 4.15                      | 4.43                     | 3.93                    | 4.02                      | 3.80       | 3.98                          | 4.13         | 3.40                    |
|           |             | ↓           | ↓                  | ↓                         | ↓                        | ↓                       | ↓                         | ↓          | ↓                             | ↑            | ↓                       |
|           | difference  |             |                    | **                        | **                       |                         |                           |            |                               |              |                         |
| KRŠKO     | M0          | 3.83        | 3.76               | 4.13                      | 4.29                     | 4.00                    | 4.06                      | 3.88       | 3.63                          | 3.64         | 3.39                    |
|           | M18         | 4.07        | 3.83               | 3.90                      | 4.22                     | 3.83                    | 3.99                      | 3.78       | 3.68                          | 3.86         | 3.81                    |
|           |             | ↑           | ↑                  | ↓                         | ↓                        | ↓                       | ↓                         | ↓          | ↓                             | ↑            | ↑                       |
|           | difference  |             |                    |                           |                          |                         |                           |            |                               |              |                         |
| DRAVOGRAD | M0          | 3.60        | 3.67               | 3.77                      | 4.13                     | 3.50                    | 3.61                      | 3.44       | 3.28                          | 3.20         | 3.03                    |
|           | M18         | 4.01        | 3.97               | 3.78                      | 4.40                     | 3.68                    | 4.03                      | 3.64       | 3.42                          | 3.37         | 3.67                    |
|           |             | ↑           | ↑                  | ↑                         | ↑                        | ↑                       | ↑                         | ↑          | ↑                             | ↑            | ↑                       |
|           | difference  | *           |                    |                           |                          |                         | *                         |            |                               |              | **                      |

Key:

Green indicates categories with the highest score (above 4) (these are most likely advantages of the organisation).

Yellow indicates categories assessed above average (between 3.5 and 4).

Red indicates results below average (less than 3.5) (these most likely represent challenges for the organisation).

\* Statistically significant difference (\* p < 0.10; \*\* p < 0.05)

dropped in Krško (from 71% to almost 65%), but still remains high and is somewhat higher if compared to the other two pilot environments.

If focusing on satisfaction with the payment for work performed between individual workplaces, we can determine that the employees in the care unit (AS = 2.85) were on average least satisfied with the payment for their work and those most satisfied were the employees of the independence maintenance unit (AS = 3.57). The difference is statistically significant ( $F = 1.925$ ,  $p = 0.023$ ). The difference between the employees of the care unit and assessors (AS = 3.33) is also statistically significant ( $F = 1.925$ ,  $p = 0.099$ ).

At the start of the project, administrative work presented more of a burden for the major proportion of employees than at the end. A decline in the proportion was most visible in the Celje pilot environment, i.e. 23% of employees stated that administrative work presented a burden at the start of the project and only 5% of employees were of this opinion at the end of the project. In Krško, this proportion dropped by more than one third (35.7%) to almost one quarter (27.8%), and from one half to one third in Dravograd.

One of the aspects of the quality of employee working life is also workload. The figure below shows the proportion of employees who returned home from work too tired to do certain necessary household chores several times a month, and the proportion of those who had difficulties in meeting their family obligations due to the time they spent at work. At the onset of project implementation, the latter totalled about 20% of employees in all pilot environments (somewhat less in the Celje pilot environment), and the number of employees who returned home from work too tired to do certain necessary household chores several times a month amounted to more than one half in Krško and Dravograd, while their proportion was lower in Celje (38%). At the end of the project, this proportion decreased in all pilot environments. In the Celje and Dravograd pilot environments, the proportion of employees who had difficulties in meeting their family obligations due to the

**Figure 2: Proportion of employees who are (un)satisfied with the payment for work performed (in %) (N=41 (M0), N=52 (M18))**

### CELJE

M0



M18



### KRŠKO

M0



M18



### DRAVOGRAD

M0



M18



### TOTAL

M0



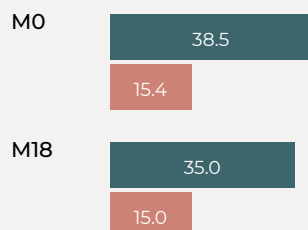
M18



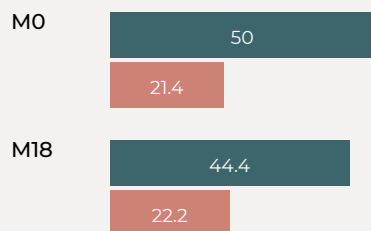
(Very) dissatisfied  
 Neither dissatisfied neither satisfied  
 (Very) satisfied

**Figure 3: Proportion of the respondents who experienced what is stated below several times a month (in %) (N=41 (M0), N=53 (M18))**

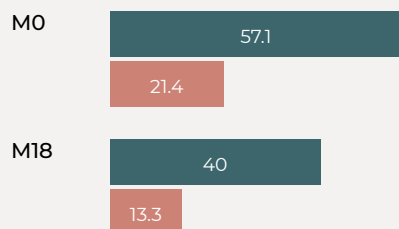
### CELJE



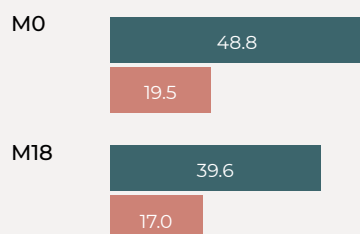
### KRŠKO



### DRAVOGRAD



### TOTAL



■ I returned from work too tired to do certain household chores which should have been done at home.  
 ■ Due to the time spent at work, I had difficulties in meeting my family obligations..

time they spent at work decreased, while this proportion somewhat increased in Krško.

A comparison of self-assessment of employee health at two points of time reveals a minimally lower assessment at the end of the project in the Celje and Krško pilot environments, but still the employees in all three pilot environments assessed their health conditions as good at both the start and end of the project.

An important aspect of the employees' working life is also the possibility of supervision in pilot projects. Supervision was organised in the Celje pilot environment in various teams (team for activities of daily living and instrumental activities of daily living had four supervisions, the independence maintenance team had one supervision and the assessors had three). In the Krško pilot environment, the supervision took place in two teams; one for assessors and both coordinators (the project coordinator and the LTC coordinator) and the second one in the integrated care team. Since September 2019 and at the supervisor's initiative, one group consisted of a LTC coordinator, and the project coordinator and the second group included the integrated care team and assessors. Certain supervisions involved all employees in the project. Supervision was also established in the Dravograd pilot environment, but it only included expert workers of the care team. The employees of the independence maintenance unit and assessors at the single entry point expressed no need for supervision, but they did meet at intervision meetings. By means of the dynamics and structure of supervision groups, the criterion of the indicator (ten times a year) was thus met in the Krško and Celje pilot environments. Supervision was established in Dravograd, but it only involved expert workers of the care team and the indicator was thus not met.

## Cooperation and provision of mutual support among the employees

The networks of exchange of assistance and support between colleagues in individual pilot environments are presented below. Only the employees who responded to the question set in the survey were included in the analysis, which means that persons who could be mentioned by others and those to whom others could turn for help were excluded, but they themselves did not respond to the question. The reason for this was significant staff turnover, especially in the Celje pilot environment. With the elimination of units from the analysis mentioned above, we obtained a complete network of employees for each pilot environment, i.e. final and completed group of employees.

This is a targeted network in which connections between two units (employees) are targeted, thus the direction of connection is important and the relations between persons are presented as asymmetrical connections. If two persons select one another, we can also speak about symmetrical connection (Carrington, Scott, & Wasserman, 2009).

Figure 4 shows a complete network of information exchange related to work in the Celje pilot environment. There are no isolated units or employees in the network to whom no one would turn for information. To the greatest extent possible, the employees turned for information to one of the LTC coordinators (14 employees); according to the number of entry connections, these are followed by the assessor (13 employees turned to them) and two employees from the care unit (12 employees turned to one of them and 11 to the other).<sup>59</sup>

The employees turned for information related to work on average to 7.4 colleagues or one half of them turned to fewer than seven colleagues and half of them to more than seven.

For expert advice when resolving work challenges, the majority (11) of colleagues turned to the LTC coordinator. Several employees (four or five) turned for advice to two employees at the single entry point. On average, the employees turned for expert advice to 1.7 persons and no one turned to seven persons (five of these were working at the care unit, one at the independence maintenance unit and one at the single entry point).

The most frequent source of support in the form of a conversation was the assessor, to whom eight colleagues turned. Other frequent sources of such support include another employee in the care unit and the LTC coordinator. On average, the employees discussed work problems with 3.4 colleagues, and no one turned to two employees.

For emotional support<sup>60</sup> (discussion about important personal matters), the employees in the pilot environment turned to fewer colleagues than in the case of other types of support. It is revealed that mutual exchanges occur between certain employees, i.e. two or more persons speak about important personal matters.

In the Dravograd pilot environment, the questionnaire on the support network was responded to by 14 persons who were working in the pilot project during its implementation. Regarding information related to work, the majority (nine) of employees turned to the LTC coordinator and the employee in the independence maintenance unit. Six employees turned to the project coordinator, two assessors and two employees in the care unit. On average, the employees turned for work-related information to more than 4.6 persons; half of them contacted more than five and a half persons and one half of employees turned to fewer than five and a half persons. Only two persons were not contacted by any of their colleagues for information.

Narrow teams were also formed within the pilot environment, between which mutual communication or work-related exchange of information took place. The information exchange

<sup>59</sup> In the figure, the LTC coordinator is marked by KDO, assessor by EVT, an employee from the care unit by EO, and an employee from the independence maintenance unit by EOS.

<sup>60</sup> Emotional support is assistance at a major or minor life crisis (death of a loved one, divorce, problems in the family or at the workplace, etc.).

Figure 4: Network for information exchange related to the work in the Celje pilot environment (entry connections), complete network (N=18)

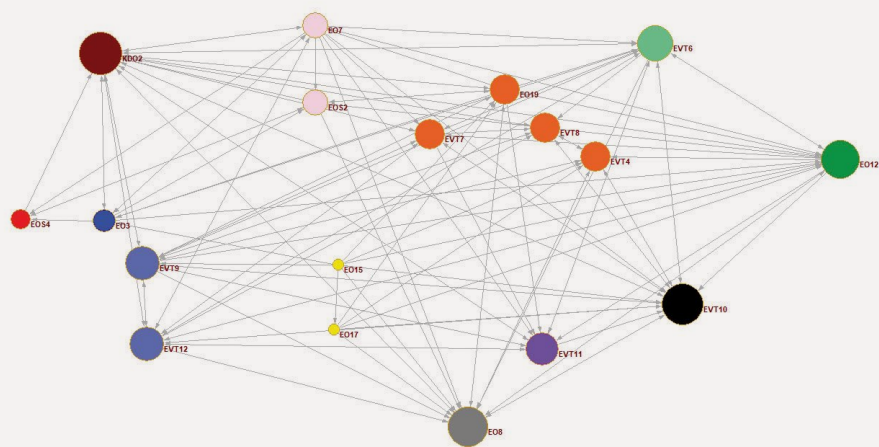


Figure 5: Network for information exchange related to the work in the Dravograd pilot environment (entry connections), complete network (N=14)

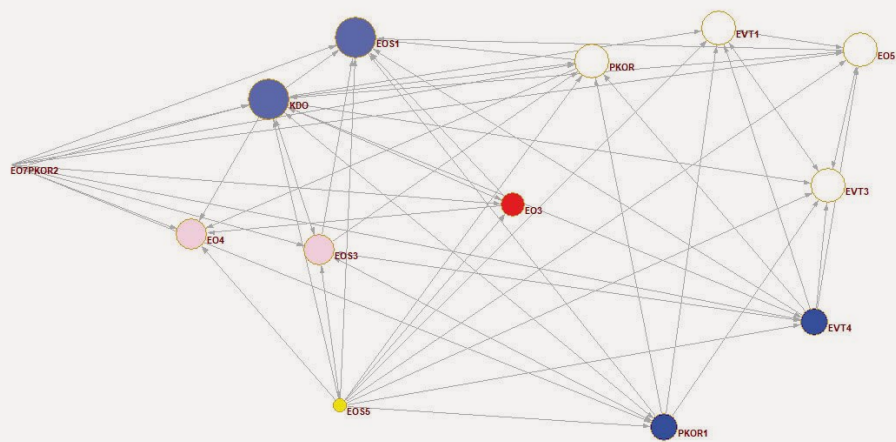


Figure 6: Network for information exchange related to the work in the Krško pilot environment (entry connections), (N=18)

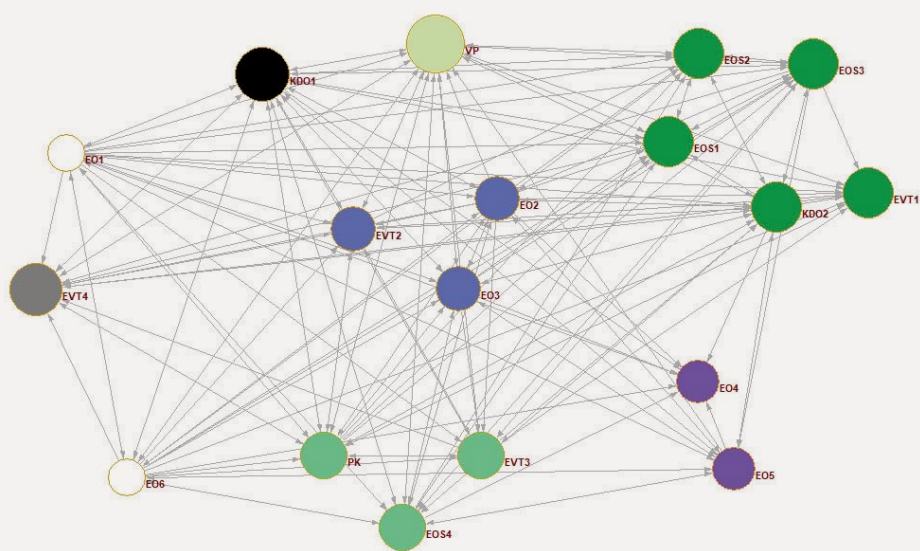
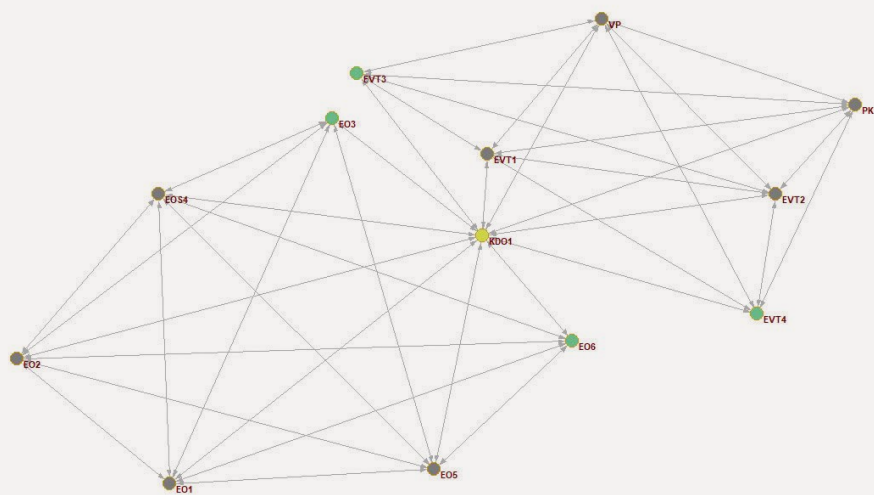


Figure 7: Two-way connections (work-related information exchange) between employees in the Krško pilot environment



took place between the LTC coordinator and project coordinator, and also between the LTC coordinator, one employee in the care unit and one assessor. The second triad represents an employee in the care unit and two assessors.

The central person in the network of expert advice exchange when resolving work challenges was the LTC coordinator. The latter was contacted by eight colleagues for expert advice. One of the employees in the independence maintenance unit, to whom four colleagues turned for expert advice, i.e. three in the care unit and one in the independence maintenance unit, played a minor central role. On average, the employees turned to 1.5 persons for expert advice and six colleagues were not contacted by any of the employees for expert advice.

The central role regarding discussions about problems at work was also played by the LTC coordinator in the Dravograd pilot environment, who was contacted by seven colleagues. Other important sources of such support were two assessors and one employee in the care unit, whom four colleagues turned to. On average, the employees contacted 2.3 persons to discuss work-related problems, and two persons were not contacted by any of the employees.

Mutual discussions about work-related issues took place between two assessors and one employee in the care unit. These were also the employees contacted by three other colleagues.

Emotional support was sought by the majority (four) employees in the Dravograd pilot environment with the LTC coordinator and an assessor. On average, the employees turned to 1.5 colleagues for emotional support and six colleagues were not contacted by any of the employees for such support. As in mutual discussions about work-related issues, a two-way exchange of emotional support took place between three employees, i.e. two assessors and one employee in the care unit.

In the Krško pilot environment, the questionnaire was responded to by 17 persons who were working in the pilot project during its

implementation. The majority of employees (15) contacted the project manager for work-related information, somewhat fewer people turned to the LTC coordinator (13) and the assessor (12). Eleven employees sought information from three employees in the independence maintenance unit, the assessor and the second LTC coordinator. If compared to the other two environments, the average number of colleagues to whom employees turned was the highest in Krško, i.e. ten people (the median had the same value), and the minimum number of employees (6) who contacted their colleagues for information exchange was also the highest.

The strong connection between the employees in the Krško pilot environment regarding the exchange of work-related information can also be seen in Figure 7, which shows the network of employees between whom at least five two-way connections take place. This means that each employee specified at least five persons with whom they exchanged work-related information, and at least five persons also indicated that same person as a source of information exchange. For example: the project manager contacted the project coordinator for information, and four assessors turned to the LTC coordinator. The latter was a distinctly central person as mutual exchange of information took place between them and twelve employees.

The majority of employees (14) turned for expert advice when resolving work challenges to the project manager. Seven employees contacted the LTC coordinator for expert advice and six employees turned to two assessors and one employee in the independence maintenance unit. On average, the employees contacted 4.8 persons when seeking expert advice regarding work challenges and they minimally contacted two persons.

The central role in the Krško pilot environment was played by the employee of the independence maintenance unit regarding discussions about work-related problems, as they were contacted by nine colleagues. Other important sources of such support include the project manager (contacted by eight employees) and both LTC coordinators, who were contacted



by six colleagues. On average, the employees contacted somewhat fewer than four persons to discuss work-related problems, and one employee contacted the fewest persons, i.e. one.

Mutual discussions about work-related issues took place between two employees in the care unit and one employee of the independence maintenance unit. These were also the employees contacted by three other colleagues.

The largest proportion of employees (8) in the Krško pilot environment contacted either the project manager or the employee in the independence maintenance unit for emotional support. Important sources of emotional support are also the LTC coordinator, employees in the independence maintenance unit and two assessors who were contacted by five colleagues. On average, the employees talked to 3.4 people about important personal issues, while four employees contacted only one colleague. When examining the number of two-way connections regarding emotional support between employees, we can determine that the exchange of such support took place particularly between two colleagues.

## Integration with other important stakeholders in the community

Integrated long-term care does not only denote the integration of various profiles in one organisation or project, but also the integration of various organisations and actors in the provision of care in a community. The pilot projects particularly integrated various profiles within the project, while cooperation with other actors in the community was not established at the level of direct user care, which was also not one of the project's objectives. The LTC coordinators did not incorporate service providers in the personal and implementation plan who were outside the scope of the pilot project, i.e. in the community. Nevertheless, the employees in pilot environments cooperated with the stakeholders in the local environments at other levels.

At the start of the project, they cooperated for the most part with users' relatives, employees of centres for social work, home help providers and employees of the retirement home. In the Celje pilot environment, where the single entry point was located in the health care centre, the cooperation with the community nursing service and doctors was most intensive (if compared with other environments). On the other hand, the Krško pilot environment most intensively cooperated with home help providers and employees of the occupational activity centre. In the Dravograd pilot environment, the cooperation was most intensive with the employees of the retirement home because the LTC coordinator was located there.

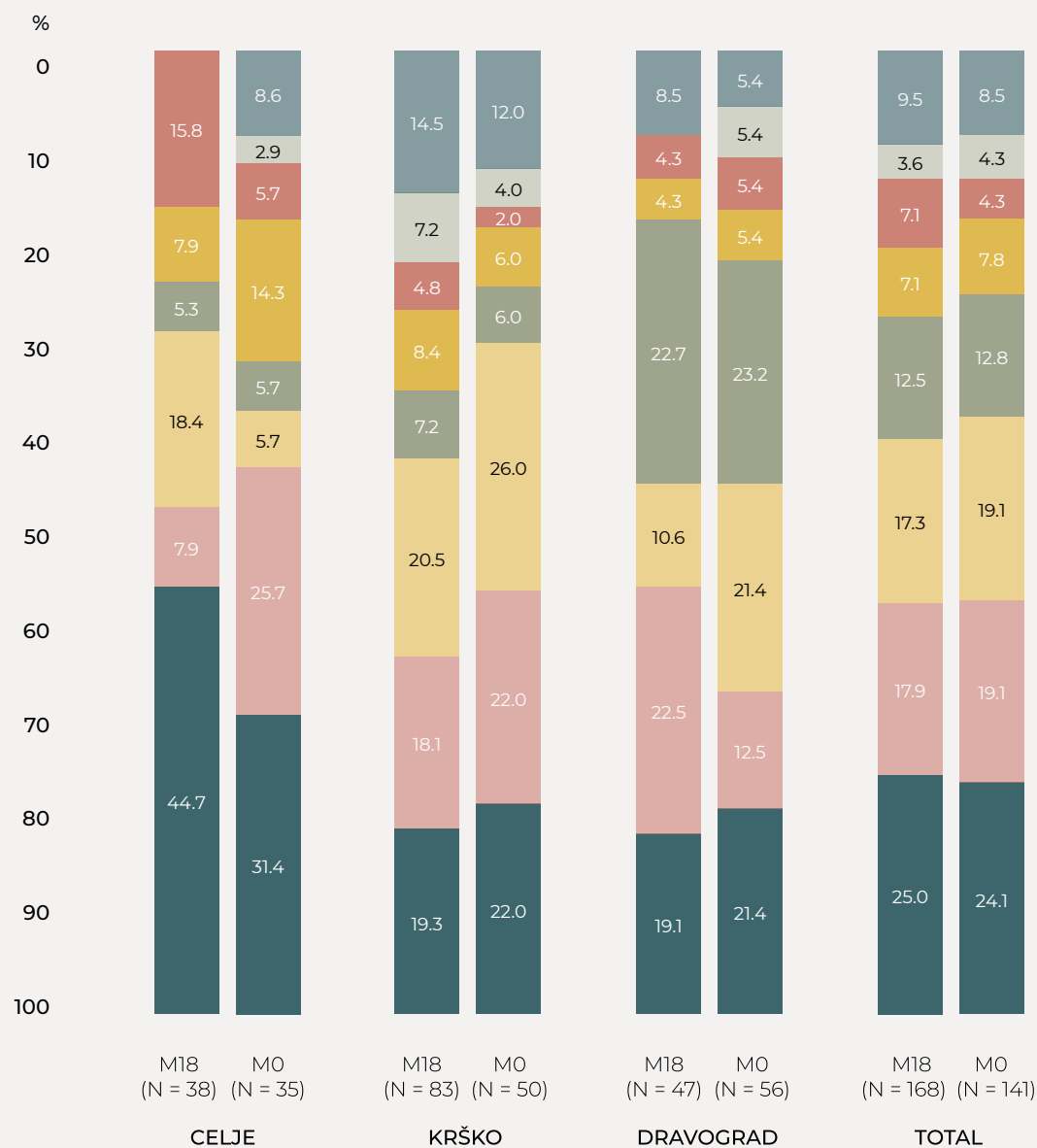
At the end of the project, the Celje pilot environment enhanced cooperation with users' relatives and neighbours and home help providers on the one hand, while on the other hand, the cooperation with the employees of the centres for social work was somewhat less intensive. The Krško pilot environment strengthened cooperation with the community nursing service, doctors and other stakeholders, including volunteers, employees of the occupational activity centre and NGOs. The cooperation of the Dravograd pilot environment with home help providers was on the one hand less intensive than at the start of the project, while the cooperation with the employees of the centres for social work and retirement home and other stakeholders was more intensive, particularly with the employees of NGOs.

## Discussion with key messages

The establishment of teamwork in pilot projects was examined from several aspects, i.e. on the basis of the dynamics of meetings between and within individual teams, within the framework of measuring organisational climate and from the viewpoint of exchanging different types of support between the employees.



**Figure 8: Proportion (in %) of external colleagues with whom the employees cooperate at least once a week in their work (M0 and M18)**



- Users' relatives
- Employees at centres for social work
- Home help providers
- Employees at retirement home
- Community nursing service
- Users' neighbours
- Volunteers
- Others

The dynamics of meetings in all pilot environments revealed that the condition of the indicator, which anticipated at least five regular meetings between LTC coordinators, care teams and assessors, at which information was exchanged about possible work challenges and open issues, was fulfilled. Irrespective of the indicator's criterion, we assess that the number of formal meetings in the Celje pilot environment was rather low, as they mostly took place on a monthly basis and in certain periods even once per two months. Among the organised meetings in the Dravograd pilot environment, a large number of meetings held between the team of assessors and the LTC coordinator stood out, which was also the result of the fact that the assessors and the LTC coordinator were based at different locations. All three pilot environments explained that the major part of communication and information exchange about the developments on the project and resolution of possible work challenges was implemented on a daily basis in the form of informal discussions among the employees. The Krško pilot environment can be highlighted as an example of good practice when establishing teamwork, as great attention was paid at the start of the project to the employees getting to know each other and learn as much as possible about the entire procedure of long-term care implementation, which included the work of other teams and that of different organisations related to long-term care, even if these did not participate in the project.

The data about the provision of mutual assistance between the employees testifies that mutual cooperation between the employees in the pilot environments was intensive. The role of the LTC coordinator proved to be very important in this respect as they stand out in all environments as a person to whom other employees turned for information and advice to the greatest extent. High level of cooperation between the employees was seen especially in the Krško pilot environment, where the average number of colleagues contacted by the employees was the highest (ten people). The latter could be the result of the good practice

mentioned above, i.e. that the employees became familiar with the entire procedure of long-term care implementation, including the work of other teams.

The data on the networks showed that smaller teams also formed between the employees in the Krško and Dravograd pilot environments, among whom assistance and support were more intensive. It is encouraging to know that not many isolated units were in the networks, i.e. employees to whom no one turned for help.

When introducing changes or new solutions, the assessment of organisational climate is very important because it enables us to identify weak areas of the organisation and strive towards improvements accordingly, in addition to identifying areas which are critical for the wellbeing of employees. Numerous studies in healthcare and other fields reveal that the employees are more satisfied and deal with less stress and burnout if they work in environments in which leadership offers support, and mutual support, cooperation and consensus building are promoted (Stone, Pastor, & Harrison, 2006).

The assessments of individual categories of organisational climate in the pilot environments were lowest at the start of the project regarding the knowledge of the project's objectives, organisation, communication and management from the viewpoint of all and individual pilot environments. The assessments of organisation and knowledge of objectives increased at the end of the project. An increase in the category of knowledge of objectives failed to occur only in the Celje pilot environment. The latter can be attributed to the fact that numerous employees joined the project during its implementation (and in later phases), which is why they perhaps received insufficient information and knowledge about the pilot project's objectives, or they failed to participate in the initial phases of the project when guidelines and objectives are usually formed.

Successful establishment of cooperation or teamwork among the employees is also indicated by a high score in the category of internal relations, which increased during the project in Krško and Dravograd. Supervision also proved

to be an important element of working life and a significant advantage for the employees.

The quality of employee working life was determined on the basis of satisfaction with individual aspects of working life. Average satisfaction assessments were high in all environments, which means that employees were satisfied with individual aspects; they were less satisfied with working conditions and their direct superiors, and they are more satisfied with the work they did, working hours and their position in the project. The employees in the care unit were on average least satisfied with the payment for their work and those working in the independence maintenance unit were the most satisfied.

As the main reason for dissatisfaction with the payment, the employees mentioned differences in salary grades between pilot environments. The pilot environments classified their employees in salary grades in different ways, usually in respect of whether they were employed within healthcare or social care. The latter had a poor effect on the motivation to work, including mutual cooperation and integration between the colleagues of various professions. The employees also highlighted that salaries were too low considering the complexity and scale of the work, an issue which was associated with the resignations of some employees. Least satisfied with the payment for their work were the social carers, who, in accordance with the uniform wage system of the public sector, are classified in salary grades that are even lower than those of comparable professions such as personal assistant.

Regarding employee workload, it may be deduced from the results that a lot of work in the initial phase of pilot project implementation concentrated on the preparation of the project itself and suitable documentation, which resulted in more administrative work. Suitable records and documentation were for the most part established at the end of the project implementation and, as a result, less time was dedicated to administrative tasks.

We determined that work in pilot projects was quite tiresome for the employees, especially at the start as almost half of them reported that they were unable to perform certain household chores after work due to tiredness. Some 20% of employees spent so much time at work that they had problems meeting their family obligations. The workload somewhat decreased at the end of the project, whereby it is impossible to determine from the data whether the reason for such reduction lies, for example, in a better workflow of the project, a lower number of applications filed than at the start of the project, or whether the reduction would be more pronounced if the Covid-19 epidemic had not begun during the surveying and completing period of the project.

An important finding arising from the survey on user satisfaction was that, when being asked to state at least one thing with which they were satisfied in the pilot project, the majority of users mentioned the employees who were visiting them at their homes. They mentioned the employees' personal qualities (kindness, care, good spirits, helpfulness), their assistance, professionalism and accessibility/humanity ("they ask me things", "they give me advice"). Socialising and discussion with the employees were also assessed as positive.

The employees' cooperation with other stakeholders in the community was not based on the implementation level because the LTC coordinator incorporated in personal and implementation plans particularly the services provided within the pilot projects. At the implementation level, they were thus unable to establish actual integration between social care and healthcare into integrated and comprehensive user care. Nevertheless, the employees cooperated with stakeholders in the local environment in other ways. The intensity of employee cooperation in individual pilot environments somewhat differed, as it depended on, for example, the employee profile, location of the single entry point in the pilot environment, prior cooperation with the relevant stakeholders, etc.

## BIBLIOGRAPHY

- Berberoglu, A. (2018). *Impact of organisational climate on organisational commitment and perceived organisational performance: empirical evidence from public hospitals*. BMC Health Service Research, 18(399).
- Boštjančič, E. (2009). *Vpliv nezavednih motivov na stil vodenja*. Psihološka obzorja. 18(4), p. 37–57.
- Carrington, J. P., Scott, J., & Wasserman, S. 2009. *Models and Methods in Social Network Analysis*. Retrieved from [https://www.researchgate.net/publication/200465300\\_Models\\_and\\_Methods\\_in\\_Social\\_Network\\_Analysis](https://www.researchgate.net/publication/200465300_Models_and_Methods_in_Social_Network_Analysis)
- D'Amour, D., & Oandasan, I. (2005). *Interprofessionality as the field of interprofessional practice and interprofessional education: an emerging concept*. Montreal: Faculty of Nursing, University of Montreal.
- Emilsson, M. U., Strid, A-L., & Söderberg, M. (2020). *Lack of Coordination between Health Care and Social Care in Multi-Professional Teamwork – the Obstacle for Coherent Care of Older People Suffering from Multi-Morbidity*. Journal of Population Ageing. doi: 10.1007/s12062-020-09300-8
- Gorše, A. 2011. *Zadovoljstvo zaposlenih v podjetju X*: diplomsko delo. Ljubljana: Fakulteta za družbene vede.
- Hagmaier, T., & Abele, A., E., (2012). *The multidimensionality of calling: Conceptualisation, measurement and a bicultural perspective*. Journal of Vocational Behaviour 81, p. 39–51.
- McWinner, Y. (2020). *Organisational Climate and Job Satisfaction: A Literature Review*. International Journal of Current Research. 12(02), p. 10013–10018.
- Mrvar & Batagelj, 1996–2020. *Pajek, Program for Large Network Analysis*. Retrieved from <http://mrvar.fdv.uni-lj.si/pajek/>
- Schwendimann, R., Dhaini, S., Ausserhofer, D., Engberg, S., & Zúñiga, F. (2016.) *Factors associated with high job satisfaction among care workers in Swiss nursing homes – a cross sectional survey study*. BMC Nurs 15, 37.
- Stone, P., Pastor. K.D., & Harrison, I.M. (2006). *Organisational Climate: Implications for the Home Healthcare Workforce*. Journal of Healthcare Quality. 28(1), p. 4–11.

# **IMPLEMENTING AND STRENGTHENING LONG-TERM HOME CARE SERVICES**

Lea Lebar  
University of Ljubljana, Faculty of Social Sciences

Boris Majcen  
Institute for Economic Research

Valentina Prevolnik Rupel  
Institute for Economic Research

Izidor Natek  
University of Ljubljana, Faculty of Social Sciences

*IMPLEMENTING AND  
STRENGTHENING LONG-TERM  
HOME CARE SERVICES*

## KEY MESSAGES

- In three pilot environments, users received a total of more than 100,000 services in more than 37,000 visits. By introducing services to maintain independence in the users' home environment, the pilot project contributed to the equalisation of the rights of persons in institutional care and at home.
- Users expressed very high satisfaction, recognised the usefulness of the new services they received in the pilot projects, and reported positive effects on their independence and quality of life. The introduction of new services from the pilot project is therefore also necessary and desirable at the system level.
- The analysis of services and needs in the local environment was hampered by methodological challenges in data collection and recording. Data regarding services already received by users in the local environment are collected unsystematically, which poses a systemic problem that pilot projects have failed to overcome.
- The data shows large differences between the services envisaged in the implementation plans and the services actually implemented. Based on the available data, we can conclude that the providers mostly did not follow the implementation plan closely or changed the services during the implementation phase.

## Introduction

As regards the current provision of rights, which, according to the definition, fall within the field of long-term care, it can be said that in Slovenia they are provided in different ways, in different social protection systems, through different social and health care services and cash benefits. In Slovenia, home care is provided through health care with the community nursing service and through social care with family support at home<sup>61</sup>, with the responsibility for organising home care being further divided between the state and local authorities. Slovenia, like most European countries, is facing fragmented provision of services in the field of long-term care, i.e. a lack of integration of health and social work, and the slow development of both, especially in the user's home and in the context of demographic change and the rapid increase in needs. Zavrl Džananović (2019) concludes for the community nursing sector that the structure of employees is currently inadequate and that the community nursing sector is not adequately prepared in terms of staffing to meet the challenges and needs brought about by demographic trends. Despite the proven importance of prevention, it is difficult to upgrade the predominantly curative activity to a preventive one with such staffing levels, although according to the Institute of Macroeconomic Analysis and Development (Bratuž Ferk et al., 2021), they are being strengthened. The increasing demand for community nursing services is linked to the ageing population, the higher incidence of chronic diseases and the insufficient capacity of social care services to support families at home<sup>62</sup> (Bratuž Ferk et al., 2021). For home help, regular monitoring by the Social Protection Institute of the Republic of Slovenia has shown for many years that geographical, temporal and price access varies across Slovenian municipalities. In fact, the service is only available in 209 municipalities (it is not available in three municipalities), including

57 municipalities only on weekday mornings. The price per user varies from 0 EUR to 9.52 EUR per hour, which puts the inhabitants of municipalities with higher prices in a highly unequal position. Not all people who need the service receive it due to the heavy workload of the staff; as of 31 December 2019, there were 772 people waiting for the service in Slovenia, and providers have further estimated that at least 446 more people could be included in assistance at home, but for various reasons they are not (Kovač, Orehek, & Černič, 2020). The profession therefore points to the need to expand existing services and bridge inequalities in access on the ground, as well as to the necessity of developing new innovative forms of community-based services and programmes (e.g. Flaker, Nagode, Rafaelič, & Udovič, 2011; Flaker, Mali, Rafaelič, & Ratajc, 2013; Nagode, Kovač, Lebar, & Rafaelič, 2019). The A-Qu-A project of Zavod za oskrbo na domu has shown, *inter alia*, that people living at home need more health services, counselling on health topics and issues, nursing care, physiotherapy and occupational therapy (Perko, 2016). At the same time, the development of new home-based services is essential if Slovenia is to follow the European Commission guidelines that commit Member States to deinstitutionalisation, which, as Ilinca, Leichenring and Rodrigues (2015) point out, can only be achieved through a well-coordinated combination of informal and formal, user-centred community care, and through improved coordination between different disciplines and areas of care. The development of new services must go hand in hand with the strengthening of existing services in the user's home, with the common aim of preventing or at least postponing the institutionalisation of users and delaying (or preventing) the emergence of more extensive needs through preventive measures.

The need to strengthen services in the home environment is also highlighted in strategic documents. The Resolution on the National

61 Home care also includes personal assistance, family assistants and residential groups (Nagode et al., 2014; Bratuž Ferk et al., 2021), but these are not analysed in detail in the pilot projects.

62 In the text we also use the term assistance at home.

Social Protection Programme 2013–2020<sup>63</sup> in its second objective highlights the improvement of the availability and diversity as well as ensuring the accessibility and affordability of services and programmes. The Resolution on the National Health Plan 2016–2025 “Together for a Healthy Society”<sup>64</sup> highlights the need to raise awareness among decision-makers and the population for greater societal and individual responsibility for health, to move from disease to health and to upgrade and attribute importance to prevention activities. Data from the World Health Organisation (WHO, 2014) shows that prevention and health promotion activities are cost-effective in the long term; therefore, the Draft Long-Term Care Act (2021) also addresses the area of a new set of services, i.e. services to maintain and enhance independence. These are expected to significantly slow down the progression to higher levels of dependency on the help of another person, and to improve the quality and safety of life of long-term care users and their relatives, who often take on the role of informal carers. As the Ministry of Health explains in the introduction to the Draft Long-Term Care Act (2021<sup>65</sup>), they want to reduce the current inequalities in service provision, as the current system does not provide the same range of services in the community or at home compared to institutions, despite the comparable needs of citizens.

In response to these initiatives, the public tender highlighted the second key objective of the pilot projects as “testing new services and integrated treatment of the user in the home environment”. In the pilot projects, two teams provided services: a care team and an independence maintenance team. The former team consisted of a social carer, a nursing carer and a nursing assistant, and provided basic activities of daily living services (ADL), instrumental activities of daily living services (IADL) and nursing services.

In the team for maintaining independence, a physiotherapist, an occupational therapist, a master in kinesiology and/or a social carer provided services to home users in accordance with their professional competences. The services they provided are called “new services for maintaining independence” (also: new services) in this chapter and are intended to prevent falls, improve motor independence, raise awareness of health strengthening, counsel for greater independence in living spaces, advise informal carers on the correct approaches to working with the user and prevent burnout of informal carers, and prevent and manage mental distress.

## Methodology

The chapter focuses mostly on the results of testing new services to maintain independence, looking at user satisfaction with the new services, the perceived usefulness of the new services, the perceived effects of engagement with the new services, and satisfaction with the work of the independence maintenance team. We include the views of users and staff in the pilot environments. We monitored three key indicators, specifically *the proportion of users receiving services relative to all eligible users living at home, the proportion of users who are satisfied with the new services and the proportion of users who perceive the new services as useful*.

In this chapter, we corroborate the quantitative data with qualitative data collected in different databases. Quantitative data on the services provided was extracted from the central information system (frequency and duration of each service) and *from users’ personal plans* (analysis of implementation plans, in which we monitor the number of times each service is recorded in the implementation plan). We have only considered data on the services implemented

63 Resolution on the National Social Protection Programme 2013–2020 (Official Gazette of the Republic of Slovenia [Uradni list RS], No. 39/13) Resolution on the National Health Care Plan 2016–2025 »Together for a healthy society« (Resolucija o nacionalnem planu zdravstvenega

64 varstva 2016–2025 (ReNPZV16–25))

65 Vlada Republike Slovenije. (2021). Predlog zakona o dolgotrajni oskrbi



in the pilot projects. We do not include the remaining services under the existing rules in the analyses, as individualised anonymised data is not systematically collected at the national level, nor collected by the providers in the framework of the project.

User satisfaction with the new services and with the independence maintenance team and the perceived usefulness of the new services were measured *in a questionnaire after one year of involvement in the project (M12)*. This part of the questionnaire was co-designed with the independence maintenance teams in the three environments by transforming the list of ten new services into the five key tasks of the team that they perform in their direct work with the users and where we expect the highest impact. The main aim was to simplify understanding and reduce the burden on users in the interview process. In the following, we relate the quantitative data mainly to the following five key tasks:

- provision of services to maintain and improve motor independence;
- motivation in learning to live independently;
- the provision of psycho-social support services;
- advice on possible activities in the local environment or assistance in exercising rights; and
- assistance in adapting the living environment.

156 users responded to the questionnaire on the new services provided to users in the pilot project. Of these, the largest proportion (two thirds) reported receiving services to maintain and improve motor independence, 41.7% services to motivate them to learn to live independently, 35.5% psychosocial support services, 33.8% services to advise them on networking activities in their environment or to help them exercise their rights, and 29.9% services to help them adapt their living environment.

To measure the effects of the new services, we used a modified validated Psychosocial Impact

of Assistive Devices Scale PIADS-10 translated into Slovenian (Day & Jutai, 1996; Hsieh & Lenker, 2006; Jutai & Day, 2002; Jutai et al., 2007). In order to make the questionnaire as simple and short as possible for users, we used only four of the ten indicators, which we assumed would be the most relevant to describe the change in the situation of users. The scale takes into account the effects on specific aspects of daily life (rated on a scale of -3 to 3)<sup>66</sup>. Satisfaction with the work of the independence maintenance team was measured using the MRPS (The MedRisk Instrument for Measuring Patient Satisfaction with Physical Therapy Care) (Beattie, Turner, Dowda, Michener, & Nelson, 2005), with only one of the two factors (i.e. the user-provider interaction factor). We have omitted the factor related to external factors of care, as this is linked to the institutional environment.

We supplemented the data with qualitative methods. We analysed the semi-annual staff reports and the open-ended responses of users to the M6 and M12 questionnaires. We included the reports of the staff members in the independence maintenance team and marked their quotes in the text with PZ. In order to understand the experiences of users and informal carers involved in the pilot activities, we conducted 21 semi-structured interviews with users and 21 with informal carers. The interview guidelines were the measuring instrument for the interviews and followed the four main research objectives of the evaluation (i.e. procedures, methods, people, system) and also included framework questions regarding satisfaction with the new services. The topics covered were the strengths and weaknesses of the new services, the user power aspect, the adequacy of the number of hours, the missing services. In the text, quotes from the user interviews are denoted by I-UP. Quotes from interviews with informal carers are marked I-NF.

<sup>66</sup> The scale is used to determine whether the use of the service to strengthen and maintain independence greatly decreased (-3), significantly decreased (-2), slightly decreased (-1), neither decreased nor increased (0), slightly increased (1), significantly increased (2) or greatly increased (3) the individual aspect of the user's daily life.

## Results

We present the results of the (new) service provision in the pilot projects in three areas: in the first part, we present a general overview of the provision of long-term care services in users' homes, mentioning *all* of them, and highlighting the new services in the home environment. This is followed by an overview of user satisfaction with the provision of services and finally the perceived usefulness and effects of receiving the new services.

### Providing long-term care services in users' homes

The services provided in the users' homes under the project can be divided into four groups: basic activities of daily living services, instrumental activities of daily living services, nursing services and independence maintenance services. A total of 549 users<sup>67</sup> (178 in Celje, 220 in Krško and 151 in Dravograd) received services under the pilot project. Beneficiaries were those living at home; almost half of the beneficiaries in Celje (47.1%), two thirds of the beneficiaries in Dravograd (65.7%) and three quarters of the beneficiaries in Krško (76.1%) received at least one service. Any adult citizen of the Republic of Slovenia who was assessed as eligible for long-term care on the basis of an application submitted in the prescribed procedure was qualified to become a beneficiary of the services.

Users received a total of 100,028 services in a total of 37,182 visits. On average, a user received 182.2 services from the project<sup>68</sup>, with an average of 2.7 services per visit. A total of 43,378 services were provided in Celje, 40,423 in Krško and 16,227 in Dravograd. Of the total, 3,122 services were recorded as newly added services, which were recorded only in the Krško pilot environment. According to them, they (mainly social carers)

carried out activities that could not be recorded within the set of services in the pilot project, which unduly reduced their effective time. Therefore, in Krško, additional services were defined and entered in the information system which were not originally in the codebook:

S11 – Short telephone conversation: used by the social carer to inform users and informal carers and other stakeholders involved in the user's treatment.

S12 – Informing formal providers: informing doctors and community nurses.

S13 – Placement in a hospital or a care home: includes all communication between the user or their informal carer and the representatives of the institution.

S14 – Safe discharge.

S15 – Volunteering: introducing volunteers, keeping their records, introducing them to work with users.

S16 – Longer telephone conversation: i.e. psychosocial assistance to users over the telephone that is of a longer duration than 15 minutes.

We find that the largest number of nursing services was performed (36,016 or 36.0%), followed by supportive daily tasks (24,722 or 24.7%) and basic daily tasks (21,731 or 21.7%), the smallest number represents the independence services (17.6%). Access to the latter services was more time-limited in terms of volume (see Table 2). There are some differences between the pilot environments, with nursing services predominating in Krško and Dravograd, and basic and supportive daily tasks in Celje.

We find that the vast majority of users who were included in the services (N=549) received at least one new service, 88.8% of users in Celje, 95.9% of users in Krško and 95.4% of users in Dravograd. The receipt of new services is presented in the table 1, where we present two data sets from the information system: the proportion of those who had an actual service recorded in the field and the proportion of those who had a service recorded

<sup>67</sup> The calculation does not include users who only had a recorded visit from a long-term care coordinator.

<sup>68</sup> In the calculation of the average, we do not include users who did not engage in services for various reasons.

in the implementation plan. There are significant differences between the two figures, with either services listed in the implementation plan not having been implemented or services not recorded in the implementation plan being implemented in the field (see Table 1). We therefore suggested that the implementation plans be updated accordingly during the implementation of the project. The result indicator that we monitored does not precisely define the tolerances for deviations of the proportion of services implemented from the proportion indicated in the implementation plan. However, we consider that the differences are too pronounced. The gap between what is written in the implementation plan and the implementation of services was also pointed out by the long-term care coordinators in interviews (see chapter *Personal planning and coordination in long-term care: identifying needs and planning care together with the user*).

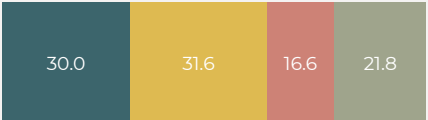
The public tender set the expected hours of services in each eligibility category (see Table 2) and severely limited access by users. Based on the available data, we find that the providers visited users in the Celje pilot environment on an average of 11 times per month or a little more than 2.5 times per week, in Dravograd on an average of 9.3 times per month or 2.2 times per week and in Krško 16.6 times per month or slightly less than 4 times per week (see Table 2))<sup>69</sup>. At the same time, users also received unchanged services under the current legislation; these hours are not included in the analyses.

The absolute differences between the number of hours performed in the field and the number of hours foreseen in the Draft Long-Term Care Act (2020) increase as the eligibility category increases. Although data on the services users receive under current legislation is not systematically collected, we tried to identify possible differences in the number of services provided and the duration of services for two groups of users: the first group included users

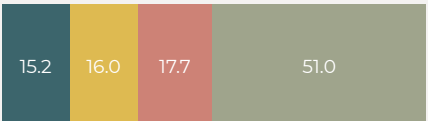
69 To calculate the average, we took into account the number of weeks the user received visits and the number of visits per team during this period.

Figure 1: Structure of services provided by sets in the pilot environments (%) (N1=43,378 (Celje), N2=40,423 (Krško), N3=16,227 (Dravograd) and N4=100,028 (total))

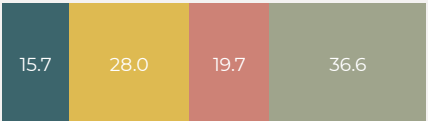
CELJE



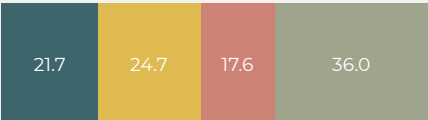
KRŠKO



DRAVOGRAD



SKUPAJ



% 0 20 40 60 80 100

- Activities of daily living
- Instrumental activities of daily living
- Independence maintenance services
- Nursing care

**Table 1: Proportion of users who received each new service to maintain their independence (% ex.) and the proportion of users who had each service written in their implementation plan (% IP) (n=548)**

| <b>Pilot environment</b> |                                                                                                                    | Celje |      | Dravograd |      | Krško |      |
|--------------------------|--------------------------------------------------------------------------------------------------------------------|-------|------|-----------|------|-------|------|
|                          | <b>Name of service</b>                                                                                             | % ex. | % IP | % ex.     | % IP | % ex. | % IP |
| <b>S1</b>                | User assessment and evaluation – initial and final                                                                 | 77.5  | 64.0 | 65.6      | 11.9 | 91.4  | 0.5  |
| <b>S2</b>                | Informing and involving team members or other stakeholders in the treatment process, reporting to the coordinator  | 16.3  | 7.9  | 74.8      | 10.6 | 50.9  | 0.9  |
| <b>S3</b>                | Advice for environment adaptation                                                                                  | 48.9  | 43.8 | 39.7      | 6.6  | 28.6  | 12.7 |
| <b>S4</b>                | Advice and training for informal carers to ensure quality and safe care for the user                               | 18.0  | 9.0  | 24.5      | 8.6  | 42.3  | 28.6 |
| <b>S5</b>                | Prevention, counselling and empowerment of the user for independent living                                         | 60.7  | 38.2 | 41.1      | 9.9  | 46.8  | 44.5 |
| <b>S6</b>                | Services to maintain motor independence: flexibility, strength, stability, mobility, endurance and fall prevention | 82.6  | 61.2 | 41.7      | 16.6 | 58.6  | 58.2 |
| <b>S7</b>                | Counselling for the management of chronic non-communicable diseases                                                | 6.7   | 1.1  | 19.2      | 2.0  | 42.3  | 40.5 |
| <b>S8</b>                | Health and healthy lifestyle promotion programmes and counselling for the user and the informal provider           | 12.4  | 3.4  | 51.0      | 4.6  | 51.8  | 42.7 |
| <b>S9</b>                | Psychosocial support for users and/or relatives                                                                    | 54.5  | 25.3 | 80.1      | 17.2 | 66.8  | 31.8 |
| <b>S10</b>               | Assistance in integration of the user into the community                                                           | 0.0   | 0.6  | 32.5      | 10.6 | 12.3  | 16.8 |

\*Note: The first number (% ex.) for each pilot environment represents the percentage of users with a service recorded in the IT system (among users who received services in the pilot environments, not among all users who were eligible for services); the second number (% IP) for the pilot environment represents the percentage of users who had a service foreseen in the implementation plan.

**Table 2: Foreseen number of hours in each eligibility category for ADL/IADL and nursing services (hours per month) according to the Draft Long-Term Care Act (2020), foreseen number of hours in the pilot projects and average number of care team visits and hours implemented per environment.**

|                   | Foreseen number of hours in each care category (per month) – Draft Act, 2020 | Foreseen number of hours in each category of care defined in the project (per month)* | Celje (average number of visits and hours per month)* |            | Dravograd (average number of visits and hours per month)* |            | Krško (average number of visits and hours per month)* |            |
|-------------------|------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|-------------------------------------------------------|------------|-----------------------------------------------------------|------------|-------------------------------------------------------|------------|
|                   |                                                                              |                                                                                       | Visits                                                | Hours      | Visits                                                    | Hours      | Visits                                                | Hours      |
| <b>Category 1</b> | 20                                                                           | 7                                                                                     | 6.1                                                   | 3.9        | 6.9                                                       | 4.5        | 13.6                                                  | 3.1        |
| <b>Category 2</b> | 40                                                                           | 10                                                                                    | 7.9                                                   | 4.9        | 9.6                                                       | 6.9        | 22.7                                                  | 7.6        |
| <b>Category 3</b> | 60                                                                           | 16                                                                                    | 10.1                                                  | 7.1        | 9.5                                                       | 7.6        | 16.5                                                  | 6.8        |
| <b>Category 4</b> | 80                                                                           | 19                                                                                    | 14.9                                                  | 9.5        | 10.3                                                      | 7.4        | 13.5                                                  | 5.2        |
| <b>Category 5</b> | 110                                                                          | 24                                                                                    | 18.3                                                  | 12.5       | 11.4                                                      | 10.2       | 17.4                                                  | 9.2        |
| <b>Total</b>      |                                                                              |                                                                                       | <b>10.9</b>                                           | <b>7.2</b> | <b>9.3</b>                                                | <b>7.0</b> | <b>16.6</b>                                           | <b>6.2</b> |

\* Does not include data from the independence maintenance team.

who had received neither formal nor informal care before the eligibility assessment, and the second group included users who had already received informal care or formal home care services. Given the limitation on the number of hours of care per month, we would expect the second group to receive fewer services and shorter visit times compared to the first group. However, the analysis of the results did not reveal significant differences in the average length of each visit (the average length of each visit was a little more than five minutes longer in the second group compared to the average length of each visit in the first group which was 40.3 minutes), nor in the average number of long-term care services (2.3 services per visit in the second group and 2.2 services per visit in the second group). The existing receipt of formal and/or informal forms of care does not appear to have had a significant impact on further limiting the length of each visit or reducing the number of services.

We therefore note that the average number of hours implemented by providers per user is low, which is due to the project specificity that limited the number of hours by category (see Table 2))<sup>70</sup>. The limits of hours set in the project are higher than the limits of hours set in the Draft Long-Term Care Act (2021), which results in the number of hours performed per month in each setting being significantly lower than the legal limits.

Consequently, it is of course not possible to draw conclusions about the actual needs of users on the ground solely on the basis of data from the pilot projects. The data shows that only a good third of the users in the pilot projects (35.1%) considered that they had received enough assistance. The largest proportion (39.6%) would like a little more help, and 22.1% would like a lot more help than they received in the framework of new services. They would like *“more frequent visits”* (M6) and *“services to last longer”* (M12). One user also argues that visits are too short because: *“the carers didn’t manage to arrange everything”* (M12), while another points out that: *“One hour*

*in the day goes by very quickly, I wish there was more time in one piece”* (M6). However, many of the users who expressed in the survey that they do not receive enough hours of assistance directly relate to a desire for more services provided by a physiotherapist: *“I wish the physiotherapist came more often”* (M12), *“It’s a pity there is not more physiotherapy!!!”* (M6). Staff overload led to long waiting queues (see chapter *From application to service: experience of procedures in pilot projects for more details on waiting lists*), to which the environment also responded by offering only e-care to individuals. The latter is reflected in a greater degree of dissatisfaction in Celje, as two of the users say: *“I am waiting for services, and I only have e-care”* and *“we did not get the services we wanted”*. The pilot environments tell us that more and more older individuals need services to maintain their independence, so the demand for these services will continue to grow in the future: *“As a physiotherapist, I see problems especially in the area of norms. There is a high demand for physiotherapy services in the field. In our environment, we have two part-time employees, which is totally insufficient”* (PZ).

In the context of scope, providers of new services point to the inadequate distribution of hours according to the eligibility category of users and the lack of flexibility in determining the scope of services for maintaining independence. They argue that especially users in the lower categories of care have too few hours and suggest a more individualised approach to each user, with more discretion for providers in determining the time for each user.

*“What and how we work with our care recipients is for physiotherapists to decide, within the limits of our competences and health legislation. Those with the lowest rating have the lowest hourly rates and those with a higher rating have the highest. I think it should be the other way around. It is precisely for this reason that the patients with lower rating need more physiotherapy, so that they*

<sup>70</sup> The employees in the pilot environments were able to apply to the Ministry of Health for an increase in the number of hours for users who were assessed as needing more assistance. The Ministry approved all requests received.

Table 3: Perceived satisfaction with the new services in pilot environments

|                                                                                            | Celje |     |     | Dravograd |     |     | Krško |     |     | TOTAL |     |     |
|--------------------------------------------------------------------------------------------|-------|-----|-----|-----------|-----|-----|-------|-----|-----|-------|-----|-----|
|                                                                                            | N     | AS  | SD  | N         | AS  | SD  | N     | AS  | SD  | N     | AS  | SD  |
| motivation in learning to live independently                                               | 36    | 4   | 1.1 | 10        | 4.9 | 0.3 | 19    | 4.6 | 0.5 | 65    | 4.3 | 1.0 |
| assistance in adapting the living environment                                              | 27    | 4.2 | 0.7 | 6         | 4.2 | 1.6 | 13    | 4.4 | 0.7 | 47    | 4.2 | 0.8 |
| maintaining and improving motor independence                                               | 62    | 4.6 | 0.6 | 28        | 4.5 | 1.1 | 13    | 4.5 | 0.5 | 103   | 4.5 | 0.8 |
| psychosocial support                                                                       | 31    | 4.2 | 0.9 | 8         | 4.4 | 0.7 | 16    | 4.3 | 0.6 | 55    | 4.2 | 0.8 |
| advice on possible activities in the user's environment or assistance in exercising rights | 29    | 4.1 | 0.6 | 3         | 4.7 | 0.6 | 19    | 4.4 | 0.7 | 51    | 4.3 | 0.6 |

Note: N... number of units of analysis; AM... asymmetric mean; SD... standard deviation

*do not get into higher categories of care over the years and consequently become more dependent on our care in all aspects (especially care)” (PZ).*

*“For category 1, for example, 55 minutes per month is absolutely too little and meaningless. Half an hour a week would be optimal. Otherwise, it varies from person to person – some need less, others need much more. I think we should have more freedom in determining the time and frequency of visits to maintain independence” (PZ).*

## User satisfaction with new services to maintain independence

As part of the satisfaction survey, we focused on the overall satisfaction with the new services and satisfaction with the providers. To assess overall satisfaction, we asked users to rate each received new service on a scale from 1 – very dissatisfied to 5 – very satisfied the statement “Considering all the experiences you have had with the service up to this point, how satisfied have you been with it?”. Based on the results of the survey, we find very high satisfaction among users for all groups of new services, with the highest level of satisfaction for services to maintain and improve motor independence (AM=4.5; SD=0.8). We find that users are slightly more satisfied with the service “motivation in learning to live independently” in Krško (AM=4.9; SD=0.3) and Dravograd (AM=4.6; SD=0.5) compared to Celje (AM=4.0; SD=1.1) (Kruskall-Wallis H=10.8; p=0.005) (see Table 3), while for the other services we did not find statistically significant differences between the environments. There were no other statistically significant differences by gender, age, environment or eligibility category.

The interviews and open-ended responses confirm the identified satisfaction of the users, who state, for example, that *“it helps me because I am active again due to the new activities... /.../ the occupational therapist pushes you forward, I get a new impetus, I also take care of the occupational*

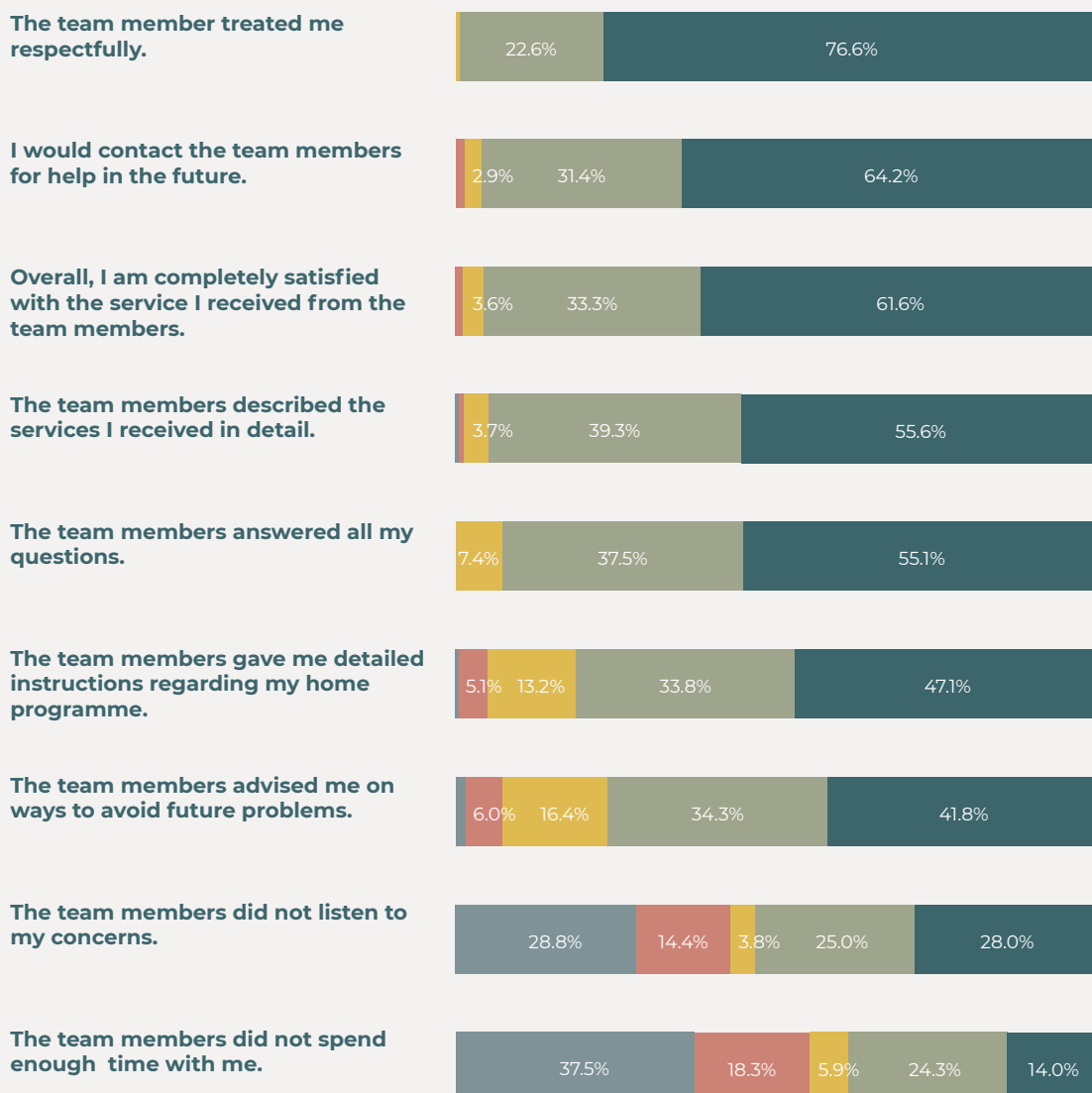
*therapy and I do it regularly, and the lady who does it with me always tells me how it's okay not to make mistakes, because sometimes you do something and you are doing yourself harm” (I-UP).* Furthermore, in the open-ended questions, the psycho-social support services are also largely highlighted by the users, more specifically the social aspect is mentioned as one of the key strengths of the project: *“To have someone come to me and talk, socialise, help” (M6).*

When asked about their satisfaction with the attitude of the providers of the new services (the independence maintenance team) towards the users (rated on a scale from 1 to 5), the users attribute the highest level of satisfaction to the respectfulness of the team members towards the users (AM=4.8; SD=0.4). The attitude of the team members is also highlighted by users as a key positive aspect of the project in the open-ended questions (questionnaires M6 and M12). Most of them consider that the contractors are friendly, respectful, good humoured and do quality work: *“respectful attitude, kindness, willingness to help, advise...” (M6), “kindness, helpful, all praise for the contractors” (M12).* In the interview, one user also stresses the importance of trust between service providers and recipients: *“Trust. Yes, trust, that was fine” (I-UP).* The majority of users also felt that the team members described the services they received in detail (AM=4.5; SD=0.7) and that all the questions they asked were answered (AM=4.5; SD=0.6): *“To have someone professional to ask about my body. I fall asleep in the evening with real physical tiredness and not a single muscle hurts, which means that the exercises are really well composed, that the whole body is happy” (I-UP).*

The majority of users would contact the team members for help in the future (AM=4.6; SD=0.6), and the majority of users are overall quite satisfied with the services provided by the team members (AM=4.6; SD=0.6). *“Everyone who comes wants to do more than 100%, as I see it, as I assess people” (I-UP).* Satisfaction with the quality of service is also reported by users in the survey, in which they highlight the efficiency, reliability and generally

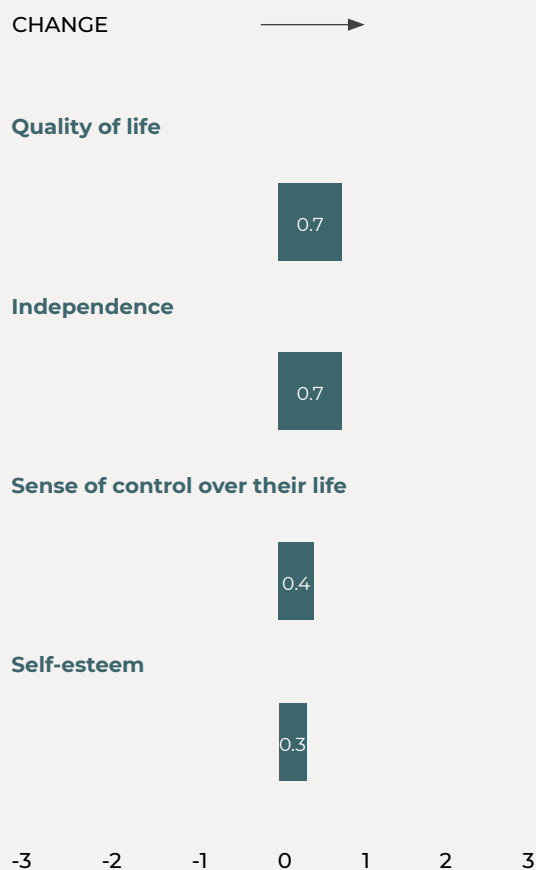


**Figure 2: User satisfaction with the work of the independence maintenance team (%), all pilot environments**



I completely disagree.  
 I disagree.  
 I neither agree nor disagree.  
 I agree.  
 I completely agree.

**Figure 3: Identified impacts of new services on users (modified PIADS-10, change)**



good work. Informal carers also report satisfaction with service providers: *"I shouldn't forget to say this, the kinesiotherapist showed me a few things, how to make it as easy as possible... not to torture myself and not to make my spine hurt. And he watched me, and the kinesiotherapist was surely there 3 or 4 times"* (I-NF). Most of them agreed that the team members had presented all the service options to them and answered their questions.

### Identified benefits and effects of receiving new services

For the services received, users also answered the question *How useful is each of the received services to you? Please rate on a scale from 1 to 5, where 1 means that the service is not useful at all to you and 5 means that it is very useful*. The highest perceived usefulness is found for services designed to maintain and improve motor independence (AM=4.6; SD=0.7) and services designed to motivate users to learn to live independently (AM=4.5; SD=0.6). *"Those 13 hours were fine, because he came regularly, and it made a difference. /.../ Yes, yes, it was extraordinary to tell you that, I couldn't believe it, he put him on his feet, he put a stick in his hand, and he stood by the bed, I thought the heavens were going to open up to me, let's say. /.../ I couldn't do it, I don't even know the moves, I'm not such a poor amateur, but I tried so hard that I learnt quite a lot of his exercises"* (I-NF).

We find that the service "motivation in learning to live independently" was more frequently identified as useful by users in Krško (AM=4.8; SD=0.4) and Dravograd (AM=4.6; SD=0.5) compared to Celje (AM=4.3; SD=0.6) (Kruskal-Wallis H=10.8; p=0.005). Similarly, the perceived usefulness of the services of advice on possible activities in the local environment and assistance in exercising rights is higher in Dravograd (AM=4.7; SD=0.6) and lower in Celje (AM=4.1; SD=0.8). In Krško, there were not enough units of analysis for comparison (see Table 4). The service of motivation in learning to live independently is

Table 4: Perceived usefulness of the new services in pilot environments

|                                                                                                   | Celje |     |     | Dravograd |     |     | Krško |     |     | TOTAL      |            |            |
|---------------------------------------------------------------------------------------------------|-------|-----|-----|-----------|-----|-----|-------|-----|-----|------------|------------|------------|
|                                                                                                   | N     | AM  | SD  | N         | AM  | SD  | N     | AM  | SD  | N          | AM         | SD         |
| <b>motivation in learning to live independently</b>                                               | 36    | 4.3 | 0.6 | 10        | 4.8 | 0.4 | 19    | 4.6 | 0.5 | <b>65</b>  | <b>4.5</b> | <b>0.6</b> |
| <b>assistance in adapting the living environment</b>                                              | 27    | 4.2 | 0.7 | 6         | 4.7 | 0.5 | 13    | 4.3 | 0.6 | <b>46</b>  | <b>4.3</b> | <b>0.7</b> |
| <b>maintaining and improving motor independence</b>                                               | 62    | 4.5 | 0.7 | 28        | 4.7 | 0.5 | 13    | 4.8 | 0.4 | <b>103</b> | <b>4.5</b> | <b>0.7</b> |
| <b>psychosocial support</b>                                                                       | 31    | 4.2 | 0.7 | 8         | 4.3 | 0.9 | 16    | 4.3 | 0.6 | <b>55</b>  | <b>4.3</b> | <b>0.7</b> |
| <b>advice on possible activities in the user's environment or assistance in exercising rights</b> | 29    | 4.1 | 0.8 | 3         | 4.7 | 0.6 | 19    | 4.6 | 0.7 | <b>51</b>  | <b>4.3</b> | <b>0.8</b> |

Note: N... number of units of analysis; AM... asymmetric mean; SD... standard deviation

perceived as more useful by users in the higher long-term care categories (categories 3, 4, or 5) (Mann-Whitney U test  $Z=-1.287$ ;  $p=0.022$ ). There were no other statistically significant differences by gender, age, environment or eligibility category.

The analyses show that users report the greatest positive change as a result of receiving the new services in the areas of quality of life ( $AM=+0.7$ ) and independence ( $AM=+0.7$ ). The other two aspects (sense of control over life and self-esteem) show less pronounced, but still positive, changes. Only four users report negative changes (mostly related to a decrease in independence). There were no other statistically significant differences by gender, age, environment or eligibility category.

## Discussion with key messages

The initial analysis of the situation, prepared as part of the evaluation, showed that all three pilot project environments at their starting point were more successful in developing community services than the national average. This is important, as it is easier to organise such innovations when the starting point is better, the processes more established and the providers more coordinated. In our initial analysis of the environments, we found that Celje and Krško in particular had a good foundation for further work and development, or that they sailed into the pilot project with very good predispositions and developed community services better than the vast majority of other Slovenian municipalities. In Dravograd, too, they did not lag far behind. The data shows that they have intensively started to develop home help in recent years and have increased the number of users by as much as 77% since 2009, the price of the service being low compared to the national average. If we connect these indicators with the development of institutional care, we find that the Krško pilot environment is primarily focused on community

forms (less on institutional care), Celje intensively develops both types of care, and the Koroška pilot environment achieves average results in both forms but is advancing rapidly in the development of both.

However, the municipalities involved in the project face similar challenges as the others, especially in the area of community services. The Institute of Macroeconomic Analysis and Development (Bratuž Ferik et al., 2021) notes that access to the long-term care services has been deteriorating for a number of years for a variety of reasons, that formal long-term care services at home are significantly less developed in Slovenia than in other EU countries, and that among people over 50 years of age in Slovenia, as many as 5% have unmet needs for long-term care services.

A total of 549 users received services from the project, receiving a total of 100,028 services from the basic daily tasks, supportive daily tasks, nursing care and new services to maintain independence in 37,182 visits. Of the total, 3,122 services were recorded as newly added services, which were recorded only in the Krško pilot environment. The pilot projects highlighted the challenge of urgently determining the adequacy of the proposed set of services – i.e. whether it covers all the necessary services and, if not, which services should be added. It is evident that in Celje a much higher proportion of users received basic and supportive daily tasks services, while in Krško a much higher proportion received nursing services, which is related to the initial potentials and the organisation of the local environment. The municipal provider of home-based family support, Dom ob Savinji Celje, was not a project partner and several of these services had to be provided by the project providers themselves. This partly explains the higher frequency of these services compared to the other two environments, which are also providers of assistance at home themselves. In contrast, in the context of nursing care services, they were less frequently provided in Celje, where the lead partner is a health care centre, and more frequently in Dravograd and Krško.

New services to maintain independence were provided by physiotherapists, occupational therapists, social carers and masters of kinesiology. There was a very high level of satisfaction and recognition of the usefulness of the team's work and the delivery of all services, and the effects included a perceived increase in quality of life and independence among users. Contrary to some calls from professionals for the new services to be strengthened mainly in the lower categories of care due to their preventive nature, the data show higher user satisfaction in categories 3, 4 and 5. This suggests that the implementation of such services makes sense irrespective of the long-term care eligibility category in which users are classified. Similar activities were carried out some time ago by the Zavod za oskrbo na domu Ljubljana and its partners in the framework of the Active and Quality Ageing in the Home Environment (A-Qu-A) project, with comparable results. The A-Qu-A project has also shown that the needs are high and that such services are effective; for example, marked improvements in health status, increased mobility and motivation of users to exercise regularly, higher quality of life, positive long-term impact on patients' independence, and faster reintegration into the community have been reported (Štepic, 2016). In addition to the challenges with movement, the long-term care pilot projects have also importantly addressed the hardships associated with loneliness of older people. A survey in Domžale (Nagode et al., 2021) showed that loneliness and social isolation

constitute the second biggest challenge faced by older people, after a poor financial situation. It therefore makes sense to think carefully about how to help and involve people who live alone and have weak social or support networks.

The results therefore show that new services to maintain independence should be expanded, strengthened, and funded in a sustainable way, as a matter of urgency and sense. It should be added that the pilot environments have not, however, been able to respond to all the long-term care needs in the local environment. The public tender limited the number of hours available to users, which meant that the number of hours of care received was relatively low. The low number of hours cannot and should not be used as a basis for concluding that the average needs of users are (relatively) low; in addition to this limitation, many of them received other services in the existing system in addition to the project activities mentioned above, which are not considered in the calculation. The pilot projects have therefore highlighted a high level of need for long-term care services, but at the same time the pilot activities have not been able to fully meet this need. However, the pilot projects have taken an important step towards equalising the rights of users at home and in institutional care by reinforcing existing services and, in particular, by extending the range of community services to include physiotherapy, occupational therapy, social work and kinesiology.

## BIBLIOGRAPHY

- Beattie, P., Turner, C., Dowda, M., Michener, L., & Nelson, R. (2005). *The MedRisk Instrument for Measuring Patient Satisfaction With Physical Therapy Care: a psychometric analysis*. *The Journal of Orthopaedic and Sports Physical Therapy*, 35(1), 24–32.
- Bratuž Ferik, B., Čelebič, T., Gregorčič, M., Kajzer, A., Kokalj, A., Koprivnikar Šušteršič, M., ... Zver, E. (2021). *Evropski steber socialnih pravic, Slovenija 2000-2020*. Ljubljana: Urad RS za makroekonomske analize in razvoj.
- Day, H., & Jutai, J. (1996). *Measuring the psychosocial impact of assistive devices: The PIADS*. *Canadian Journal of Rehabilitation*, 9(3), 159–168.
- Džananovič Zavrl, D. (2019). *Delovanje patronažnega zdravstvenega varstva Slovenije v letih 2014 do 2019 - kadri in odziv stroke na demografske spremembe*. *National Institute of Public Health*. Retrieved from [https://www.nijz.si/files/publikacije-datoteke/zaposleni\\_v\\_vzd\\_2019\\_končna.pdf](https://www.nijz.si/files/publikacije-datoteke/zaposleni_v_vzd_2019_končna.pdf)
- Flaker, V., Nagode, M., Rafaelič, A., & Udovič, N. (2011). *Nastajanje dolgotrajne oskrbe: ljudje in procesi - eksperiment in sistem*. Ljubljana: Fakulteta za socialno delo.
- Flaker, V., Mali, J., Rafaelič, A., & Ratajc, S. (2013). *Osebnostno načrtovanje in izvajanje storitev*. Ljubljana: Fakulteta za socialno delo.
- Hsieh, Y.-J., & Lenker, J. A. (2006). *The Psychosocial Impact of Assistive Devices Scale (PIADS): Translation and psychometric evaluation of a Chinese (Taiwanese) version*. *Disability And Rehabilitation*. *Assistive Technology*, 1(1–2), 49–57.
- Kovač, N., Orehek, Š., & Čeranič, M. (2020). *Analiza izvajanja pomoči na domu v letu 2019*. Retrieved from [https://www.irss.si/upload2/Analiza%20izvajanja%20PND%20za%20leto%202019\\_30.9.2020\\_pop2.pdf](https://www.irss.si/upload2/Analiza%20izvajanja%20PND%20za%20leto%202019_30.9.2020_pop2.pdf)
- Ilinca, S., Leichsenring, K., & Rodrigues, R. (2015). *From care in homes to care at home: European experiences with (de) institutionalisation in long-term care*. *European Centre, policy brief December 2015*. Retrieved from <https://www.euro.centre.org/downloads/detail/>
- Jutai, J., & Day, H. (2002). *Psychosocial impact of assistive devices scale (PIADS)*. *Technology and Disability*, 14(3), 107–111. doi:10.3233/tad-2002-14305
- Jutai, J., Day, H., Coulson, S., Demers, L., Fuhrer, M.J., Lenker, J., & DeRuyter, F. (2007). *Developing a short form of the Psychosocial Impact of Assistive Devices Scale (PIADS)*. RESNA Annual Conference, Phoenix, AZ, June 15–19.
- Nagode, M., Zver, E., Marn, S., Jacovič, A., & Dominkuš, D. (2014). *Dolgotrajna oskrba – uporaba mednarodne definicije v Sloveniji*. Urad RS za makroekonomske analize in razvoj. Retrieved from [https://www.umar.gov.si/fileadmin/user\\_upload/publikacije/dz/2014/DZ\\_02\\_14.pdf](https://www.umar.gov.si/fileadmin/user_upload/publikacije/dz/2014/DZ_02_14.pdf)
- Nagode, M., Kovač, N., Lebar, L., & Rafaelič, A. (2019). *Razvoj socialne oskrbe na domu: od besed k dejanjem*. Ljubljana: Fakulteta za socialno delo.
- Nagode, M., Črnak Meglič, A., Ficko, K., Lebar, L., Pirec, S., & Rafaelič, A. (2021). *Dolgotrajna oskrba: potrebe in izzivi v Domžalah*. Ljubljana: Inštitut RS za socialno varstvo.
- Perko, L. (2016). *Integrirana oskrba na domu*. V L. Batič, R. Pišot, M. Tomšič, M. Sedmak, J. Hrovatin, D. Maraž, & M. Preglau (ed.), *Aktivno in kvalitetno staranje v domačem okolju (A-Qu-A)*. Ljubljana: Solos.
- WHO. (2014). *The Case for Investing in Public Health – A Public Health Summary Report for EPHO 8*. Retrieved from [http://www.euro.who.int/\\_data/assets/pdf\\_file/0009/278073/Case-Investing-Public-Health.pdf](http://www.euro.who.int/_data/assets/pdf_file/0009/278073/Case-Investing-Public-Health.pdf)
- Vlada Republike Slovenije. (2021). *Predlog zakona o dolgotrajni oskrbi*. (2020). Retrieved from <https://e-uprava.gov.si/drzava-in-druzba/e-demokracija/predlogi-predpisov/predlog-predpisa.html?id=7885>
- Vlada Republike Slovenije. (2021). *Predlog zakona o dolgotrajni oskrbi*. Retrieved from [https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Dolgotrajna/ZDO\\_parafa.pdf](https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Dolgotrajna/ZDO_parafa.pdf)
- Resolucija o nacionalnem planu zdravstvenega varstva 2016–2025 »Skupaj za družbo zdravja« (ReNPZV16–25). Retrieved from <http://pisrs.si/Pisweb/pregledPredpisa?id=RESO102>
- Štepič, M. (2016). *Ko celostni pristop pomembno pripomore k izboljšanju življenja uporabnika na domu*. V L. Batič, R. Pišot, M. Tomšič, M. Sedmak, J. Hrovatin, D. Maraž, & M. Preglau (ed.), *Aktivno in kvalitetno staranje v domačem okolju (A-Qu-A)*. Ljubljana: Solos.
- Ministrstvo za zdravje. (2018). *Javni razpis »Izvedba pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi«*. Retrieved from <https://www.uradni-list.si/glasilo-uradni-list-rs/vsebina/2018002400003/javni-razpis-za-izbor-operacij-izvedba-pilotnih-projektov-ki-bodo-podpirali-prehod-v-izvajanje-sistemskega-zakona-o-dolgotrajni-oskrbi-st--303-1201816-ob-198618>

# **PERCEPTION OF THE USE OF ASSISTIVE TECHNOLOGIES**

Lea Lebar

University of Ljubljana, Faculty of Social Sciences

Simona Hvalič Touzery

University of Ljubljana, Faculty of Social Sciences

Izidor Natek

University of Ljubljana, Faculty of Social Sciences

Vesna Dolničar

University of Ljubljana, Faculty of Social Sciences

## KEY MESSAGES

- We estimate that the proportion of users living at home who have chosen to use e-care services is rather high (16.9%), suggesting that there is an interest in this form of care. Based on combinations of various measurement instruments, we find that both e-care services users and informal carers are very satisfied and acknowledge the benefits of these services. We also establish the desire among users for the further use of e-care services on the assumption that they will be co-financed.
- Although Slovenia is currently lagging behind in this area, the data shows that the areas of e-care and e-health need to be systematically developed. The importance of assistive technologies has increased due to the Covid-19 epidemic.
- Due to all the positive effects reported in relation to assistive technologies, we appeal to policy-makers to make these technologies affordable and accessible, particularly for vulnerable groups, for example by enabling co-financing or exemption from payment, to enable people to remain in their home environment longer and reduce other potential forms of inequality among the older population.



## Introduction

Innovation in long-term care is increasingly focused on technology-supported care services (or “assistive technologies”) as a key component of the integration of health and social care. Assistive technologies (AT) is the collective term for information and communication technology (ICT)-based systems designed to support recipients of long-term care services at home and their informal carers. They include e-care and e-health services. E-care and e-health enable the provision of health and social care services at a distance, in users’ homes<sup>71</sup>. Modern e-care support systems<sup>72</sup> refer to a range of smart technologies that are connected with 24-hour accessible services. These include personal alarms (a small device triggered upon adverse event – the need for assistance), environmental sensors (e.g. gas leaks, smoke), mobility-related devices (e.g. fall detector, motion sensors), and a GPS system for positioning or monitoring movements. They can be connected to an assistance centre that provides a 24-hour response to any alarms, or to the mobile phone of an (in)formal carer (Cook et al., 2018). E-health refers to the exchange of physiological data between a patient at home and medical staff at a distance in order to facilitate the diagnosis and monitoring of the disease (Goodwin, 2010). In this paper, we distinguish between two types of e-health services: vital functions monitoring services (in which monitoring is implemented by trained staff at an assistance centre) and telemedicine treatment (in which monitoring is implemented by medical staff employed by a hospital)<sup>73</sup>.

Slovenia still lags far behind many European countries in the adoption of assistive technologies (Börsch-Supan, 2019). In Slovenia, less than 1% of older people use a personal alarm (Kubitschke & Cullen, 2010; Börsch-Supan, 2019), which places us at the bottom of the list of European countries together with Poland, Croatia and Greece (Börsch-

Supan, 2019). Technology-supported care services, with one exception, are not nationally available and are not included in the national health or social care system as part of formal health and social care services in Slovenia (Dolničar & Nagode, 2010; Nagode & Dolničar, 2010; Dolničar et al., 2018a). In the 2017 SHARE international survey, informal carers reported on the use of a personal alarm for the persons they care for. Among 2,243 informal carers, only seven (0.3%) reported that the persons they care for use a personal alarm. However, a more recent Slovenian survey in 2021 among informal carers aged 40+ who care for an elderly relative (n=612) showed that e-care services designed to monitor activities remotely (e.g. personal emergency alarm, automatic fall detector, motion sensors, and GPS positioning system) are used by 4.9% of carers and their elderly relatives. An additional 2.5% have used these services in the past (Dolničar, Hvalič Touzery, Trkman, Berzelak, & Bartol, 2021).

Various factors inhibit the widespread use of assistive technologies (Dolničar & Nagode, 2010; Nagode & Dolničar, 2010; Petrovčič, Peek, & Dolničar, 2019). One of the key ones is the limited usability of assistive technologies, which is linked to the lack of systemic involvement of end-users in their design and development. The usability of such technologies has been identified in the literature as a critical aspect of the end-user experience (Vermeulen et al., 2013). Additional restrictions include: 1. insufficient information for potential users and the general public about the existence and functionalities of e-care and e-health services; 2. poor understanding of the needs, fears, wishes, abilities and circumstances of potential older users; 3. insufficient exploitation of the existing knowledge; 4. lack of cooperation between key stakeholders, operational plans for service implementation, user-friendly design of assistive technologies, integration of services and technological solutions, strategic

<sup>71</sup> In this chapter, we use the term user to refer to the primary e-care users.

<sup>72</sup> The e-care services tested by users in the pilot projects include the Basic and Premium packages (Telekom Slovenije d. d.) and the In life smartwatch (Jožef Stefan Institute).

<sup>73</sup> Vital functions monitoring services were provided by Telekom Slovenije d. d. and telemedicine treatment by MKS Electronic Systems d. o. o.

planning, interdisciplinary and interdepartmental cooperation and integration, business models and funding models (Dolničar and Nagode, 2010). Slovenia has taken a step forward by adopting the Active Ageing Strategy (Government of the Republic of Slovenia, Ministry of Labour, Family, Social Affairs and Equal Opportunities and Institute of Macroeconomic Analysis and Development, 2017), which recognises the positive impacts of assistive technologies on a long-lived society, but there have been too few concrete steps to support such technology. For example, the results of a recent online survey to assess the situation in smart health and care, conducted among stakeholders (n=544) in nine European regions as part of the ITHACA project, show that among the nine regions analysed, Slovenia is the region with the weakest services supporting innovation and the weakest policy framework in this area (Dolničar et al., 2018a). A key finding of the national meeting organised after the survey, attended by stakeholders from business, politics, research and the civil society, was that politics is a key barrier to the development of new ideas and the development and use of innovative products. Two additional barriers are the reluctance of older people to use ICT and the lack of financial support. Stakeholders mentioned that there are no clearly defined standards and norms related to assistive technologies; that smart health and care is not a political priority; that cooperation between different stakeholders is poor; and that there is a lack of financial support. They also failed to recognise the major benefits of being involved in innovation partnerships (Dolničar et al., 2018b).

Researchers agree (Goodwin, 2010; Sanders et al., 2012; Melchiorre et al., 2018) that there is a lack of studies that would systematically analyse and empirically test the benefits of assistive technologies for end-users. However, existing research finds that assistive technologies can increase the sense of security (Peek et al., 2014; 2016; Tsertsidis, Kolkowska, & Hedstrom, 2019; Jaschinski & Ben Allouch, 2019; Hvalič Touzery, Smole-Orehek, & Dolničar, 2021) and freedom, and increase awareness of the condition and signs of illness

(Dolničar, Müller, & Santi, 2011; Tsertsidis et al., 2019; Prevodnik, Hvalič Touzery, Dolničar, Laznik, & Petrovčič, 2021). Research findings also show that assistive technologies promote independence (Peek et al., 2014; Tsertsidis et al., 2019; Jaschinski & Ben Allouch, 2019; Hvalič Touzery et al., 2021) and social interaction and reduce the social isolation of older people (Tsertsidis et al., 2019; Verloo, Kampel, Vidal, & Pereira, 2020) and can contribute to different dimensions of their quality of life (Dolničar et al., 2011; Dolničar, Petrovčič, Šetinc, Košir, & Kavčič, 2017; Verloo et al., 2020).

The effects of assistive technologies are also evident among informal carers, as they can reduce the burden, stress and anxiety of informal carers of older people (Andersson, Erlingsson, Magnusson, & Hanson, 2017; D'Onofrio et al., 2017; Dolničar et al., 2017; Smole-Orehek et al., 2019; Hvalič Touzery et al., 2020a) and at the same time increase their well-being and peace of mind (Andersson et al., 2017; Smole-Orehek et al., 2019; Hvalič Touzery, Lebar, Petrovčič, Smole-Orehek, & Dolničar, 2020a).

The research conducted in the context of the long-term care pilot projects builds on existing knowledge in this area in a meaningful way. Although we have monitored e-care and e-health services in the pilot projects, in the present paper we focus mainly on the former. We only briefly introduce e-health services.

In this paper, we present the results of a survey, complemented by semi-structured interviews among users of e-care services. We analyse the assessment of overall satisfaction, perceived usefulness and ease of use, and the impact of using e-care services. In this paper we present mainly the results for the target group of users, but we also touch on the results among informal carers.

## Methodology

The evaluation monitored the implementation of assistive technologies in the pilot environments, focusing on the overall satisfaction of the long-

term care users with e-care and their assessment of the ease and usefulness of use. During the evaluation, we monitored three indicators, namely the proportion of beneficiaries who lived in the community and used assistive technologies, the number of e-care interventions and the number of e-health interventions.

The survey design was broad: on a monthly basis we collected data on e-care and e-health which was anonymised by service providers and developed questionnaires for e-care and e-health users and their informal carers. At the same time, semi-structured interviews were conducted with a sample of users and informal carers in one of the pilot environments.

In the pilot environments, data on assistive technologies were reported monthly in collaboration with assistive technology service providers. Reporting started when the first user was involved or when the evaluators agreed with the pilot environments on how to monitor service delivery. Data for the previous month was reported in Krško from February 2019, in Celje from July 2019, and in Dravograd from October 2019 (e-care) or November 2019 (smartwatch and telemedicine). The environments sent the reports until the end of June 2020 (Dravograd) and August 2020 (Celje and Krško). The reports included the user code, start and end date of use, details of the service and equipment received, reasons for any non-involvement or early termination, and information on interventions. We further distinguished between users of assistive technologies according to their activity, considering users as “active” if they had used the assistive technologies for at least 25 days.

We surveyed e-care users at one point in time, with the majority of users being surveyed between May and August 2020. We used a face-to-face interviewing method in which the evaluator recorded the answers in an online platform (on a mobile phone). The survey was short, lasting on average less than five minutes (excluding three respondents who stopped the questionnaire for a long period of time), with half of the respondents completing the survey in less than four minutes.

At the time of the survey, users had been involved in the e-care service for between 58 days and 526 days, with an average of 262 days. A separate paper survey was also conducted among informal carers. In this paper, we refer to these results only exceptionally. 44 informal carers (31.4%) completed the questionnaire.

In order to obtain an understanding of the experiences of e-care users and their informal carers, we also conducted seven semi-structured interviews with e-care users and nine with informal carers. As the scope of the study went beyond interviewing all users of the different types of assistive technologies, we wanted to describe only the experiences of those who had tested the combination of the basic Telekom Slovenije package and the fall detector. We decided to do this based on a review of personal plans and focus groups among EVT staff and long-term care coordinators, in which the main focus was on the advantage of a quick response to a fall. All the users involved were from the Krško pilot environment, where they suggested candidates for interview in accordance with our guidelines. The interview cues included the following key themes: use and experience, change, e-care in the context of the Covid-19 epidemic, recommendations, and (for informal carers only) the burden of providing care. Due to the complexity of the telephone interviews and the specificities of the population involved (the older people found it difficult to talk for long periods on the phone, they were less able to hear and sometimes understand), the interviews were shortened slightly and lasted between 18 and 43 minutes (27 minutes on average).

In the long-term care pilot project, a total of 152 users tested assistive technologies, among them 131 tested only e-care services, 9 e-care and e-health services and 12 telemedicine support services. This represents 16.9% of all long-term care beneficiaries in the pilot projects who were assessed at home. In the first part we present the sample of e-care users, followed by a brief presentation of e-health users. Due to the low number of units of analysis, all further analyses are prepared for e-care users only.

## Presentation of a sample of e-care users and the intervention process

Information on experiences with e-care was obtained from 79 users (56.4% of all active users from all three pilot environments), specifically 31 users from the Celje pilot environment, 35 users from Krško and 13 users from Dravograd. The majority of users are female (70.9%), with an average age of 82.7 years ( $SD^{74}=10.2$ ) (see Table 1).

The majority of users (92.4%) used the E-care service (58.2% Basic package and 34.2% Premium package), while the remaining 7.6% used the In Life smartwatch (Dravograd pilot environment). Of these, about two thirds of users (65.8%) used assistive technologies for more than six months and less than one year, 24.1% for more than one year, 8.9% for up to three months and only one user for less than three months. 83.8% of the users answered the questionnaire themselves, and for the remaining either an informal carer or another relative answered the questionnaire. Users were active in their use of e-care. In the period between January and August 2020, when a total of 140 active users were involved in all three pilot environments, providers report the following assistance was provided:

- ▷ 775 alarms triggered (40.5% from Celje, 52.5% from Krško and 7.0% from Dravograd);
- ▷ 4024 alerts from automatic detection (98.6% from Celje, 1.0% from Krško and 0.5% from Dravograd);
- ▷ 785 interventions (80.6% from Celje, 17.1% from Krško and 2.3% from Dravograd);
- ▷ 316 social calls (39.2% from Celje, 50.6% from Krško and 10.1% from Dravograd).

## Presentation of a sample of e-health users and the intervention process

In this section, we briefly mention the descriptive results regarding the use of e-health

services. Due to the low number of completed questionnaires ( $N=14$ ), we do not present the results in detail. However, we dedicate a specific part of the discussion to users who have been involved in e-health services, which we consider relevant especially in the context of the Covid-19 epidemic.

A small number of users (21 in total) used e-health services in the pilot projects, specifically 12 users of telemedicine support in Dravograd and nine users of home-based vital functions monitoring equipment in Celje or Krško. The latter nine were also included in the e-care services. In contrast to e-care users, e-health users are predominantly male (57.1%). The average age of users was 80.4 years ( $SD=7.0$ ), which means that e-health users were on average younger than e-care users. The proportion of more educated users was also higher, with 42.1% having a vocational or secondary education and just under a third having a short-cycle higher education or higher, while only 26.3% of users had primary education. The statistics obtained from the service providers show that e-health users used the service very frequently. They are therefore active users.

During the project period, the telemedicine support users performed a total of 6,621 measurements (7.4% additional measurements) out of the planned 5,791 measurements. Persons with heart failure (10 persons) took 5,970 measurements (6.3% more) out of the planned 5,614 measurements, and two persons with type 2 diabetes took 251 measurements (41.8% more) out of the planned 177 measurements. In total:

- ▷ 61 telemedicine centre interventions (55 for people with heart failure and 6 for people with type 2 diabetes) were implemented. In total, 5 home visits, 30 CEZAR calls to users and 3 calls by the user to the centre were made as a result of telemedicine monitoring. 23 general observations were also recorded.
- ▷ 28 interventions by a specialist doctor (all for people with heart failure) were made. The specialist doctor advised users 16 times, in 12 cases changing their therapy.
- ▷ 18 technical support interventions (14 for people

<sup>74</sup> Standard deviation.

Table 1: Sociodemographic characteristics of e-care users by pilot environment

|                                    |                                        | N  | %    |
|------------------------------------|----------------------------------------|----|------|
| <b>Pilot environment</b>           | Celje                                  | 31 | 39.2 |
|                                    | Krško                                  | 35 | 44.3 |
|                                    | Dravograd                              | 13 | 16.5 |
| <b>Gender</b>                      | Male                                   | 23 | 29.1 |
|                                    | Female                                 | 56 | 70.9 |
| <b>Age</b>                         | < 65 years                             | 3  | 3.8  |
|                                    | ≥ 65 ≤ 80 years                        | 26 | 32.9 |
|                                    | > 80 years                             | 50 | 63.3 |
| <b>Education</b>                   | primary school or below                | 36 | 48.0 |
|                                    | vocational or secondary education      | 34 | 45.3 |
|                                    | short-cycle higher education or higher | 5  | 6.6  |
| <b>Marital status</b>              | married                                | 17 | 21.5 |
|                                    | divorced                               | 4  | 5.1  |
|                                    | widowed                                | 48 | 60.8 |
|                                    | single                                 | 9  | 11.4 |
|                                    | common-law partnership                 | 1  | 1.3  |
| <b>Number of household members</b> | 1                                      | 53 | 67.9 |
|                                    | ≥ 2                                    | 25 | 32.1 |
| <b>Net income</b>                  | Up to 500 EUR                          | 15 | 21.7 |
|                                    | > 500 ≤ 750 EUR                        | 27 | 39.1 |
|                                    | > 750                                  | 27 | 39.1 |

**Table 2: Overview of the providers and the name of the assistive technologies available in the pilot environments**

#### **E-care service (Basic package)**

Provider Telekom Slovenije

|       |           |       |
|-------|-----------|-------|
| CELJE | DRAVOGRAD | KRŠKO |
| ✓     | ✓         | ✓     |

#### **E-care service (Premium package)**

Provider Telekom Slovenije

|       |           |       |
|-------|-----------|-------|
| CELJE | DRAVOGRAD | KRŠKO |
| ✓     |           | ✓     |

#### **home vital functions monitoring package**

Provider Telekom Slovenije

|       |           |       |
|-------|-----------|-------|
| CELJE | DRAVOGRAD | KRŠKO |
| ✓     |           | ✓     |

#### **additional equipment**

Provider Telekom Slovenije

|       |           |       |
|-------|-----------|-------|
| CELJE | DRAVOGRAD | KRŠKO |
| ✓     |           | ✓     |

#### **In life smartwatch**

Provider A.L.P. Peca (developer Jožef Stefan Institute)

|       |           |       |
|-------|-----------|-------|
| CELJE | DRAVOGRAD | KRŠKO |
|       | ✓         |       |

#### **Telemedicine support**

Provider MKS Elektronski sistemi d. o. o.

|       |           |       |
|-------|-----------|-------|
| CELJE | DRAVOGRAD | KRŠKO |
|       | ✓         |       |

with heart failure and 4 for people with type 2 diabetes) were implemented.

## **Introducing e-care and e-health services**

The e-care services tested by users in the pilot environments include various packages offered by Telekom Slovenije and the In life smartwatch developed by the Jožef Stefan Institute. In the pilot environments, different services were offered (see tabel 2): in all three environments, the Basic E-care package by Telekom Slovenije, in Celje and Krško also the Premium E-care package by Telekom Slovenije and the vital functions monitoring package, and in Dravograd the In life smartwatch developed by Jožef Stefan Institute and the telemedicine support from MKS Elektronski sistemi d. o. o.

As can be seen from the tabel 2, Telekom Slovenije offers three different packages – E-care (Basic package), E-care (Premium package) and home vital functions monitoring. The E-care basic package provides a 24-hour availability of the assistance centre and an immediate call for help by pressing a button on the pendant or on the protection unit. The assistance is organised by the medical staff at the assistance centre. If the assistance centre is unable to reach the user, the informal carer is contacted, or help is organised through the appropriate intervention service (ambulance, fire brigade or police). The E-care Premium package additionally allows alarms to be triggered automatically when the user is unable to initiate a call for help due to an emergency (e.g. fall, nausea, etc.). The package also includes five motion sensors and two magnetic sensors. The system automatically triggers certain notifications that are forwarded to the contact persons and the assistance centre through the E-care app. The assistance services in all three pilot environments are provided by Telekom Slovenije's contractual partner, Doktor 24 d. o. o. The condition for the use of E-care is the involvement of one to three

contact persons (e.g. informal carers). If the user's needs change (e.g. the need for more support in independent living), the E-care service can be upgraded with additional equipment: a remote trigger, a waterproof fall detector, environmental sensors and detectors in the living environment (a gas detector, a smoke detector, a temperature detector and a water leakage detector, a magnetic sensor that detects the opening and closing of the refrigerator door, and the automatic switching on of the lights when there is movement) (Telekom Slovenije, d. d.).<sup>75</sup> Telekom Slovenije also enabled the monitoring of vital functions in the users' homes as part of pilot projects. Users could receive a blood pressure monitor, a blood sugar monitor and a weighing scale.

The In life smartwatch<sup>76</sup> was also used in the Dravograd pilot environment. A.L.P. Peca provided technical support to users. The smartwatch enables an automatic call for help in the event of a fall, call for help using a special button, locating the user in the event of danger, measuring heart rate and sending reminders. The user could measure their heart rate using the watch, and the watch also allowed remote heart rate measurement through an app. The watch allows the setting up of a so-called virtual fence which is controlled by the contact person using a mobile app. If the user crosses the virtual fence, the contact person receives an SMS notification including a link to the Google map and the coordinates where the user is located. For this function to work properly, a GPS signal on the user's side and an internet connection on the contact person's side are required. The smartwatch is managed by the contact person through a mobile application.

In the Dravograd pilot environment, a telemedicine provider (MKS elektronski sistemi d. o. o.) was selected to support people with chronic diseases in self-care at home (more specifically, patients with heart failure and/or type 2 diabetes).

The measurement equipment used – blood pressure monitor, weighing scale, blood sugar monitor, information and telecommunication infrastructure and clinical portal – came from the Centre for Telehealth (CEZAR Centre) (Rudel, 2020). A person with a chronic disease has telemedicine monitoring equipment installed at home (meters with a mobile phone). The patient measures vital functions with the devices as instructed by the specialist (the target group of patients with heart failure measuring blood pressure, heart rate and body weight, and patients with type 2 diabetes measuring blood sugar). The meters automatically transmit the data through a wireless Bluetooth connection to the mobile phone which immediately forwards the data to the telemedicine centre (CEZAR Centre at Slovenj Gradec General Hospital) where the data is processed. If the data exceeds personally defined thresholds, this is brought to the attention of the healthcare professional, a coordinator in the telemedicine centre. The telemedicine coordinator contacts the patient by telephone to confirm the authenticity of the measured results (Rudel, 2020).

## Results

In this chapter we analyse (1) the perceived ease of use, (2) satisfaction and (3) the usefulness of using e-services. Next, we evaluate (4) the perceived psychosocial effects of the use of e-care services in the group of users involved in the long-term care pilot projects.

*For perceived usefulness*, we tested agreement with the statement *“Overall, I found the e-care service easy to use”*, which users rated on a scale from 1 (do not agree at all) to 5 (strongly agree). The majority of users (80.8%) agreed or strongly agreed that e-care services are easy to use ( $AM^{77}=4.1$ ;  $SD=0.9^{78}$ ), with a slightly higher

<sup>75</sup> More detailed information on the packages is available on Telekom Slovenije's website [www.telekom.si](http://www.telekom.si).

<sup>76</sup> The following presentation of the functionality is based on the information received in the focus group and the personal interview. See also [https://www.telekom.si/en/about-us/company/press-releases/The\\_E\\_oskrba\\_service\\_for\\_safe\\_living](https://www.telekom.si/en/about-us/company/press-releases/The_E_oskrba_service_for_safe_living)

<sup>77</sup> Arithmetic Mean.

<sup>78</sup> Standard deviation.



prevalence of those aged under 80 (AM=4.3; SD=0.6) compared to those aged 80 and over (AM=4.0; SD=0.9)<sup>79</sup>, and of males compared to females (AM=4.2; SD=0.8 and AM=4.0; SD=0.9, respectively), although the differences are not statistically significant<sup>80</sup>. No differences were found in the eligibility category for long-term care. Informal carers were also involved to varying degrees in helping with care; as indicated in the questionnaire, just under a third (30.7%) were involved on a regular basis (at least several times a week), while the remainder were involved less frequently. A quarter did not engage in care at all, and a further 35.9% engaged in care once or less than once a month. The majority of users (76.6%) also consider that using the service is worth the effort they put into it.

To assess overall satisfaction, we asked users to rate on a scale from 1 (very dissatisfied) to 5 (very satisfied) the statement “*Considering all the experiences you have had with the e-care service up to this point, how satisfied have you been with it?*”. Based on the results of the survey, we conclude that satisfaction with e-care services is high. The survey results show that 75.6% of users are satisfied or very satisfied with their use of e-care (AM=4.0; SD=0.9). There is slightly higher satisfaction among men (AM=4.2; SD=0.7) compared to women (AM=3.9; SD=0.9)<sup>81</sup> and among people in the top three care categories (3, 4 or 5) compared to people in the first two care categories (AM=4.2; SD=0.9 and AM=3.9; SD=0.9 respectively)<sup>82</sup>, but the differences are not statistically significant. No differences by age are observed.

To assess usefulness, we asked users to rate on a scale from 1 (very low) to 5 (very high) *how useful they found the e-care service they have used or are still using*. Users also rated the usefulness of

using the e-care services very positively (AM=4.3; SD=0.8). In reasoning, they placed the greatest emphasis on a quick response to a fall and on situations where the person is alone. Slightly higher usefulness was identified by men compared to women (AM=4.5; SD=0.7 and AM=4.2; SD=0.9 respectively)<sup>83</sup> and by users in the long-term care categories 3, 4 or 5 (compared to categories 1 or 2)<sup>84</sup>, with no differences according to age.

In the questions related to the experience of using the e-care services during the Covid-19 epidemic, we find that the majority of users (more than 90%) did not change their opinion on the frequency and usefulness of using e-care services during the epidemic. However, we observe some changes in the opinion and usefulness of e-care services during the epidemic among informal carers. Among them, 16.7% report that they have become more favourable to e-care services and 20.0% that e-care services are even more useful at this time.

## Identified effects of e-care use

To measure the effects of e-care on users, we used the validated PIADS-10 scale, translated into Slovenian (*Psychosocial Impact of Assistive Devices Scale*) (Day & Jutai, 1996; Hsieh & Lenker, 2006; Jutai & Day, 2002; Jutai et al., 2007; Hvalič Touzery, Dolničar, Prevodnik, Škafar, & Petrovčič, 2020b)<sup>85</sup>. The scale takes into account the psychosocial effects of assistive technology use on specific aspects of daily life (rated on a scale of -3 to 3)<sup>86</sup>.

We find that a significant proportion of e-care users have a positive perception of the impact of e-care on their lives. These effects vary according to the area of daily life. Users report the greatest

79 A non-parametric Mann-Whitney U test was implemented, and the differences are statistically significant at the 10% level of significance ( $p < 0.1$ ).

80 A non-parametric Mann-Whitney U test was performed, and the differences are not statistically significant.

81 A non-parametric Mann-Whitney U test was performed, and the differences are not statistically significant.

82 A non-parametric Mann-Whitney U test was performed, and the differences are not statistically significant.

83 A non-parametric Mann-Whitney U test was performed, and the differences are not statistically significant.

84 A non-parametric Mann-Whitney U test was performed, and the differences are not statistically significant.

85 Cronbach alpha on the analysed data shows excellent scale reliability ( $\alpha \geq 0.9$ ).

86 The scale is used to determine whether the use of assistive technology greatly decreased (-3), significantly decreased (-2), slightly decreased (-1), neither decreased nor increased (0), slightly increased (1), significantly increased (2) or greatly increased (3) the individual aspect of the user's daily life.



positive change in the areas of their independence (AM=+0.8; SD=0.9), sense of control over their life (AM=+0.8; SD=0.9) and overall quality of life (AM=+0.7; SD=0.8), which are also among the key dimensions listed, especially in the context of long-term care. In addition to these changes, more than one third of e-care users report an increase in their sense of happiness, ability to take advantage of opportunities offered, and ability to adapt to daily activities. The remaining positive effects (increased productivity, self-esteem, eagerness to try new things and ability to participate) are reported by between 20% and 30% of users. With the exception of one user, no one reported any negative effects of use. In the interviews, users and informal carers mainly and most often point to the increased safety of users and, on the other hand, the consequent increased peace of mind of informal carers. The concept of greater safety is not included in the PIADS-10 scale but is included in the extended version of the PIADS-26 scale.

## Discussion with key messages

A number of studies drawing on different conceptual models – most often the TAM model: *Technology Acceptance Model* (Davis, Bagozzi, & Warshaw, 1989) – examine factors influencing the (non-)acceptance of assistive technologies among older people (e.g. Peek et al., 2016; Jaschinski & Ben Allouch, 2019). The decision on whether an individual will adopt a particular technology depends, among other things, on the individual's ability to judge whether the benefits of using the technology outweigh the risks associated with its use. Older people have a different perception of the usefulness and barriers to the adoption of new technologies in health and social care than younger people, and it is crucial to consider their suggestions and opinions when further designing assistive technologies. In this context, it is also important to monitor their satisfaction, in which several aspects are relevant, including ease of

Figure 1: Impact of e-care for users in pilot environments (PIADS-10, change) (N=78)



use, quality of service, adaptability to change, perceived effects in daily life, sense of control, trust in technology, perception of costs, responsiveness and support in use, and quality of care (Jaschinski & Ben Allouch, 2019; Verloo et al., 2020; Hvalič Touzery & Dolničar, 2021).

In this paper, we present results on *overall satisfaction, perceived usefulness, ease of use, and effect*, which we identify as key in the context of user acceptance and continued use of technology. Assistive technologies were tested in the pilot projects by 16.9% of all those eligible and assessed in their homes, which we consider to be a high proportion.

Concerns about the use of new technologies among older people and long-term care users may reflect a lower knowledge and less skill with using new technologies (Tsertsidis et al., 2019; Hvalič Touzery & Dolničar, 2021). Nevertheless, Tsertsidis et al. (2019) note that a number of studies have identified the positive experience of older people with ease of use (Peek et al., 2016; Dupuy, Consel, & Sauzéon, 2016; Vaziri et al., 2016; Jaschinski, Allouch, Peters, Cachucho, & Dijk, 2021; Tsertsidis et al., 2019), which has also been confirmed in the long-term care pilot projects. Indeed, the majority of users (80.8%) agreed or strongly agreed that e-care services were easy to use, but this was true slightly more often for people younger than 80 years.

*Usability or usefulness* is also an important factor that has a positive effect on the acceptance of new technologies among long-term care recipients. The degree of perceived usefulness varies over time, according to existing research, e.g. perceived usefulness becomes stronger with long-term use (e.g. Pino, Boulay, Jouen, & Rigaud, 2015; Dupuy et al., 2016). Analyses show that long-term care users in the pilot projects were satisfied with the services and mostly perceived them as useful. The positive effects of the use of e-care services are also an important result of the present research. The biggest positive change resulting from the use of e-care is observed by e-care users in the areas of their independence, sense of control over their lives and overall quality of life, which

are key and most expected among the PIADS-10 dimensions in the long-term care context. The results of the qualitative study primarily show psychological effects; participants report mainly an increased sense of security, a concept not measured by the PIADS-10 scale but included in the extended version of the PIADS-26 scale.

Testing of e-care and e-health services and user surveys took place during the first wave of the Covid-19 epidemic. As a result of the physical distancing measures, we expected a change in attitudes about the usefulness of such services among users and informal carers. The results of the pilot projects suggest that the testing period was too short or that users' views on the usefulness of e-care services remained largely unchanged during the first wave of the epidemic. Informal carers became slightly more favourable to e-care during this period. Despite this result, the potential of using existing technologies to improve access to services while minimising the risk of human-to-human transmission should not be overlooked. These potentials of e-care were better recognised by informal carers of older people in the national survey, which was also conducted during the Covid-19 epidemic. In this study, 41% of informal carers found e-care services more useful than before the pandemic (Dolničar, et al., 2021). In this light, the use of technology has a number of advantages. One of them is overcoming at least part of the experience of loneliness and staying in contact with relatives and service providers. Despite a limited service provision, the pilot environments intensively cooperated with service users via telephone. In the pilot environment of Celje, *statistics of social contacts* were recorded which show that in the period from 23 March 2020 to 30 April 2020, they conducted more than 1,000 telephone conversations with users and relatives. In overcoming loneliness, video calls came to the fore, especially in institutional care, but data from the environments show that users at home did not use them. In fact, only 9 users in total reported using them, and only 12.5% had a desire to stay in contact with their family during self-isolation

in this way (M12 data, N=96). This result is not surprising even for the first wave of the epidemic and is an indicator of new/deeper inequalities; many older people do not have a smartphone or tablet, nor the skills to handle this type of technology. As Rudel (2020) points out, the Covid-19 epidemic has also increased the vulnerability of adults with heart failure, who may experience more severe complications and require ongoing management to achieve the necessary blood pressure, heart rate and blood oxygen saturation levels. Telemedicine treatment of already involved persons was uninterrupted even in this case and

proved to be a key manner of providing services and a successful method of support to these persons, taking place despite less accessible health care institutions. All persons with chronic disease involved in telemedicine support had regular measurements during the epidemic, thus enabling any necessary medical intervention without the risk of virus infection. The heart failure specialist regularly reviewed the data and called each patient at least once during the epidemic. For some, she also adjusted therapy during this time (Rudel, 2020).

## BIBLIOGRAPHY

- Andersson, S., Erlingsson, C., Magnusson, L., & Hanson, E. (2017). *Information and communication technology-mediated support for working carers of older family members: An integrative literature review. International Journal of Care and Caring*, 1(2), 247–273. doi:10.1332/239788217x14957228181753
- Börsch-Supan, A. (2019). *Survey of health, ageing and retirement in Europe (SHARE) Wave 6*. Release version: 7.0.0. Retrieved from <http://www.share-slovenija.si/strani/6valLraziskave>
- Cook, E. J., Randhawa, G., Guppy, A., Sharp, C., Barton, G., Bateman, A., & Crawford-White, J. (2018). *Exploring factors that impact the decision to use assistive telecare: Perspectives of family care-givers of older people in the United Kingdom. Ageing & Society*, 38(9), 1912–1932. doi:10.1017/s014686x1700037x
- Davis, F. D., Bagozzi, R. P., & Warshaw, P. R. (1989). *User acceptance of computer technology: A comparison of two theoretical models. Management Science*, 35(8), 982–1003. doi:10.1287/mnsc.35.8.982
- Day, H., & Jutai, J. (1996). *Measuring the psychosocial impact of assistive devices: The PIADS. Canadian Journal of Rehabilitation*, 9(3), 159–168.
- Dolničar, V., Müller, S., & Santi, M. (2011). *Designing technologies for older people: A user-driven research approach for the Soprano Project. V F. Colombo (ed.), Broadband society and generational changes*. P. Lang, 5, 221–246.
- Dolničar, V., & Nagode, M. (2010). *Overcoming key constraints on assistive technology uptake in Slovenia. Teorija in praksa: revija za družbeno vprašanja*, 47(6), 1295–1315. Retrieved from [http://dk.fdvuni-lj.si/db/pdfs/tip20106.dolnicar\\_nagode.pdf](http://dk.fdvuni-lj.si/db/pdfs/tip20106.dolnicar_nagode.pdf)
- Dolničar, V., Petrovčič, A., Šetinc, M., Košir, I., & Kavčič, M. (2017). *Understanding acceptance factors for using e-care systems and devices: Insights from a mixed-method intervention study in Slovenia. Lecture Notes in Computer Science*, 362–377. doi:10.1007/978-3-319-58536-9\_29
- Dolničar, V., Šetinc, M., Burnik, T., Hvalič Touzery, S., Petrovčič, A., Rudel, D., & Berzelak, J. (2018a). *Assessing smart health and care in nine EU regions: ITHACA's self-assessment online survey. 30 let izkušenj v podporo digitalizaciji zdravstva. Journal: Slovensko društvo za medicinsko informatiko*, 120–126. Retrieved from [https://www.researchgate.net/publication/336170445\\_Assessing\\_smart\\_health\\_and\\_care\\_in\\_nine\\_EU\\_regions\\_ITHACA%27s\\_self-assessment\\_online\\_survey](https://www.researchgate.net/publication/336170445_Assessing_smart_health_and_care_in_nine_EU_regions_ITHACA%27s_self-assessment_online_survey) Ocena stanja pametnega zdravstva in oskrbe v devetih EU regijah spletna anketa projekta ITHACA 14. 11. 2018 Kong
- Dolničar, V., Šetinc, M., Burnik, T., Hvalič Touzery, S., Petrovčič, A., Rudel, D., & Berzelak, J. (2018b). *Ocena stanja pametnega zdravstva in oskrbe v devetih EU regijah spletna anketa projekta ITHACA. Predstavljeno na Kongres MI 2018 – 30 let izkušenj v podporo digitalizaciji zdravstva. Zreče.*
- Dolničar, V., Hvalič Touzery, S., Trkman, M., Berzelak, N., & Bartol, J. (2021). *Pomoč starejšim osebam s strani družinskih članov ali sorodnikov in njihov odnos do novih tehnologij: Sumarni pregled frekvenčnih porazdelitev in opisnih statistik zbranih podatkov (raziskovalno poročilo na ARRS projektu J5-1785). Ljubljana: Fakulteta za družbene vede.*
- Dupuy, L., Consel, C., & Sauzéon, H. (2016). *Self determination-based design to achieve acceptance of assisted living technologies for older adults. Computers in Human Behaviour*, 65, 508–521. doi:10.1016/j.chb.2016.07.042
- Goodwin, N. (2010). *The state of telehealth and telecare in the UK: Prospects for integrated care. Journal of Integrated Care*, 18(6). doi:10.5042/jic.2010.0646
- Hsieh, Y.-J., & Lenker, J. A. (2006). *The psychosocial impact of assistive devices scale (PIADS): Translation and psychometric evaluation of a Chinese (Taiwanese) version. Disability and Rehabilitation: Assistive Technology*, 1(1–2), 49–57. doi:10.1080/09638280500167217
- Hvalič Touzery, S., Lebar, L., Petrovčič, A., Smole-Orehek, K., & Dolničar, V. (2020a). *Psychological outcomes of telecare use for working family carers of older people. Proceedings of Smart Living Forum 2019*, 26–33. Villach: Norderstedt: BoD. Retrieved from [https://www.researchgate.net/publication/341372241\\_Psychological\\_Outcomes\\_of\\_Telecare\\_use\\_for\\_Working\\_Family\\_Carers\\_of\\_Older\\_People](https://www.researchgate.net/publication/341372241_Psychological_Outcomes_of_Telecare_use_for_Working_Family_Carers_of_Older_People)
- Hvalič Touzery, S., Dolničar, V., Prevodnik, K., Škafar, M., & Petrovčič, A. (2020b). *The importance of patients' user experience with a telehealth system for their evaluation of its psychosocial impacts. In: Lattacher, S.L. (ed.), Proceedings of Smart Living Forum 2019, 14 November 2019, Villach, Austria. Norderstedt: BoD*, 19–25.
- Hvalič Touzery, S., Smole-Orehek, K., & Dolničar, V. (2021). *Exploring reciprocity in perceptions on telecare within the informal carer-care receiver dyad. Teorija in praksa*, 58(3), 840–859. doi:10.51936/tip.58.3.840-859
- Hvalič Touzery, S., & Dolničar, V. (2021). *Odnos do podpornih tehnologij med starejšimi osebam in neformalnimi oskrbovalci v Sloveniji = Attitudes towards smart technologies among older people and their informal carers in Slovenia. In: Petelin, A. (ed.), Zdravje starostnikov : 5. znanstvena in strokovna konferenca z mednarodno udeležbo, [17. september 2021] : zbornik povzetkov z recenzijo = Health of the elderly : 5th Scientific and Professional International Conference, [17th September 2021] : book of abstracts. Free electronic edition. Koper: Založba Univerze na Primorskem: = University of Primorska Press, 2021.*
- Jaschinski, C., & Ben Allouch, S. (2019). *Listening to the ones who care: Exploring the perceptions of informal carers towards ambient assisted living applications. Journal of Ambient Intelligence and Humanised Computing*, 10(2), 761–778. doi:10.1007/s12652-018-0856-6
- Jaschinski, C., Allouch, S. B., Peters, O., Cachucho, R., & Dijk, J. A. G. M. van. (2021). *Acceptance of Technologies for Aging in Place: A Conceptual Model. Journal of Medical Internet Research*, 23(3), e22613. doi:10.2196/22613
- Jutai, J., & Day, H. (2002). *Psychosocial impact of assistive devices scale (PIADS). Technology and Disability*, 14(3), 107–111. doi:10.3233/tad-2002-14305
- Jutai, J., Day, H., Coulson, S., Demers, L., Fuhrer, M. J., Lenker, J., & DeRuyter, F. (2007). *Developing a short form of the Psychosocial Impact of Assistive Devices Scale (PIADS). RESNA Annual Conference, Phoenix, AZ, June 15–19.*
- Kubitschke, L., & Cullen, K. (2010). *ICT & ageing. European study on users, markets and technologies. Final report. Retrieved from https://www.ifap.ru/library/book400.pdf*
- Melchiorre, M. G., Papa, R., Rijken, M., van Ginneken, E., Hujala, A., & Barbabella, F. (2018). *eHealth in integrated care programs for people with multimorbidity in Europe: Insights from the ICARE4EU project. Health Policy*, 122(1), 53–63. doi:10.1016/j.healthpol.2017.08.006
- Nagode, M., & Dolničar, V. (2010). *Assistive technology for older people and its potential for intergenerational cooperation: Critical review of the present situation and identification of key constraints for wider uptake. Retrieved from http://dk.fdvuni-lj.si/db/pdfs/tip20106\_nagode\_dolnicar.pdf*
- Peek, S. T. M., Wouters, E. J. M., van Hoof, J., Luijk, K. G., Boeijs, H. R., & Vrijhoef, H. J. M. (2014). *Factors influencing acceptance of technology for aging in place: A systematic review. International Journal of Medical Informatics*, 83(4), 235–248. doi:10.1016/j.ijmedinf.2014.01.004
- Peek, S. T. M., Luijk, K. G., Rijnaard, M. D., Nieboer, M. E., van der Voort, C. S., Aarts, ... Wouters, E. J. M. (2016). *Older adults' reasons for using technology while aging in place. Gerontology*, 62(2), 226–237. doi:10.1159/000430949
- Petrovčič, A., Peek, S., & Dolničar, V. (2019). *Predictors of seniors' interest in assistive applications on smartphones: Evidence from a population-based survey in Slovenia. International Journal of Environmental Research and Public Health*, 16(9), 1623. doi:10.3390/ijerph16091623
- Pino, M., Boulay, M., Jouen, F., & Rigaud, A.-S. (2015). *"Are we ready for robots that care for us?" Attitudes and opinions of older adults toward socially assistive robots. Frontiers in Aging Neuroscience*, 7. doi:10.3389/fnagi.2015.00141
- Prevodnik, K., Hvalič Touzery, S., Dolničar, V., Laznik, J., & Petrovčič, A. (2021). *Patients' experience with telemedicine in primary care: a focus group study. In: Care: challenges & solutions for a sustainable future: 12th - 30th April 2021: conference booklet. Sheffield: The University, 82–83. Retrieved from http://circle.groupshef.ac.uk/wp-content/uploads/2021/04/Conference-booklet\_April-2021-2.pdf*
- Rudel, D. (2020). *Telemedicinska storitev v integrirani oskrbi kroničnih bolnikov v domačem okolju (vsebinsko poročilo za projekt PPDO št. pog. PPDO-03-19/JNMV-TM/02). Ljubljana: MKS elektronski sistemi d. o. o.*
- Sanders, C., Rogers, A., Bowen, R., Bower, P., Hirani, S., Cartwright, M., ... Newman, S. P. (2012). *Exploring barriers to participation and adoption of telehealth and telecare within the Whole System Demonstrator trial: a qualitative study. BMC Health Services Research*, 12(1). doi:10.1186/1472-6963-12-220
- Smole-Orehek, K., Hvalič-Touzery, S., Petrovčič, A., Dolničar, V., Debevc, M., & Kožuh, I. (2019). *Psychological outcomes of eCare technologies use for informal carers: A scoping study. Gerontechnology*, 18(1), 15–28. doi:10.4017/gt.2019.18.1.002.0
- Telekom Slovenije (b. d.). *E-oskrba*. Retrieved from <https://www.telekom.si/zasebni-uporabniki/ponudba/e-oskrba>
- Tsertsidis, A., Kolkowska, E., & Hedström, K. (2019). *Factors influencing seniors' acceptance of technology for ageing in place in the post-implementation stage: A literature review. International Journal of Medical Informatics*, 129, 324–333. doi:10.1016/j.ijmedinf.2019.06.027
- Vaziri, D. D., Aal, K., Ogonowski, C., Von Rekowski, T., Kroll, M., Marston, H. R., ... Wulf, V. (2016). *Exploring user experience and technology acceptance for a fall prevention system: results from a randomised clinical trial and a living lab. European Review of Aging and Physical Activity*, 13(1). doi:10.1186/s11556-016-0165-z
- Verloo, H., Kampel, T., Vidal, N., & Pereira, F. (2020). *Perceptions About Technologies That Help Community-Dwelling Older Adults Remain at Home: Qualitative Study. Journal of Medical Internet Research*, 22(6). doi:10.2196/17930
- Vermeulen, J., Neyens, J., Spreeuwenberg, van Rossum, E., Sijpers, Habets, ... de Witte, (2013). *User-centred development and testing of a monitoring system that provides feedback regarding physical functioning to elderly people. Patient Preference and Adherence*, 8(4). doi:10.2147/ppa.s45897
- Government of the Republic of Slovenia, Ministry of Labour, Family, Social Affairs and Equal Opportunities and Institute of Macroeconomic Analysis and Development. (2017). *Active Ageing Strategy. Retrieved from https://www.gov.si/assets/ministrstva/MDPSZ/Direktorat-za-starejse-in-deinstitucionalizacijo/strategije/Active-Ageing-Strategy-2017.pdf*

# **HOW PILOT PROJECTS CONTRIBUTED TO THE QUALITY OF LIFE AND THE STATE OF HEALTH OF USERS**

*HOW PILOT PROJECTS  
CONTRIBUTED TO THE QUALITY OF LIFE  
AND THE STATE OF HEALTH OF USERS*

## KEY MESSAGES

- The self-assessment of the state of health of users, as measured by the EQ-5D questionnaire, increased slightly on average at the end of the implementation of the pilot projects. It is important to note that the proportion of users who reported moderate or major difficulties in walking, performing daily activities, and moderate or major feelings of pain and discomfort decreased during the project. We estimate that the pilot projects also contributed to this.
- The average assessment of the quality of life of users did not change significantly during the intervention. This is a subjective assessment of the quality of life of users, which was obtained on the basis of a questionnaire for measuring the quality of life of the elderly (CASP-12). Despite the questionnaire being adapted for the elderly, we find that the questions were incomprehensible and sensitive for some users, so we must be careful when interpreting the results.
- Despite these limitations, it is indicated that the pilot activities had a certain positive effect on users, especially in terms of their state of health or well-being. It is unreasonable to expect major changes in the self-assessment of the state of health as well as in the quality of life of users within a relatively short period of pilot activities, as the effects of such social concepts usually show only after longer periods of intervention. It would thus be sensible to observe the pilot activities for a longer period of time.
- From a methodological point of view, we assess that the use of the CASP-12 questionnaire for the population included in long-term care is not the most appropriate, while the EQ-5D questionnaire is recommended.

## Introduction

Quality of life is an amorphous concept for which there is no generally accepted definition or measuring instrument. There are many different views or definitions of quality of life, with definitions based on objective indicators, satisfaction of needs, subjective assessment of well-being, assessment of ability and subjective assessment of health or health-related quality of life being predominant (Brazier et al., 2014). The latter means that quality of life is treated in the context of health and disease. It is a concept that includes areas related to physical, mental, emotional and social functioning as well as the social context in which people live (Ferrans, 2015).

The concept of health-related quality of life overlaps in many aspects with the concept of health and quality of life. The difference between quality of life and health is relatively clear, while it is more difficult to make a distinction between health-related quality of life, health and quality of life. Most instruments for measuring health-related quality of life actually measure self-assessment of the state of health. Karimi and Brazier (2016) propose that separate measuring of health and quality of life may perhaps be more appropriate.

Since there is not a uniform position or clear definition of quality of life, researchers face difficulties in any attempt to measure quality of life, and some are sceptical about the value of such measuring due to the inconsistent definition. Regardless of the non-uniform practice, it is crucial that instruments that measure various aspects of quality of life are included in the evaluation of public policy interventions that focus on improving the lives of individuals (Brazier et al., 2014).

When determining how pilot projects in the field of long-term care have contributed to the quality of life of users, we used two measuring instruments (EQ-5D and CASP-12) in order to cover the broadest possible range of an individual's life. We also took into account the fact that the users of the pilot projects were mostly older persons (more than three quarters of the users were 76 years old

or older), so we looked for tools that are adapted to the older population in terms of ease of use and understanding.

The EQ-5D questionnaire was used to measure the state of health. It is a simple generic measuring instrument that is used to measure the state of health of users in five categories (mobility (walking); self-care such as washing and dressing; performing usual activities such as household chores, family activities and leisure; feeling of pain, discomfort and anxiety, depression). To measure quality of life, the CASP-12 questionnaire developed by Hyde et al. (2003) was used. On the basis of a theory based on the satisfaction of needs, the latter proposed a model of quality of life that includes four dimensions or areas of life: control over life, autonomy, self-realisation (realisation of your ideas) and pleasure. On this basis, they created the CASP-19 questionnaire or scale, which features 19 questions, of which four are related to the control of life, and five each to the remaining three dimensions or areas. They defined autonomy as the right of an individual to renounce the interference of others in their life, while control over life means the ability to be active in the environment in which the individual lives. These two dimensions are the basic conditions that must be met in order for someone to freely participate in society. Once these are met, the individual can pursue the other two dimensions - self-realisation through activities that provide them with pleasure. Following the success of the scale in the original study, it was adopted for use in the English Longitudinal Study of Ageing (ELSA), and from there a revised version (CASP-12) was included in the Survey of Health, Ageing and Retirement in Europe (SHARE).

## Methodology

With the evaluation, we tried to determine whether the life of a user who receives long-term care services in the home environment is safe and of high quality in various areas of their life. For this

purpose, we prepared a questionnaire for users that included questions from the standardised CASP-12 and EQ-5D questionnaires.

The CASP-12 questionnaire is a revised version of the longer CASP-19 questionnaire. It features 12 questions or statements that respondents answer on a four-point scale: “often”, “sometimes”, “rarely”, “never”. The result is the sum of the answers to these questions, which ranges from 12 (minimum) to 48 (maximum). A high score means a high quality of life (Mehrbrödt, Gruber, & Wagner, 2019).

EQ-5D is a standardised questionnaire for measuring the state of health that was developed by the EuroQol Group with the aim of providing a simple, generic measuring instrument for assessing the state of health. It includes simple questions within five categories: mobility, self-care (washing and dressing), carrying out usual activities (household chores, family, leisure), feeling of pain, discomfort and feeling of anxiety, depression. Users thus assessed the problems they face in individual categories, with five response levels: 1. no problems, 2. slight problems, 3. moderate problems, 4. severe problems, 5. unable to perform an activity (e.g. cannot walk)/extreme problems (e.g. feeling extreme anxiety or unbearable pain). Based on the answers, a total of 3,125 states are defined. Each status is displayed by a five-digit code. For example, code 11111 means that the user has no problems by individual dimensions, while code 12345 means that the user has no mobility problems, has slight problems with washing and dressing, moderate problems with performing usual activities, feels severe pain or discomfort or feels extremely anxious or depressed. The answers by individual categories (dimensions) can also be converted into an index value (Van Reen et al., 2019). The questionnaire was included in the evaluation in accordance with the recommendation of the European Centre for Social Welfare Policy and Research (Kahlert, Boehler, & Leichenring, 2018).

Users were surveyed upon entering the project (first assessment) (M0) and after (at least)

one year of involvement in the project (M12). A descriptive (e.g. presentation of proportions) and bivariate (t-test) data analysis was performed on the collected data. In interpreting the data, we also used some data from interviews with users.

## Results

In the article, we present data on the quality of life of users and their state of health before the beginning of pilot activities and after (at least) one year of involvement in the project. By comparing the results at both measurement points, we observe the effects of the intervention on the quality of life and the state of health of users.

The questionnaire was answered by 713 users in the first assessment (M0), and 161 users answered the questionnaire after one year of involvement in the project or after the services were provided (M12). Of these, 133 answered both the questionnaire in point M0 and the questionnaire in point M12. The latter are those whose quality of life and state of health can be monitored both at the beginning and at the end of the project, which means that we can determine whether and to what extent the quality of their lives and the state of health have changed during the project or the provision of service.

### Who were the users of the services in the pilot long-term care projects?

We first show below the basic characteristics of the users who responded to the questionnaire at both points of time. There were 69 such users in the pilot environment of Celje, 42 in the pilot environment of Krško and 22 in the pilot environment of Dravograd.

Women accounted for almost 60% of the surveyed users, with their proportion being largest in Celje (more than two-thirds), and the smallest in Dravograd (slightly more than 36%). In terms



of age, those aged between 76 and 85 years prevailed, with their proportion in all pilot environments combined amounting to just under 39% - it was the largest in Celje (almost 45%) and the smallest in Dravograd (just under 29%). People aged over 85 represented 37% in all pilot environments, which means that more than three-quarters of the surveyed users were in the two highest age groups. People younger than 65 (adults) accounted for just under 10% of respondents, with the smallest proportion of them being surveyed in Celje (just under 9%) and the largest share in Krško (just under 12%).

If the population of surveyed users is compared with the total population of recipients of services as part of the pilot projects (N=549), we find that women also dominated the structure of service recipients (over 58%) - they represented the largest proportion in the Celje pilot environment (just under 66%), while their proportion in Krško and Dravograd was just under 55% and 55%, respectively. While the gender structure of surveyed users in the Dravograd pilot environment is quite different from the total population of recipients of services, the structure in Celje and Krško is quite similar.

The differences in the share of users in terms of the age structure between service users and respondents, observed for all pilot environments together, are not large. The differences are slightly larger by individual environments, especially in Dravograd, where the proportion of respondents aged 65 to 75 years is higher and the proportion of those aged 76 to 85 years is lower, and in Krško, where on the one hand the proportion of surveyed users in the 65-75 age group and in the 76-85 age group is lower, while on the other hand the proportion of people over 85 years of age is higher than in the total population of service users.

**Table 1: Basic characteristics of respondents (N=133)**

| <b>GENDER<sup>87</sup></b> | FEMALE        |                  | MALE             |               |
|----------------------------|---------------|------------------|------------------|---------------|
| <b>TOTAL</b>               | <b>59.4%</b>  |                  | <b>38.3%</b>     |               |
| <b>CELJE</b>               | 66%           |                  | 30.4%            |               |
| <b>DRAVOGRAD</b>           | 36.4%         |                  | 59.1%            |               |
| <b>KRŠKO</b>               | 59.5%         |                  | 40.5%            |               |
|                            |               |                  |                  |               |
| <b>AGE GROUPS</b>          | < 65<br>YEARS | 65 - 75<br>YEARS | 76 - 85<br>YEARS | > 85<br>YEARS |
| <b>TOTAL</b>               | <b>9.8%</b>   | <b>14.4%</b>     | <b>38.6%</b>     | <b>37.1%</b>  |
| <b>CELJE</b>               | 8.7%          | 15.9%            | 44.9%            | 30.4%         |
| <b>DRAVOGRAD</b>           | 9.5%          | 28.6%            | 28.6%            | 33.3%         |
| <b>KRŠKO</b>               | 11.9%         | 4.8%             | 33.3%            | 50.0%         |

<sup>87</sup> Some respondents in Celje and Dravograd did not state their gender, so the combined proportion of men and women together is not 100%.

**Table 2: Basic characteristics of all users, recipients of services (N=549)**

| <b>GENDER</b>     | FEMALE        |                  | MALE             |               |
|-------------------|---------------|------------------|------------------|---------------|
| <b>TOTAL</b>      | <b>58.3%</b>  |                  | <b>41.7%</b>     |               |
| CELJE             | 65.7%         |                  | 34.3%            |               |
| DRAVOGRAD         | 55.0%         |                  | 45.0%            |               |
| KRŠKO             | 54.5%         |                  | 45.5%            |               |
| <b>AGE GROUPS</b> | < 65<br>YEARS | 65 - 75<br>YEARS | 76 - 85<br>YEARS | > 85<br>YEARS |
| <b>TOTAL</b>      | <b>12.0%</b>  | <b>12.2%</b>     | <b>40.4%</b>     | <b>35.4%</b>  |
| CELJE             | 12.4%         | 11.7%            | 40.6%            | 35.3%         |
| DRAVOGRAD         | 10.4%         | 13.2%            | 38.9%            | 37.5%         |
| KRŠKO             | 12.7%         | 11.8%            | 41.4%            | 34.1%         |

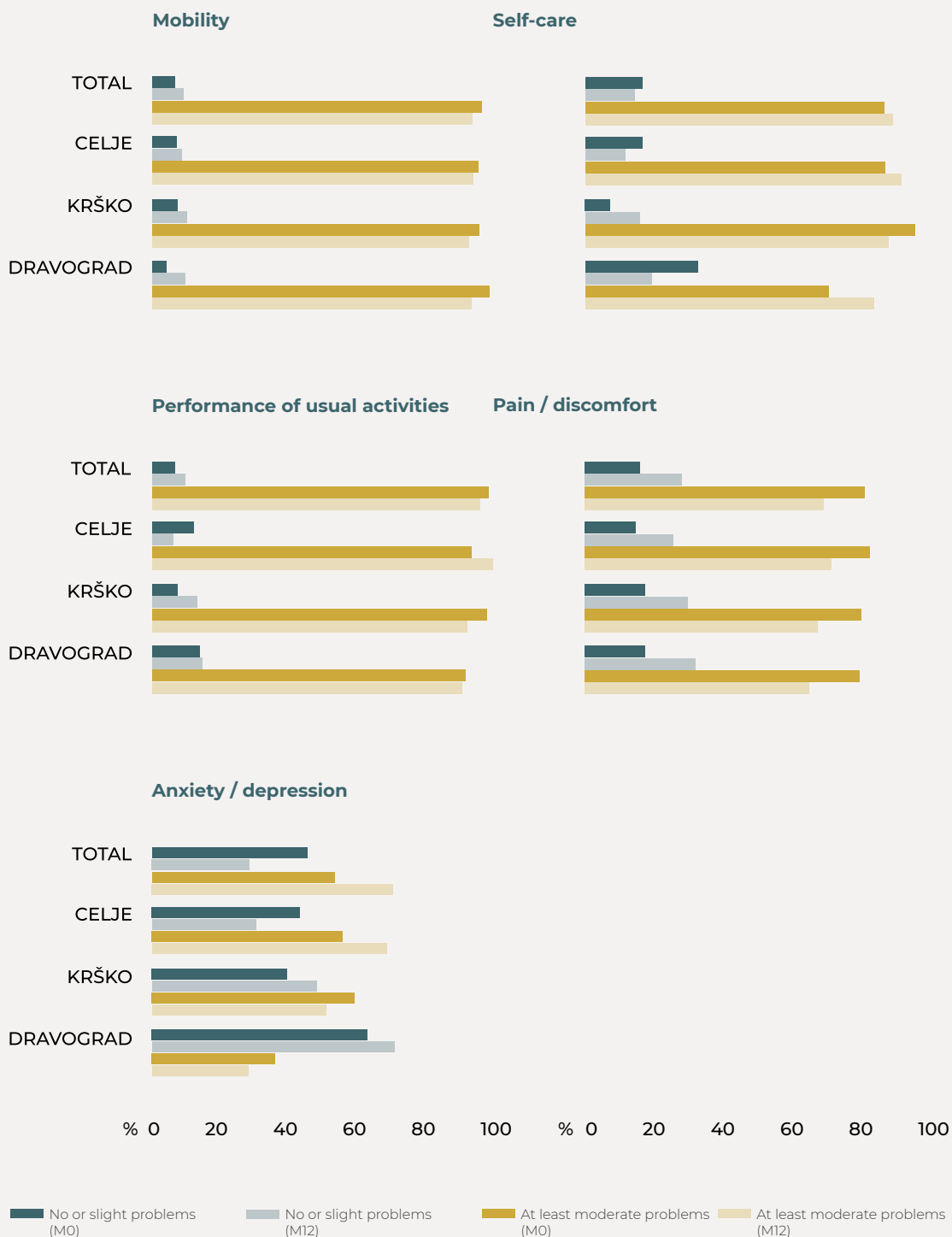
## How has the quality of life of users changed after the pilot activities?

In this sub-chapter, we establish whether and to what extent the health-related quality of life of users and their state of health have changed during their involvement in the pilot project. We first focus on the state of health of users, as part of which we present the proportion of users who have experienced problems with mobility, self-care, performance of usual activities, feelings of pain, discomfort and anxiety and depression, both in the first and last measurements and possible differences between the two measurements.

More than 92% of users in all pilot environments reported at least moderate walking difficulties in the first survey, with the largest proportion of these users in the Dravograd pilot environment (95.5%). Also associated with mobility is the performance of usual activities, as evidenced by the high proportions of users with at least moderate difficulties in performing these activities. In the first survey, there were 93% of them in total - more than 92% in Krško, slightly more than 86% in Dravograd and more than 88% in Celje. The proportion of users who report at least moderate problems with washing and dressing (self-care) varies considerably between pilot environments at the time of the first survey. The largest proportion was recorded in the Krško pilot environment (92.5%), and the smallest in Dravograd (over 68%). At least moderate pain was reported by more than 83% of users in all pilot environments at the time of the first measurement, and a similar proportion shows in individual pilot environments. More than half of users also reported at least a moderate feeling of anxiety and depression during the survey, the largest share of such users being in Krško (60%) and the smallest in Dravograd (over 36%).

In the second survey, the proportion of users with at least moderate problems with walking decreased in all pilot environments. In total, the proportion of users who have at least moderate difficulties in performing usual activities and

Figure 1: Proportion of users in terms of the level of walking difficulties (mobility), self-care (washing and dressing), performance of usual activities (household chores, family, leisure) and the level of pain/discomfort and anxiety/depression (N=130)



the proportion of those who experience at least moderate pain or discomfort also decreased. Viewed by individual environments, the proportion of users who report moderate problems with self-care also decreased in Dravograd and Krško, while in Celje it slightly increased (from 88.2% to 94%). Meanwhile, the proportion of users who reported at least moderate pain decreased in all pilot environments.

Compared to the first survey, the proportion of users with at least moderate problems with self-care increased in the second, both in total and in Dravograd and Celje, while the proportion of users with greater problems with washing and dressing in Krško significantly decreased (from over 92% to just under 85%). The total proportion of users who reported at least moderate feelings of anxiety and depression also increased (from 54% to 71%), mostly due to an increase in the proportion in the Celje pilot environment (from over 56% to 69%). In Krško and Dravograd, the proportion of users with a moderate feeling of anxiety and depression decreased.

Figure 2 presents the proportions of users by individual age groups who have at least moderate problems or feelings in individual observed categories. All younger users (under the age of 65) report at least moderate walking difficulties at both points of time. In other age groups, the proportions are slightly lower at the first measurement point, with at least moderate walking problems being found in 90% of people aged 76 to 85, in 95% of those aged 66 to 75 and in 85% of those aged 85 and over. In the first measurement, more than three-quarters of users in all age groups reported at least moderate self-care problems. The highest proportion of these users was in the oldest age group (slightly less than 92%). At least moderate difficulties in performing usual activities are mostly reported by users aged between 66 and 75 (just under 95%). In the first measurement, the majority of users (the proportion ranges from 75% in the youngest age group to 89% of the oldest) reported at least moderate or severe pain, and at least a moderate feeling of anxiety or depression

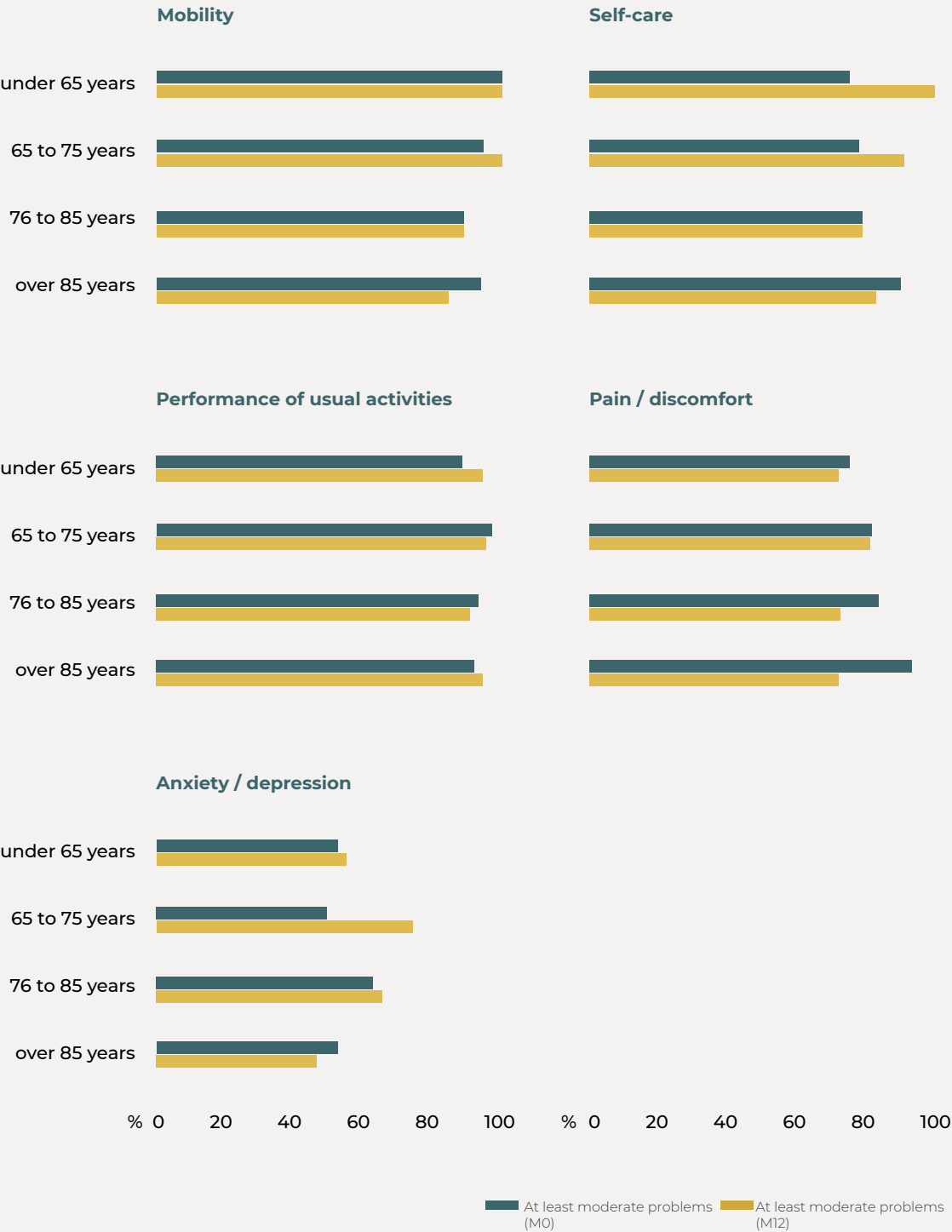
was reported by half of the users in the youngest and oldest age groups - just below half of those aged 66 to 75 and more than 60% of those aged 76 to 85.

In the second measurement, the proportion of users who reported at least moderate walking problems decreased in the oldest age group in comparison to the first measurement (from 94% to 85%), while in other age groups it either increased slightly or remained the same. A slightly higher proportion of users in the youngest and oldest age groups reported at least moderate difficulties in performing usual activities in the second measurement, while the proportion of users aged between 76 and 85 slightly decreased (from 90% to 86%). The proportion of users aged 66 to 75 who report at least moderate difficulties in performing usual activities is similar to that in the first measurement. In the last measurement, at least moderate difficulties with self-care were reported by a higher proportion of users in all age groups, except the oldest one, in which the proportion slightly decreased. In the second measurement, the proportion of users who report at least moderate pain or discomfort decreased in all age groups, to the greatest extent among the oldest users. However, the share of users with moderate or severe anxiety or depression increased in the second measurement in all age groups except the oldest, increasing the most among users aged 66 to 75.

In the survey, users chose a value on a value scale between 0 and 100, shown to them by the assessors, that corresponded to their assessment of health or well-being at the time of the survey. A value of 0 meant the worst state of health, and a value of 100 meant the best state of health they could imagine. Shown below are the estimates in the first and last measurement.

On average, men rated their health at 43.4 (M0) and 45.4 (M12), respectively, which is lower than the overall average value, while women's self-evaluation was higher than average and amounted to 44.5 (M0) and 47.4 (M12). Both men and women rated their health as medium good,

Figure 2: Proportion of users who have at least moderate problems with walking (mobility), self-care (washing and dressing), performance of usual activities (household chores, family, leisure) and at least a moderate feeling of pain/discomfort and anxiety/depression by age groups (N=130)



and it is encouraging that the values were slightly higher in the second assessment. The median value shows that half of men and half of women alike rated their health below 50 and half rated their health above 50.

In the first measurement, the worst assessment on average was made by men in the Celje pilot environment, while the highest assessments came from men and women in the Dravograd pilot community. In the second measurement, the average assessment by men in Celje increased, while the average assessment of women's health decreased. It is the opposite in Krško, where the average health assessment by men decreased and that by women significantly increased. The difference in the average health assessment is statistically significant in women ( $t=1.735$ ,  $p=0.091$ ). In Dravograd, the average health rating by both men and women decreased slightly, with the decrease for the latter being minimal.

Figure 3 shows the self-assessment of the state of health of users by individual pilot environments in terms of age groups. In two pilot environments, except in Krško, the youngest users rated their state of health better in the first measurement than in the last, which relates to the data that a higher proportion of younger users reported at least moderate problems with walking, self-care and in normal activities in the last measurement compared to the first measurement. On the other hand, older users, especially those over the age of 85, rate their health better on average in the second measurement than in the first.

If all three pilot environments are observed together, users between the ages of 66 and 75, on average, rate their health better in the second measurement than in the first, although the picture is slightly different if the pilot environments are observed individually. While users in the Celje pilot environment rate their health better in the second measurement than in the first, users in the Krško and Dravograd pilot environments rate their health worse in the second measurement.

In the survey, users chose a value on a value scale between 0 and 100, shown to them by the

assessors, that corresponded to their assessment of health or well-being at the time of the survey. A value of 0 meant the worst state of health, and a value of 100 meant the best state of health they could imagine. Shown below are the estimates in the first and last measurement.

Based on the answers by users to the questions designed to assess the problems they have by individual dimensions of the state of health, it is also possible to make a joint assessment of the state of health of users. What is important in this approach is that we can detect a change in the state of health of users at different points of time.

The index of the state of health of users in the first measurement averaged 0.201, which means poor state of health (where value 0 means the state of health equal to death, and 1 perfect state of health). If we look at the values of individual dimensions of the state of health in, for example, a random person with an index of the state of health of 0.201, we find that that person's code is 45343, which means that the person has severe difficulty walking, is unable to wash and dress themselves on their own, has slight difficulty performing usual activities, severe pain and feeling of discomfort and is moderately anxious or depressed. In this case, we can talk about a person's poor physical health and moderate mental health.

In the last measurement, the index of the state of health of users increased slightly compared to the first, to 0.241 (the difference is not statistically significant). The median was 0.361, which means that half of the users had a worse, and half had a better state of health than this value. Compared with the first measurement, the median value increased from 0.284 to 0.361. Even in individual pilot environments, we find that the index of the state of health of users in the last measurement increased slightly compared to the first, and the median values are also higher in the last assessment.

A change in the state of health can also be determined on the basis of changes in the codes resulting from the answers by individual dimensions of the health status. There are only

Figure 3: Average self-assessment of users' state of health by age groups and pilot environments (N=127)

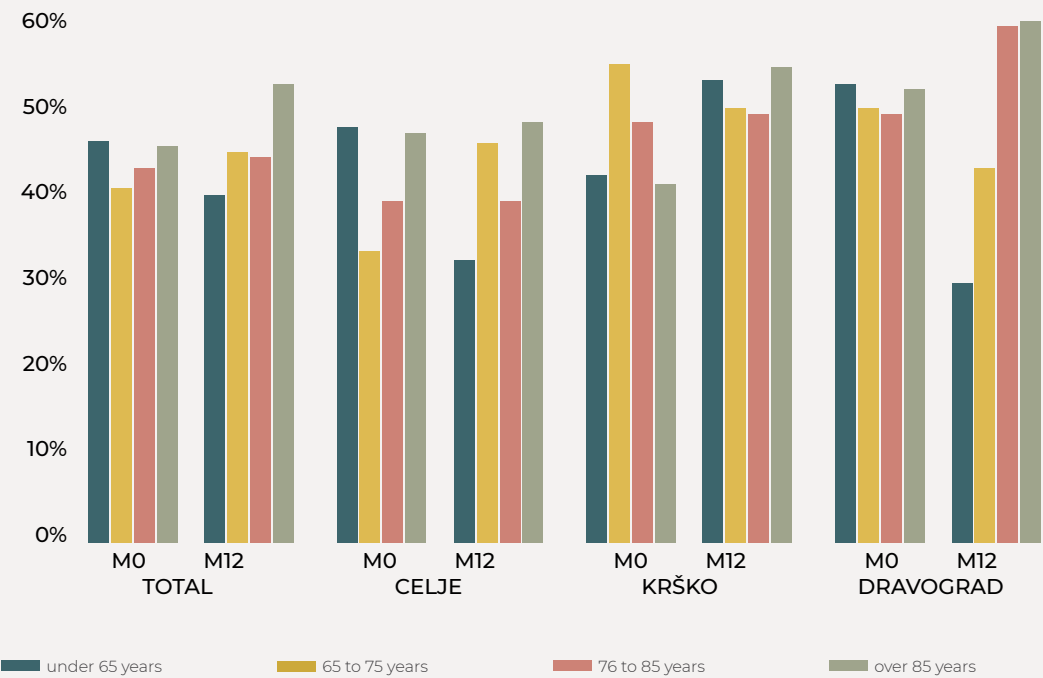
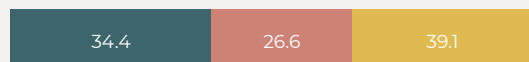


Table 3: Average health self-assessment by gender of the user (N=128)

| M0        | MALE | FEMALE | TOTAL | M12       | MALE | FEMALE | TOTAL |
|-----------|------|--------|-------|-----------|------|--------|-------|
| TOTAL     | 43.4 | 44.5   | 44.1  | TOTAL     | 45.4 | 47.4   | 46.9  |
| CELJE     | 36.1 | 44.2   | 41.4  | CELJE     | 41.0 | 42.0   | 42.4  |
| KRŠKO     | 48.1 | 41.7   | 44.3  | KRŠKO     | 46.9 | 56.1   | 52.3  |
| DRAVOGRAD | 48.4 | 54.4   | 52.0  | DRAVOGRAD | 51.1 | 52.5   | 51.6  |

**Figure 4: Proportion of users in terms of improvement or deterioration of the state of health, by gender and age group (N=122)**

#### FEMALE



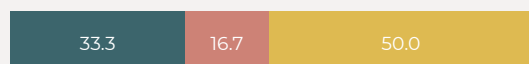
#### MALE



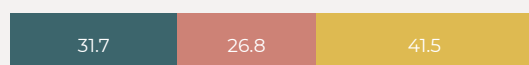
#### UNDER 65 YEARS



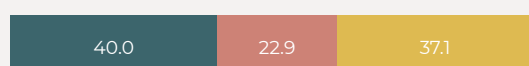
#### 65 TO 75 YEARS



#### 76 TO 85 YEARS



#### OVER 85 YEARS



#### TOTAL



0 20 40 60 80 100

■ Better  
■ Worse  
■ Mixed

four options - we can determine whether the state of health in the second measurement is better (which means that it is better in at least one dimension and not worse in any other), worse (worse in at least one dimension and not better in any other) or mixed, meaning it is better in one dimension and worse in another. The state of health may remain the same between one measurement and another, meaning that it does not change in any of the dimensions.

Figure 4 shows the proportion of users in terms of change in the state of health, both together and by gender and age groups. We find that the situation has changed for all users - for more than 35% for the better, for slightly under 23% for the worse, and for just over 41% the condition has worsened in some categories and improved in others. The state of health remained the same for none of the users. In terms of gender, the state of health improved in a higher proportion of women (39%) than men (just under 27%), and when it comes to age it turned out that the proportion of users whose state of health improved decreased with age, except in the oldest age group, where the proportion of users with better state of health in the last measurement is 40% and is higher than in the 65-75 age group (over 33%) and the 76-85 age group (up to 32%).

Presented below is the level of quality of life of users, which was calculated on the basis of twelve questions (CASP-12 questionnaire). The average quality of life of users in the first measurement was 30.1, which means a medium-high quality of life. Given the median value of 30.0, we can say that half of the users had a worse and half a better quality of life than the medium-high quality. In the Celje pilot environment, the average quality of life of users in the first measurement was minimally lower than the estimate for all pilot environments combined, it was similar in Krško, and minimally higher in Dravograd. In the last measurement, the quality of life of users remained at approximately the same level as in the first measurement, it increased minimally in all pilot environments combined and in Krško (the median



Table 4: Index of the state of health of users in the first and last assessment, combined and by individual pilot environments (N=121)

|           |     | N   | AC    | Me    | SD    | Min    | Max   |
|-----------|-----|-----|-------|-------|-------|--------|-------|
| Total     | M0  | 121 | 0.201 | 0.284 | 0.305 | -0.452 | 0.836 |
|           | M12 | 121 | 0.241 | 0.361 | 0.318 | -0.452 | 0.747 |
| Celje     | M0  | 63  | 0.190 | 0.247 | 0.320 | -0.452 | 0.836 |
|           | M12 | 63  | 0.240 | 0.349 | 0.315 | -0.397 | 0.695 |
| Krško     | M0  | 37  | 0.205 | 0.317 | 0.297 | -0.452 | 0.625 |
|           | M12 | 37  | 0.241 | 0.336 | 0.317 | -0.452 | 0.625 |
| Dravograd | M0  | 21  | 0.225 | 0.345 | 0.282 | -0.293 | 0.579 |
|           | M12 | 21  | 0.245 | 0.396 | 0.346 | -0.410 | 0.747 |

Table 5: Assessment of the quality of life of users in the first and last assessment, combined and by individual pilot environments (N=90)

|           |     | N  | AC   | Me   | SD   | Min | Max |
|-----------|-----|----|------|------|------|-----|-----|
| Total     | M0  | 90 | 30.1 | 30.0 | 4.42 | 20  | 41  |
|           | M12 | 90 | 30.3 | 30.0 | 4.09 | 19  | 42  |
| Celje     | M0  | 46 | 29.8 | 30.0 | 4.18 | 20  | 39  |
|           | M12 | 46 | 29.7 | 29.0 | 3.95 | 19  | 42  |
| Krško     | M0  | 24 | 30.0 | 29.5 | 4.91 | 22  | 39  |
|           | M12 | 24 | 30.5 | 30.5 | 4.35 | 22  | 38  |
| Dravograd | M0  | 20 | 31.0 | 30.5 | 4.48 | 25  | 41  |
|           | M12 | 20 | 31.2 | 30.5 | 4.12 | 26  | 39  |

Figure 5: Frequency distribution of users according to the quality of life assessment in the first measurement, all pilot environments combined (N=90)

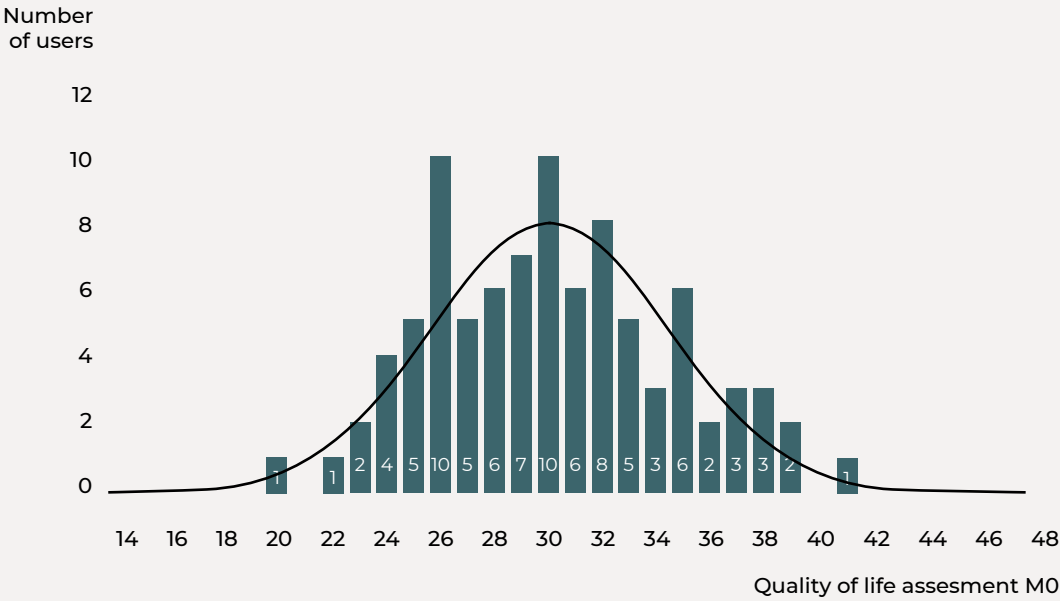
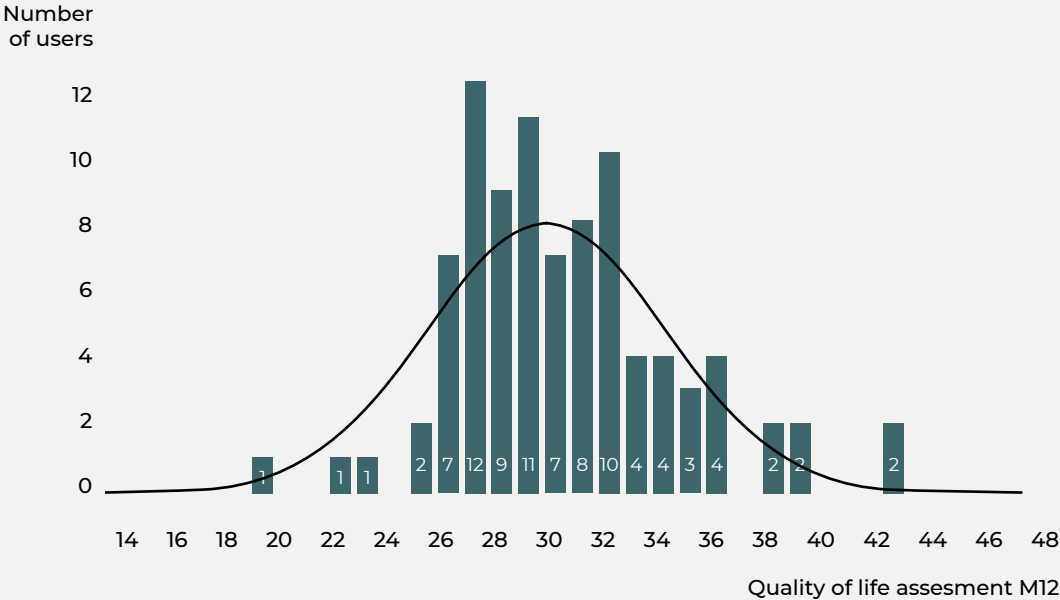


Figure 6: Frequency distribution of users according to the quality of life assessment in the last measurement (N=90)



value is also minimally higher) and Dravograd, while it decreased minimally in Celje.

If the frequency distribution of users is compared on the basis of the assessment of quality of life for all pilot environments together, we find that compared to the first measurement, there were smaller shifts in the lower half of the distribution (values lower than the median) in the last measurement. In the first measurement, users were more or less evenly distributed between the values 23 and 29 (2 to 7 users) with a higher frequency at the value 26 (10 users), and in the last measurement, a higher density between the values 26 and 29 was observed (7 to 12 users). In the upper half of the distribution, the shifts were even smaller, although the maximum value of the quality of life assessment increased by one (from 41 to 42). If individual users are observed, we find that the assessment of the quality of life of users has changed for 78% of users, for the worse for half of them and for the better for half of them, while the assessment is the same at both time points for 12% of users.

Changes in the state of health and quality of life of users were also reflected in the classification of users in individual categories of eligibility for long-term care (including eligibility categories).

If the proportion of users by individual eligibility categories in the first assessment is compared with the assessment after one year, we find that the proportion of users who are no longer eligible for services (category 0) increased, the proportion of users in the first eligibility category decreased (6% of them are no longer eligible for services), more than half (51%) moved to a higher category (34% up one category, 17% up two categories); the proportion of users in the second category also decreased (3% of them are no longer eligible for services, more than 29% moved to a lower category, and just under a third moved to a higher category), while the proportion of users in the last three categories increased. From the third category, more than 11% of users moved to lower and 32% to higher categories, from the fourth category 21% of users moved to lower categories,

and a slightly higher proportion (26%) to a higher category, while among users from the highest, fifth category of care, 22% moved to lower categories in the last assessment.

A similar trend of users moving between categories of eligibility is also reflected in individual pilot environments, although some specifics are noticeable. In Krško, after one year of involvement in the project, 9.5% of users were no longer eligible for services, while in Dravograd no user was placed in the highest eligibility category.

## Discussion with key messages

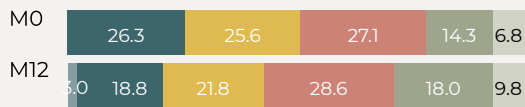
Changes in the quality of life and the state of health of users before and after at least one year of involvement in pilot activities were determined on the basis of assessment and classification in categories of eligibility for long-term care and subjective assessment by users regarding the state of health and quality of life.

From the aspect of classification in eligibility categories, we find that the involvement in pilot activities was the most positive for 3% of users, for whom the last assessment showed that they no longer need services as part of pilot projects. Other users either remained in the same eligibility category or moved to a higher or lower category. Positive changes by individual pilot environments were shown in Krško, where in the last assessment 9.5% of users were no longer eligible for long-term care and thus for services as part of the pilot project, and in Dravograd, where all users from the highest eligibility category passed into the lower ones.

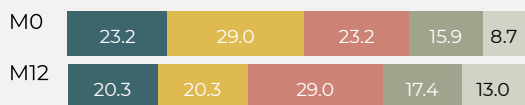
Assessments by users regarding the severity of problems they face with mobility, self-care, performance of usual activities, and feelings of pain and anxiety or depression showed positive changes in four of the five categories assessed at the time of the last measurement. The proportion of users who reported at least moderate difficulties with walking (mobility) and performing usual activities in the first measurement and at least

**Figure 7: Proportion of users by individual eligibility categories in the first and last assessment (N=133)**

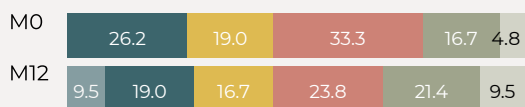
### TOTAL



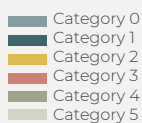
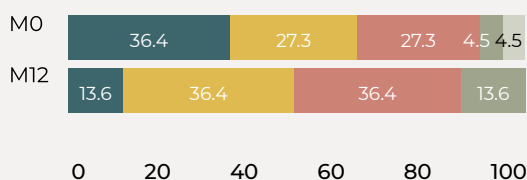
### CELJE



### KRŠKO



### DRAVOGRAD



a moderate feeling of pain or discomfort and anxiety or depression decreased slightly in the second measurement. On the other hand, we notice that the proportion of users with at least moderate anxiety or depression in the second measurement decreased only in the oldest users (aged 85 or older), while in younger users this share slightly increased. The latter results can be partly attributed to the Covid-19 epidemic, as almost half of the users surveyed were more likely to feel anxious during the epidemic than before the epidemic, half of the users reported being more isolated, and more than 2% of respondents evaluated their health as worse compared to before the epidemic.

Pilot projects have had positive effects on the state of health for at least a third of users, while either improvement in some areas or deterioration in other areas shows in the remaining users. Unfortunately, the state of health of almost a quarter of users deteriorated, which cannot be attributed to the possible ineffectiveness of pilot projects, but is a consequence of various factors which were not investigated in detail in the evaluation.

The data shows that the assessment of the quality of life of users also increased during the implementation of the pilot projects, albeit minimally. To a greater extent than the quantitative data, this is evidenced by the statements of users, which show how important for the quality of life of the user is even the smallest possible intervention, such as an employee visiting as part of a pilot project.

*"It's nice if she comes, even if you just see her, and you are already satisfied."*

*"Well, I don't know, it's a little better when I get a little exercise and that, but I'm over the hill, and you can't make miracles, they are trying but it doesn't work."*

*"It is not much, but it's great. It's easier for me and I live better that way."*

*"So that you know, there is some progress for sure. For instance, if I wait for her downstairs,*

*which she thought was not even possible, to see me there, but she did.”*

*“Actually, I feel, to be honest with you, kind of like I’m extra protected and I don’t even know from whom or from what. I feel safer, as if I have one more person to trust.”*

It is difficult to expect major changes in the self-assessment of the state of health as well as in the quality of life of users in a relatively short period of pilot activities, as such effects usually show only after longer periods of intervention. Perhaps the results would be different if objective indicators were included in the measuring of quality of life in addition to subjective indicators.

We must be particularly careful when interpreting the obtained results regarding the quality of life of users, as it is indicated that the most appropriate measuring instrument was not selected for the observed population. The CASP-12 questionnaire was based on a sample of people aged 65 to 75, and in pilot projects the average age of users was 80, and more than three-quarters were older than 75. Assessors who conducted the user survey reported that the questions were difficult to understand for some users, so there were many missing values (of the 133 users who answered the questionnaire at both points, only 90 answered all the CASP-12 questions). Users often did not understand the questions, in particular users with dementia and users who had communication problems. Some users, in

particular older ones, did not feel comfortable with some questions (e.g. the question about the future). On the other hand, the EQ-5D questionnaire proved to be an appropriate measuring instrument for (self-)assessment of the health status of users in pilot projects.

Although measuring the quality of life of individuals is not simple and poses significant theoretical as well as methodological challenges, it has proved in recent decades to be an exceptionally important part of various public policy interventions aimed at improving the lives of individuals. This is especially important for interventions that focus on the quality of life of the elderly, as it is more likely that the quality of life of this demographic will be exacerbated by events such as hospitalisation, institutionalisation, illness, death of family members or friends (Borrat-Besson, Ryser, & Gonçalves, 2015). Accordingly, as mentioned earlier, any intervention, even a small one, is exceptionally important for the quality of life of older individuals.

## BIBLIOGRAPHY

- Borrat-Besson, C., Ryser, V.-A., & Gonçalves, J. (2015). *An evaluation of the CASP-12 scale used in the Survey of Ageing and Retirement in Europe (SHARE) to measure Quality of Life among people aged 50+*. FORS Working Paper Series, paper 2015-4. Lausanne: FORS.
- Brazier, J., Connell, J., Papaioannou, D., Mukuria, C., Mulhern, B., Peasgood, T., ... Parry, G. (2014). *A systematic review, psychometric analysis and qualitative assessment of Generic Preference-Based Measures of Health in Mental Health Populations and the estimation of mapping functions from widely used specific measures*. *Health Technology Assessment*, 18:34.
- Ferrans, C. E. (2015). *Definitions and conceptual models of quality of life*. V: Lipscomb, J., Gotay, C. C., Snyder, C. (ed.) *Outcomes assessment in cancer*. Cambridge, England: Cambridge University, p. 14–30.
- Hyde, M., Wiggins, R. D., Higgs, P., & Blane, D. B. (2003). *A measure of quality of life in early old age: The theory, development and properties of a needs satisfaction model (CASP-19)*, *Aging & Mental Health*, 7:3, p. 186-194.
- Kahlert, R., Boehler, C., & Leichsenring, K. (2018). *Monitoring and Evaluating Integrated LTC Models*. Vienna: Euro Centre Publication.
- Karimi, M., & Brazier, J. (2016). *Health, Health-Related Quality of Life, and Quality of Life: What is the Difference?*. *Pharmacoeconomics* 34, p. 645–649.
- Mehrbrodt, T., Gruber, S., & Wagner, M. (2019). *SHARE: Scales and Multi-Item Indicators*. Retrieved from [http://www.share-project.org/fileadmin/pdf\\_documentation/SHARE\\_Scales\\_and\\_Multi-Item\\_Indicators.pdf](http://www.share-project.org/fileadmin/pdf_documentation/SHARE_Scales_and_Multi-Item_Indicators.pdf)
- Van Reen, M., Janssen, B., Stolk, E., Secnik Boye, K., Herdman, M., Kennedy-Martin, M., Slaap, B. (2019). *EQ-5D-5L User Guide*. Basic information on how to use the EQ-5D-5L instrument. Retrieved from <https://euroqol.org/publications/user-guides>.

**CARE FOR THOSE WHO CARE:  
STUDYING THE QUALITY OF LIFE  
OF INFORMAL CARERS**

Mateja Nagode,  
Social Protection Institute of the Republic of Slovenia

Jasmina Rosič  
KU Leuven, School for Mass Communication Research

Maja Škafar  
Social Protection Institute of the Republic of Slovenia

*CARE FOR THOSE WHO CARE:  
STUDYING THE QUALITY OF LIFE  
OF INFORMAL CARERS*

## KEY MESSAGES

- ▶ Informal care is the backbone of long-term care, and its high incidence has also been confirmed by pilot projects.
- ▶ Informal care is in the domain of women, which puts them in an unequal position to men.
- ▶ The subjective burden on informal carers did not improve during the involvement in the pilot projects, although we can identify many relief factors (option of respite care, use of annual leave, transportation, time flexibility, etc.).
- ▶ Pilot projects have had a positive impact on the lives of informal carers in terms of objective relief, which further reinforces the call for organising better support for informal carers. Measures in this field are therefore necessary, as formally organised care does not sufficiently reduce the burden of informal care, and cooperation between the two types of care is too weak.
- ▶ Organised home care and community care are an opportunity to relieve informal carers, either from certain tasks or in the sense of support and learning about how to provide care (actionable knowledge).



## Introduction

The majority of long-term care systems in Europe are based on informal care. In literature, it is thus called the backbone, the core, the main pillar or the foundation, as it is predominant in the (co-)provision of care (Huber, Rodrigues, Hoffmann, Gasior, & Marin, 2009; Naiditch, Triantafillou, Di Santo, Carretero, & Hirsch Durrett, 2013; Verbeek-Oudijk, Woittiez, Eggink, & Putman, 2014; Zigante, 2018). Estimates show that around 80% of total long-term care in Europe is provided by informal carers (Hoffmann & Rodrigues, 2010).

There is no standard definition of informal care (Zigante, 2018). What is common to the different definitions is that it is care provided to a person who needs support at home (usually lay and unpaid support) by their family members, friends or neighbours, called informal carers. Informal carers, i.e. family members, friends or neighbours, perform a lot of care work within the system of long-term care.

When it comes to the distribution of the burden of care, women are the ones who dominate and take responsibility for care, which negatively affects their participation in the labour market. Women are more likely to leave the labour market or reduce the number of working hours more than men for this purpose (Spasova et al., 2018; Colombo, Llena – Nozal, Mercier, & Tjadens, 2011; Naiditch et al., 2013; Huber et al., 2009; Rodrigues, Schulmann, Schmidt, Kalavrezou, & Matsaganis, 2013). The results of an EQLS survey (2016) indicate that the gender gap varies from country to country. The largest gender gap is in Belgium, where 13% more women than men provide informal care, similar to the Netherlands and Greece (a 10% gap). On the other hand, in the Czech Republic, for example, this proportion is equal, while in Slovakia, for example, the proportion of men (22%) is even higher than the proportion of women (17%). In Slovenia, the

proportion of women (16%) is higher than the proportion of men (13%). Differences between countries are also partly the result of women's participation in the labour market, which is generally higher in Eastern European countries. In these cases, the participation of women in informal care is lower and there is a higher probability or need for men to be involved in care (the Czech Republic, for example) (Zigante, 2018).

Research shows that the number of informal carers ranges from 10% to 25% of the total population (Spasova et al., 2018). A more recent study (Tur-Sinai, Teti, Rommel, Hlebec, & Lamura, 2020), based on three different surveys (EQLS, EHIS and SHARE), meanwhile, states that the proportion of informal carers in the population over the age of 50 in 15 European countries ranges from 12.9% to 29%. At the same time, the authors point out that the differences in the calculated proportions can be significant compared to various surveys.<sup>88</sup> However, this is not the case for Slovenia,<sup>89</sup> where data from various surveys show that on average 16% of people aged over 50 (also) perform informal care.

The high prevalence of informal long-term care may be influenced by the lack of accessible formal services, their poorer quality and high costs, and the tradition of family and intergenerational relationships (Spasova et al., 2018). Placing long-term care at home at the forefront and strengthening cooperation between informal and formal long-term care, which are characteristic trends in Europe (Spasova et al., 2018; Nagode & Lebar, 2019), brings a reflection on the division of roles and scope of care between formal and informal carers.

Providing care may be physically and mentally exhausting. Leaving the labour market puts the carer at a greater risk of poverty (European Commission, Directorate-General for Economic and Financial Affairs and Economic Policy Committee, 2016). Carers are more exposed to health-related risks (Baji et al., 2019) and mental

<sup>88</sup> For example, in Belgium, the proportion of informal carers in the population over the age of 50 is 25.3% according to the SHARE survey, 12.8% according to EHIS and 34.3% according to EQLS.

<sup>89</sup> SHARE 15.5%, EHIS 17.6% and EQLS 14.8%.

health problems (Colombo et al., 2011; Tjaden & Colombo, 2011). However, the provision of care can have a positive effect on the health and general well-being of carers (if it stems from motivation, love, affiliation, a sense of duty) (Naiditch et al., 2013). From the aspect of public finances, such informal care can be understood as a cost-effective way of preventing costly institutionalisation, while the indirect costs at the individual and state level, in particular in relation to employment, health and well-being of informal carers, are being overlooked (Rodrigues et al., 2013; Zigante, 2018). We emphasised precisely the latter in the evaluation of long-term care pilot projects, in which informal carers were one of the important target groups.

## Methodology

The purpose of the evaluation was to find out who informal carers are, how they provide care and live, and last but not least, how widespread informal care is in the pilot environments. The key goal was to find out whether the quality of life of informal carers has changed during the pilot project, in particular whether their objective and subjective burden of care has decreased. The latter serves as a basis for guidelines for the provision of long-term care services that will enable a quality life for informal carers.

In order to be able to evaluate the goal, we prepared a questionnaire for informal carers. Based on the recommendation of the European Centre for Social Welfare Policy and Research (Kahlert, Boehler, & Leichsenring, 2018), we used a standardised questionnaire on the subjective experience of the care burden, called the Zarit Burden Interview (ZBI-22), which is among the most widespread<sup>90</sup> tools for measuring this burden (Mosquera et al., 2016). We used the ZBI-22 version, which has high reliability and construct validity (Herbert et al., 2000; Mosquera et al., 2016). We

calculated the subjective workload as an index on an interval between 0 and 88 on the basis of all 22 items measured on a scale from 0 (never) to 4 (almost always): little or no burden (0–20 points), mild to moderate burden (21–40 points), moderate to severe burden (41–60 points) and severe burden (61–88 points).

To measure the objective burden, the respondents were asked how many hours per week, on average, they spend on informal care and assistance to the person included in the pilot project who listed the respondent as the key informal carer. In analysing this question, we followed guidelines from relevant literature (Moya-Martinez, Escribano-Sotos, & Pardo-Garcia 2014) and recalibrated those who reported 112 hours of care or more per week to 112 hours per week. We also collected data on the demographics and households of informal carers, on the provision of assistance and care, and on the experience and usefulness of the pilot project. We also asked them to list the three things that make them the happiest in caring for the person they care for and the three things that burden them the most. In the article, their statements are denoted by M0.

The questionnaire was completed by informal carers twice: first (M0) in the first eligibility assessment of the person they care for and again (M12) after a year of the inclusion of this person in the pilot project (third eligibility assessment). The latter was basically identical to the first one, with a set of questions related to the Covid-19 epidemic situation being added. The first questionnaire (M0) was answered by 395 informal carers (64.8% response rate<sup>91</sup>), and the second (M12) by 94 (79.7% response rate). 58 informal carers responded to both questionnaires. Univariate and bivariate statistical methods were used in the analysis of quantitative data, and thematic qualitative analysis was used in the analysis of open answers.

In addition to the questionnaire, in-depth semi-structured interviews were also conducted

<sup>90</sup> There are also, for example, Pearl's Overload Scale, Screen for Caregiver Burden, Sleep Disorders Inventory, Caregiver Distress Scale (Mosquera et al., 2016), Cost of Care Index, Burden Scale for Family Caregivers (Graessel et al., 2014).

<sup>91</sup> The response rate was calculated using data from the information system on whether the applicant receives assistance from relatives or not. Considering the type of survey (self-survey), we assess that the response rate is high.

with informal carers. Seven informal carers from each pilot environment were included in the quota sample and the following inclusion criteria were considered: eligibility category of the relative, gender of the informal carer, their employment status and distance from the relative they care for. We talked to the interviewees about the experience with the pilot project and individual activities, methods and parts of the procedure, and about the changes they have detected since they were included in the pilot project. Verbatim transcripts of interviews were thematically analysed in a deductive way (Boyatzis, 1998; Braun & Clarke, 2006; Hayes, 1997) in accordance with the principle of systematic coding as proposed by Saldana (2012). In the article, citations from interviews are denoted by I-NF.

In order to obtain in-depth results, we used mixed research methods, especially the concurrent nested design (Creswell & Plano Clark, 2007), which includes an extensive (predominant) quantitative phase with an integrated smaller qualitative part.

## Results

In this article, we first present data on the quality of life of informal carers before the implementation of pilot activities. In doing so, we rely on the data obtained upon the entry to the project (M0). We then observe the effects of the intervention on the quality of their life, comparing the situation at the start of the project (M0) with the situation after a year of inclusion in the project (M12).

### Who are the informal carers, how do they provide care and how much are they burdened?

The incidence of informal care was high in the pilot environments, as three quarters (75.1%) of all applicants for eligibility assessment received

assistance (also) from a relative:<sup>92</sup> the highest incidence was in Dravograd (80.1%), similar in Celje (79.2%) and slightly lower in Krško (66.5%).

Among the surveyed informal carers, women predominated in all three pilot environments (65.4%), with the largest proportion in Celje (68.7%) and the lowest in Krško (60.9%). On average, the informal carers were 63.2 years old, and there were no significant differences in the mean age between the environments. The youngest informal carer in Dravograd was 26 years old, in Celje 31 years old and in Krško 37 years old. The oldest carer in Dravograd was 93 years old, in Celje 88 years old and in Krško 89 years old. Three-tenths (29.4%) of all informal carers were over 70 years of age, while no underaged informal carers were recorded in the pilot projects.

Retired informal carers were predominant (48.5%). In Dravograd, the proportion of retirees was about ten percentage points higher (51.9%) than in Krško (41.8%), while in Krško there were slightly more unemployed persons and homemakers. The Dravograd pilot environment stood out with a slightly lower proportion of full-time employees compared to other environments (Celje 35.6%, Krško 35.5% and Dravograd 28.6%).

The educational structure of informal carers is also statistically significantly related to the pilot environments ( $\chi^2=22.897$ ,  $p=0.004$ ). In the Celje pilot environment, informal carers generally had a higher level of education, with 37.8% having at least higher education. In Krško, 25.5% of them had such a level of education and in Dravograd it was 22.4%.

The respondents provided informal care mostly to their parents (47.7%) or partners (33.2%), although there are differences by environments ( $\chi^2=10.931$ ,  $p=0.027$ ). Dravograd stood out with a much smaller proportion of respondents who provided care to their parents (Celje 53.6%, Krško 50.9% and Dravograd 37.8%) and a much larger proportion of those who provided care to their partners (Celje 27.8%, Krško 28.2% and Dravograd 44.1%). More than two-thirds (68.9%) of the informal carers surveyed lived in the same building

<sup>92</sup> And for whom the data on receiving assistance from a relative was also recorded.

as the persons they provided care to (either in a joint or separate household), which is statistically significantly related to the pilot environment of the informal carers ( $\chi^2=21.368$ ,  $p=0.06$ ). In the Krško pilot environment, significantly more respondents lived in the same building with the person they provided care to (76.7%) compared to Dravograd (67.3%) and Celje (63.9%), while in Celje, for example, there was a significantly higher proportion of such who live up to half an hour away (Celje 16%, Krško 3.9% and Dravograd 5.5%).

In general, we find that before the beginning of the pilot projects, informal carers mostly carried out instrumental activities of daily living, particularly domestic help. The most frequent activities were dishwashing (73.7%), cooking, helping to prepare meals or delivering food (70.3%), bed making, cleaning bedrooms (64.2%). This was followed by assistance in purchasing and taking medications (63.3%). Assistance with activities of daily living was less frequent, although not very much. Informal carers most often helped with dressing and undressing (58.5%) and slightly less (53.7%) with lying in bed and getting up, using the toilet and bathroom (46%) and maintaining and caring for care accessories (42.3%). The other tasks performed by a high proportion of the surveyed informal carers on a daily basis for the persons they provide care to include feeding (36.9%), shopping, purchasing food, household goods, cleaning products (36.8%), washing and bathing (36.4%), laundry and ironing (35.1%), minor house repairs and gardening (33.8%) and financial management (30.4%). Informal carers from Dravograd stood out with a higher proportion in the majority of tasks.

The surveyed informal carers listed nine ( $AS=9.2$ ,  $Me=9$ ) different daily tasks on average. Standing out in terms of a larger number of tasks ( $AS=10.2$ ) were the surveyed informal carers from Dravograd, who on average performed one task more per day than in Celje ( $AS=8.8$ ) and two more than in Krško ( $AS=8.4$ ). The difference between the environments is statistically significant ( $U=4.176$ ,  $p=0.016$ ).

An important aspect of the quality of life of informal carers is how burdened they feel with the provision of care, and how both the objective and subjective burdens can be measured. In terms of objective burden, it showed that the respondents provided an average of 41.2 hours of informal care per week upon entering the project, with half of the informal carers providing 28 hours or less of care per week and half of them more ( $Me=28$ ). The difference in hours of care between the pilot environments is statistically significant ( $F=6.063$ ,  $p=0.003$ ). The Dravograd pilot environment stood out with significantly more hours of care ( $AS=51$ ,  $Me=35$ ) than in the Krško ( $AS=36.4$ ,  $Me=24$ ) and Celje pilot environments ( $AS=36.3$ ,  $Me=24$ ).

We first take a look at subjective burden through the feelings that were almost always or quite often felt by at least a third of the surveyed informal carers and connect them with the findings from open answers and interviews. Then we present the final subjective burden.

The most, eight out of ten (78.9%) of the surveyed informal carers, stated that the person whom they provide assistance to is quite often or almost always dependent on them. Approximately two-thirds (61.7%) are afraid of what the future holds for the person they provide care to (*"The worry that something will happen to him, that he falls and gets hurt when no one is around."* (M0), *"To watch her deteriorate."* (M0)). More than half (55.9%) said that the person they provide care to seems to expect them to take care of them as if they were the only ones they could depend on (*"He is never satisfied with anything, so he is not able to praise or be grateful for anything."* (M0)). In the latter, the Dravograd pilot environment stood out with a slightly lower proportion of respondents (45.3%) compared to Krško (58.5%) and Celje (63.3%).

A significant proportion of the surveyed informal carers felt that they did not have enough time for themselves (39.3%). More than a third experience stress due to having to reconcile work and family life with the demands of the person they provide care to (34.8%) (*"Sometimes I can't be with my family due to the obligations with my mother."*

(M0)). A quarter of the informal carers stated that their health suffered because of the efforts related to the person they provide care to (25.9%) or they felt that they would no longer be able to care for that person for much longer (24.8%). Also, a quarter of them assessed that their social life suffered as a result of care (24.2%) (*"I don't have much social inclusion, I live like a zombie here at my father's place"* (I-NF)). One-fifth of the informal carers felt that because of the person they provide care to they did not have as much privacy as they would like to have (21.7%). Also, a fifth of them believes that they do not have enough money to take care of the person they provide care to (18.5%) (*"When you are in distress, when you suddenly get an immobile father from the hospital, with severe bedsores, you have to buy everything yourself."* (M0)).

The informal carers reported much less often that the person they provide care to exerted a negative influence on relationships with other family members and friends (3.7%). They were rarely of the opinion that they feel angry when they are with the person to whom they provide care (1.8%). A few of them stated that they felt uncomfortable having friends over because of the person they provide care to (1.8%).

Based on the reports from the informal carers in the questionnaire on the three things related to care that make them the happiest and the three that burden them the most, we identified with a qualitative analysis the incidence of two major types of care burdens and two types of factors that make informal carers happy and motivate them to provide care.

The first type of burden is related to self-care and refers to the risks associated with their own health, lack of (free) time and adjusting their time to the person they care for, abandonment of their own activities, performance of activities of daily living and instrumental activities of daily living, distance from the person they care for, negative impact of care on their finances, reduced social contacts or even social exclusion.

In the second type of burden, the descriptions referred to the care or concern for the person to

whom they provide help. They mentioned concern about the health problems of the person they provided care to, disturbing behaviour or traits or mood swings of the person they provided care to, the feeling of helplessness when the effect of help was not visible. Some lacked care competencies or were unaware of possible forms of assistance. Difficulties in cooperation with the formal assistance network were also mentioned.

Informal carers were made happy and motivated mainly by factors related to the person to whom care is provided. They were often motivated by this person's satisfaction with and gratitude for care, connection with the person and, as part of this, spending time with and having a loving and emotional relationship with the person. The visible effect of the assistance, i.e. the contribution to changes in the daily results of care recipients, was also a motivating factor. They were also made happy by the physical health of the person to whom care is provided (e.g. improvement or maintenance of the health condition) and their mental health (e.g. good mood; motivation, enthusiasm, optimism and prevention of loneliness). An important aspect of motivation for care was the provision of care at home and not in an institution, i.e. the impact on preventing institutionalisation.

On the other hand, the happiness factors in informal carers were related to a lesser extent to themselves and only indirectly to the well-being of the care recipient. They have been altruistic and helped because they enjoy it or because they value this kind of conduct. A small proportion of the informal carers helped because they had the feeling of duty to help. A handful of them were also happy about they themselves being relieved, mentioning methods of relaxation, help from formal care and help by family members.

The presentation of the subjective burden of informal care can be concluded with the index of subjective burden. The latter shows that almost half (46%) of the surveyed informal carers felt mild to moderate burden upon entering the project, just under a quarter felt no or little burden (24.3%),

**Table 1: Characteristics and burden of informal carers upon entering the project (M0) (N=395)**

|                                                         | Total               | Celje          | Dravograd    | Krško        |
|---------------------------------------------------------|---------------------|----------------|--------------|--------------|
| Number of respondents                                   | <b>395</b>          | 153            | 131          | 111          |
| Female gender                                           | <b>65.4%</b>        | 68.7%          | 64.7%        | 60.9%        |
| Age, average                                            | <b>63.2</b>         | 63.2           | 64.6         | 61.6         |
| Age [min, median, max]                                  | <b>[26, 63, 93]</b> | [31, 63, 5 88] | [26, 64, 93] | [37, 60, 89] |
| (Un)finished primary education                          | <b>14.1%</b>        | 9.3%           | 18.5%        | 15.5%        |
| Lower or secondary vocational education                 | <b>25.1%</b>        | 23.2%          | 26.9%        | 25.5%        |
| Secondary vocational or general education               | <b>31.7%</b>        | 29.8%          | 32.3%        | 33.6%        |
| Short-cycle higher or higher vocational education       | <b>12.8%</b>        | 12.6%          | 16.2%        | 9.1%         |
| Higher education, university education or higher        | <b>16.4%</b>        | 25.2%          | 6.2%         | 16.4%        |
| Unemployed                                              | <b>6.1%</b>         | 5.6%           | 5.3%         | 8.2%         |
| Employed less than full-time                            | <b>3.1%</b>         | 2.8%           | 3.8%         | 2.7%         |
| Employed full-time                                      | <b>33.3%</b>        | 35.6%          | 28.6%        | 35.5%        |
| Self-employed                                           | <b>4.0%</b>         | 2.8%           | 6.0%         | 3.6%         |
| Retired                                                 | <b>48.5%</b>        | 50.0%          | 51.9%        | 41.8%        |
| Homemaker                                               | <b>3.8%</b>         | 2.8%           | 1.5%         | 8.2%         |
| Other                                                   | <b>1.2%</b>         | 0.6%           | 3.0%         | 0.0%         |
| Partner themselves                                      | <b>33.2%</b>        | 27.8%          | 44.1%        | 28.2%        |
| Child themselves                                        | <b>47.7%</b>        | 53.6%          | 37.8%        | 50.9%        |
| I am related some other way                             | <b>19.1%</b>        | 18.5%          | 18.1%        | 20.9%        |
| They live in the same building                          | <b>68.9%</b>        | 63.9%          | 67.3%        | 76.7%        |
| They do not live in the same building, but close enough | <b>9.8%</b>         | 8.3%           | 10.0%        | 11.6%        |
| Up to a 10-minute drive apart                           | <b>7.1%</b>         | 6.5%           | 10.9%        | 4.7%         |
| Up to a half-hour drive apart                           | <b>9.3%</b>         | 16.0%          | 5.5%         | 3.9%         |
| Up to a one-hour drive or more apart                    | <b>4.9%</b>         | 5.3%           | 6.4%         | 3.1%         |
| Number of daily tasks, average                          | <b>9.2</b>          | 8.8            | 10.2         | 8.4          |
| Weekly number of hours of care [average, median]        | <b>[41.2; 28]</b>   | [36.3; 24]     | [51; 35]     | [36.4; 24]   |
| Little or no burden                                     | <b>24.3%</b>        | 18.2%          | 32.8%        | 22.6%        |
| Mild to moderate burden                                 | <b>46%</b>          | 4.5%           | 47.7%        | 45.1%        |
| Moderate to severe burden                               | <b>26.5%</b>        | 31.8%          | 18.8%        | 28.4%        |
| Severe burden                                           | <b>3.2%</b>         | 4.7%           | 0.8%         | 3.9%         |

Characteristic of informal carers

Burden



more than a quarter were moderately to severely burdened (26.5%), and less than five per cent of the surveyed informal carers felt severely burdened (3.2%). We have detected that subjective burden is statistically significantly related to the type of pilot environment ( $\chi^2=16.017$ ,  $p=0.014$ ). For example, more informal carers felt severely burdened in Celje (4.7%) compared to Krško (3.9%) and Dravograd (0.8%), while there were more carers with little or no burden (32.8%) in the Dravograd pilot environment compared to Krško (22.6%) and Celje (18.2%).

## How pilot activities have affected the lives of informal carers

We determine below to what extent the assistance of formal care or involvement in the pilot projects has contributed to changes in the quality of life of informal carers. The presented results are based on a sample of 58 informal carers who completed a questionnaire in the first assessment of the eligibility of the person they provide care to and again after one year of involvement. The results related to this sample should be read, if by individual environments at all, with methodological reservation and only illustratively, as the sample of informal carers who answered the questionnaire in two measurements is small.

If we initially focus on the type and frequency of help and tasks as part of care provided by informal carers on a daily basis, even after one year, these are still instrumental activities of daily living. The most frequent were, for example, dishwashing (M0 82.5%; M12 80.7%), cooking, helping to prepare meals or delivering food (M0 82.8%; M12 79.7%), putting to bed and getting out of bed (M0 68.5%; M12 66.7%) and home cleaning and rubbish removal (M0 71.2%; M12 65.5%). This was followed by assistance in purchasing and taking medications (M0 78.9%; M12 63.8%), in using toilet and bathroom (M0 58.2%; M12 63.6%), in dressing and undressing (M0 65.5 M12 63.6%) and bed making and cleaning of bedrooms (M0 74.1%;

M12 63.2%). More than half of the respondents also listed maintenance of care accessories, such as wheelchair, walker, hearing aid (M0 54.5%; M12 54.4%), and half of them feeding (M0 42.6%; M12 50.0%). About four-tenths of carers (M0 38.6%; M12 41.1%) helped with washing the whole body and bathing, and a similar proportion helped with washing and ironing clothes (M0 43.9%; M12 39.7%) and/or in managing finances (M0 46.7%; M12 33.9%), such as paying bills. We should also mention minor housework or renovations and gardening (M0 39.3%; M12 29.8%), shopping, purchasing food, household goods, cleaning products, etc. (M0 44.1%; M12 28.1%) and financial support, such as giving money (M0 20.0%; M12 19.6%).

An analysis of changes in the intensity of tasks in one year shows that the proportion of the surveyed informal carers who performed tasks every day decreased in most tasks. The proportion related to shopping, purchasing of food, household goods, cleaning products, etc. decreased statistically significantly ( $Z=2.288$ ,  $p=0.022$ ), by 16 percentage points, and the proportion related to assistance in purchasing and taking medications decreased by 15.2 percentage points, where the decrease is not statistically significant ( $Z=-1.708$ ,  $p=0.88$ ). In the latter, the share decreased the most in Dravograd (by 35.3 percentage points). The proportions also decreased in relation to management of finance (by 12.7 percentage points), bed making, cleaning of bedrooms (by 11 percentage points) and organisation of various forms of assistance, e.g. making a doctor appointment, contacting home assistance service, community nursing service and similar (by 9.9 percentage points).

On the other hand, a smaller proportion of the surveyed informal carers more often helped with feeding (7.4 percentage points), use of toilet and bathroom (5.5 percentage points) and washing of the whole body and bathing (2.5 percentage points).

Informal carers who completed the questionnaire at both points of time reported an average of 9.5 different daily tasks in M0 and 8.2 in M12, with the difference being borderline statistically significant ( $t=1.953$ ;  $p=0.056$ ). As for

the environments, in Dravograd, where carers performed the most daily tasks on average, the difference decreased the most, from 11.3 to 9.4.

A comparison of data regarding the objective burden of those informal carers who responded to the questionnaire at both points of time shows that they provided an average of 52.6 hours of assistance per week upon entering the pilot project, with the median being lower: 42.5 hours. After one year, informal carers performed an average of 44.9 hours, and the median somewhat decreased to 32.5 hours. Although no statistically significant change can be confirmed, the data show that the number of hours of care in all three pilot environments decreased on average. It decreased the most in the Celje pilot environment (by 9.3 hours per week on average), then in Dravograd (7.8 hours per week on average), and the least in Krško (3.1 hours per week on average).

A large standard deviation ( $SD > 30$ ) was recorded. The latter tells us that informal carers provided very different scopes of assistance, which is also reflected in the span of hours devoted to care: from two hours to 112 hours per week. In both measurements, the surveyed informal carers from the Dravograd pilot environment were the most burdened in terms of the number of hours of care, which is also related to the number of different tasks, which was also the largest in Dravograd. There is a positive correlation between the number of hours of care and the number of tasks ( $r = 0.58$ ).

Data on the subjective burden of those informal carers who answered the questionnaire both at the beginning of the project and after one year of involvement show that, on the one hand, the proportion of those who felt little or no burden increased (from 19% to 26.3%), while the proportion of those who felt severely burdened also increased (from 5.2% to 10.5%). The share of the latter increased markedly only in the Celje pilot environment (by 11.5 percentage points). In general, we can say that the subjective burden did not change significantly during the project, while we again point to the small sample of informal carers concerning whom we were able to monitor this change.

In the questionnaire, we also asked informal carers how burdened they generally feel. In the second measurement, they responded slightly more positively, as after a year of participation in pilot activities they felt less burdened on average (3.5) than when entering pilot activities (3.2), although the difference is not statistically significant.

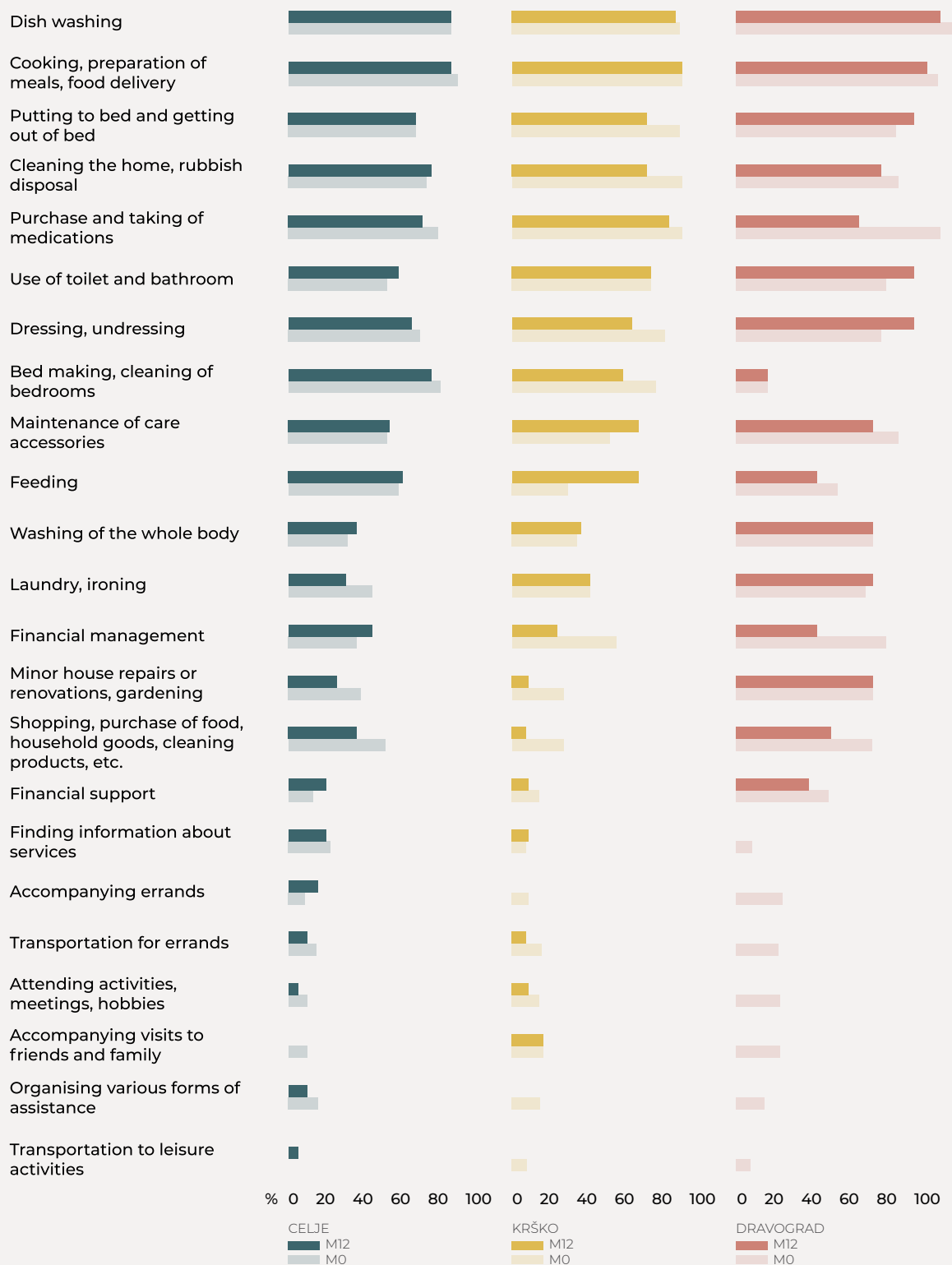
At the same time, we should not overlook the potential impact of the Covid-19 epidemic both on the type and frequency of care and on the well-being and burden of informal carers. Approximately half of the respondents (28 out of 58) answered the questionnaire after one year of inclusion and precisely during the time of the epidemic. However, based on control questions we find that the Covid-19 epidemic did not have a significant impact, at least on the measurement of objective burden, which cannot be said for the measurement of subjective burden, as we did not specifically control it.

In addition to the impact of the pilot activities on the intensity of the burden, we were also interested in how informal carers were relieved by the assistance as part of the project and what changes they have noticed since they joined the project. Help received within the project allowed some of the interviewed carers to have a little more time for themselves and for other tasks besides care. It has made it easier for those who are employed to balance work and care by enabling them to take less sick leave or annual leave. They were less concerned and had a greater sense of security because the care recipient was receiving professional care and was being taken care of during their absence.

Several informal carers were also physically relieved by the assistance, which improved their well-being and alleviated possible health problems (e.g. fewer difficulties with back pain). For those with a reduced social network, the arrival of employees on the project also represented stronger social contacts. A small proportion of carers mentioned that the free assistance as part of the project had significantly relieved them financially.



**Figure 1: Comparison of the frequency of the provision of assistance or doing chores for another person upon entering the project (M0) and after one year of the provision of services (N=58)**



Informal carers (N=58) assessed as an important contribution of the project the acquisition of new knowledge about appropriate care, as with the help of employees on the project they gained much information and knowledge about care that they did not have before. The employees explained to them and showed them the appropriate methods of work (e.g. on proper relocation, sitting, caring for pressure ulcers, etc.). Approximately two-thirds of informal carers (64.6%) reported that they had received advice on how to properly care for the person they provide care to as part of the pilot project (61.9% in Celje, 63.6% in Krško and 68% in Dravograd). A similar proportion of respondents stated that they had received information about who they could turn to for help in the local environment (e.g. associations, respite care options, self-help groups, etc.) so that they could be relieved of the burden of care of the person they cared for (47.8% in Celje, 77.8% in Krško and 75% in Dravograd).

The pilot environments paid special attention to the training of informal carers, which took place between September 2019 and September 2020.<sup>93</sup> The training covered a variety of topics, from more general ones concerning long-term care to very specific topics relevant to the provision of informal care. The training providers adapted the content of lectures in accordance with the needs detected by the long-term care coordinators in the pilot environments and in accordance with the interest of the participants. The most desirable topics for the interviewed informal carers were related to user care (proper relocation, changing clothes) and the option to test the acquired theoretical knowledge in practice. Resolving their dilemmas from practice (either from the aspect of care or relationship with users) was crucial for them. The pilot environments also organised other training for informal carers, and in selecting topics they tried to follow the needs perceived in the field.

In total, the largest number of training sessions were organised in the Dravograd pilot environment

(57), where lectures were dispersed over different municipalities (Dravograd, Kotlje, Mežica, Ravne na Koroškem, Kotlje, Črna na Koroškem) in order to get as close as possible to the living spaces of informal carers and thus make it easier for them to participate. They state that 258 different people attended the lectures and that 25 informal carers were trained, attending more than 80% of the lectures. The lectures were attended by three to 38 people, with an average attendance being 12 people. The majority of the participants thus attended only certain lectures that were related only to those topics that interested them.

In Krško, all lectures were organised in the only municipality where the pilot project was implemented. In total, 18 training sessions were conducted. The events were attended by varied numbers of participants, ranging from two to 22, with the average attendance being five. The events were attended by 28 different people.

In Celje, the events were organised only in the municipality of Celje, and not in the other municipalities that were included in the pilot project. A total of 17 training sessions were conducted, which were attended by two to 16 people, with the average attendance being seven people per one training session.

Self-help groups were also set up in all three pilot environments, and the dynamic of their work varied. In Celje, the self-help group started working just before the first wave of the Covid-19 epidemic. By the end of August 2021, they had met four times. In Dravograd and Krško, the self-help group was established as soon as at the end of 2019, and it met six times until the end of the pilot projects.

The key limiting factors in the participation in training and lectures were the distance from the place of training, transportation to organised events and the lack of time of informal carers, as well as a lack of people in their social network who would substitute for their care duties during their absence. Also related to the lack of time is, for some, the unsuitable timing of training sessions, which took

<sup>93</sup> The Ministry of Health has selected the Faculty of the Health Sciences of University of Ljubljana as an external contractor for this activity, which carried out the training in cooperation with partners.

**Table 2: Objective and subjective burden of the surveyed informal carers, comparison between M0 and M12 (N=58)**

|                                                         | Point of measurement | Total               | Celje      | Dravograd  | Krško      |
|---------------------------------------------------------|----------------------|---------------------|------------|------------|------------|
| <b>Number of daily tasks, average</b>                   | M0                   | <b>9.5</b>          | 8.5        | 11.3       | 9.1        |
|                                                         | M12                  | <b>8.2</b>          | 7.9        | 9.4        | 7.5        |
| <b>Weekly number of hours of care [average, median]</b> | M0                   | <b>[52.6; 42.5]</b> | [51.3; 40] | [61.8; 50] | [40.4; 40] |
|                                                         | M12                  | <b>[44.9; 32.5]</b> | [42; 35]   | [54; 40]   | [37.3; 32] |
| <b>Little or no burden</b>                              | M0                   | <b>19.00%</b>       | 15.40%     | 31.30%     | 12.50%     |
| <b>Mild to moderate burden</b>                          |                      | <b>44.80%</b>       | 42.30%     | 50.00%     | 43.80%     |
| <b>Moderate to severe burden</b>                        |                      | <b>31.00%</b>       | 34.60%     | 18.80%     | 37.50%     |
| <b>Severe burden</b>                                    |                      | <b>5.20%</b>        | 7.70%      |            | 6.30%      |
| <b>Little or no burden</b>                              | M12                  | <b>26.30%</b>       | 19.20%     | 46.70%     | 18.80%     |
| <b>Mild to moderate burden</b>                          |                      | <b>31.60%</b>       | 26.90%     | 26.70%     | 43.80%     |
| <b>Moderate to severe burden</b>                        |                      | <b>31.60%</b>       | 34.60%     | 26.70%     | 31.30%     |
| <b>Severe burden</b>                                    |                      | <b>10.50%</b>       | 19.20%     |            | 6.30%      |

place at times when a user needs a large amount of help, while some were deterred from committing to participate by the continuity of the training. The idea was that they attend all the training sessions, or at least most of them. Individuals also refused to participate due to their own obstacles and physical problems. All the interviewed informal carers welcomed the training, and only a minority thought that they had enough experience with long-term care and did not need training.

Let us conclude with the information that the vast majority of the surveyed informal carers (N=58) generally assessed their involvement in the pilot projects as useful (31.4%) or very useful (58.8%). A small proportion of the surveyed as well as the interviewed informal carers did not notice any major changes since joining the project or did not see the inclusion as useful. These were usually those who had previously had certain forms of formal assistance (e.g. home help) or those whose care recipients received a minimum number of hours of new services.

We also asked the interviewed informal carers what changes in their lives they expect after the completion of the pilot projects. The vast majority would like the project or a similar type of assistance to continue. The limited duration of the project has put them in an uncertain position. After the completion of the pilot project, a large proportion of them had to look for other forms of assistance, some of them already received the social care service of home help during the project or decided to have such assistance later. All other existing forms of assistance must be paid for by users and will place an additional financial burden on some interviewees.

## Discussion with key messages

Informal carers are an important link in long-term care because, as it is evident from the relevant literature, a large part of care is provided precisely

by them. That informal care is very widespread is illustrated by the fact that three-quarters of the persons evaluated in the pilot project have at least one person who provides informal care and assistance to them. A high incidence of informal care is also a common feature of long-term care in other European countries.

The care professions in the field of long-term care, including informal care, are strongly marked by the gender dimension, as women predominate in these professions, which puts them in an unequal position compared to men. The predominance of women in informal care was also confirmed by the pilot projects, in which women represented approximately two-thirds of the informal carers. Gender equality is therefore a very topical issue for Slovenia in this field and is strongly related to both employment policy (participation in the labour market) and retirement (years of active life).

Although no informal carers under the age of 18 were identified in the evaluation of the pilot projects, these special and hidden groups of informal carers should not be overlooked in policy making. A recent international survey<sup>94</sup> (Santini et al., 2020) shows that the phenomenon of underaged carers is quite widespread, reaching approximately 8% of young people in Europe who provide intensive care to a family member. The authors note that long-term care providers and policy makers should aim to help underaged carers to maintain intergenerational emotional bonds with older family members (they most frequently provide care to their grandparents), while protecting them from the negative consequences of inappropriate responsibilities that may endanger their overall health and well-being.

An important aspect that we have explored as part of the evaluation was the burden of informal carers. We looked at this subject from the aspects of objective and subjective experiences. We found that the objective burden of informal carers decreased during the pilot project, by which we may confirm that the quality of their lives has also improved somewhat. The result thus shows that in the existing

94 Slovenia was also included in the survey.

organisation of long-term care, organised home care represents too small a relief for informal care, or that there is still a lot of manoeuvring space available in which to strengthen cooperation between the two types of care. Intensive cooperation or integration of formal and informal care can lead to positive effects in the objective relief of informal carers and the pilot activities have had this impact.

Organised care in the homes of users is an opportunity to relieve informal carers both in terms of actual relief, with, for example, a formal provider performing certain tasks instead of an informal carer (as we have seen, the intensity of certain tasks carried out by informal carers decreased during the project, for example, in purchase of food, assistance in taking medications, etc.) as well as in terms of providing support to informal carers by means of an expert teaching them how to correctly perform certain tasks (e.g. feeding, using toilet and bathroom, washing) i.e. actionable knowledge (Rosenfeld, 1989; Čačinović Vogrinčič, 2002).

If the quality of life is perceived from the point of view of subjective burden, in general we cannot say that it has improved for informal carers in the year of the implementation of the pilot activities. We have already mentioned the potential impact of the Covid-19 epidemic. In addition, the range of different aspects of the burden, both from the point of view of self-care and from the point of view of the person for whom informal carers provide care, is so wide that some types of subjective burdens can be eliminated more quickly with an intervention of formally organised assistance (for example, time, coordination, financial burden, etc.). Others are more difficult to eliminate, however, as they depend on the personality of the informal carer and the relationship between them and the person to whom they provide care (for example, there are goal conflicts (Kindt, Vansteenkiste, Cano, & Goubert, 2017)), which should be explored to a greater extent in further research. At the same time, the subjective burden is the one that is more difficult to change in the short term (for example,

one year), which is one of the limitations of our research, i.e. the evaluation of the pilot projects.

However, we have identified many relief factors in terms of care. Factors that make informal carers happy that they provide care or motivate them internally are very important (Naiditch et al., 2013). Concrete support in terms of contributing (additional) hours of care for the person to whom they provide care is also important. In addition, an important factor in relieving the burden is shown to be the option of taking annual leave (e.g. at least 14 days), while the person they care for is provided with respite care in a care home, another institution or at home. We do not possess the data on the number of informal carers who actually used the option of respite care or daily care as part of the pilot project, while we find on the basis of the available material that there were very few of them.

Occasional respite care of a few hours is also exceptionally important for informal carers, so that they can carry out certain tasks in peace during this time or, for example, attend education or training sessions or meetings of self-help groups that they need and appreciate, but often experience as a burden. In this regard, informal carers need support in particular in transportation, coordination of appointments, and provision of respite care and so events should be organised in their vicinity. Informal carers are often older people who take care of their partners and who need transportation in order to attend training sessions; it would be easier for them to attend events if they were organised in their local community. On the other hand, when it comes to informal carers who are employed, the flexible timing of events is also important.

If we as a country want to overcome the strongly anchored gender inequality in the care professions and pursue the goal of making informal care a voluntary choice and not a necessity or the only emergency exit, there is a need to better support informal carers with adequate measures on the one hand and to significantly strengthen organised long-term home care services on the other.

## BIBLIOGRAPHY

- Baji, P., Golicki, D., Prevolnik-Rupel, V., Brouwer, W. B. F., Zrubka, Z., Gulácsi L. in Péntek, M. (2019). *The burden of informal caregiving & Hungary, Poland and Slovenia: results from national representative surveys. The European Journal of Health Economics*, 20, 5–16.
- Boyatzis, R. E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development*. Thousand Oaks, CA: Sage.
- Braun, V. in Clarke, V. (2006). *Using thematic analysis in psychology. Qualitative Research in Psychology*, 3, 2, 77–101.
- Colombo, F., Llena-Nozal, A., Mercier, J. in Tjadens, F. (2011). *Help Wanted? Providing and Paying for Long – Term Care*. OECD Health Policy Studies: OECD Publishing.
- Creswell, J. & Plano Clark, V. (2007). *Designing and Conducting Mixed Methods Research*. Thousand Oaks, CA: Sage.
- Čačinovič Vogrinčič, G. (2002). *Koncept delovnega odnosa v socialnem delu*. Socialno delo, 41, 2.
- European Commission, Directorate-General for Economic and Financial Affairs and Economic Policy Committee. (2016). *Joint Report in Health Care and Long-Term Care Systems and Fiscal Sustainability and its country reports*. Brussels: European Commission. Retrieved from : <https://op.europa.eu/en/publication-detail/-/publication/d6042a45-b535-11e6-9e3c-01aa75ed71a1/language-en>
- Graessel, E., Berth, H., Lichte, T. & Grau, H. (2014). Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC Geriatrics*, 14, 23.
- Hayes, N. (1997). Theory-Led Thematic Analysis: Social Identification in Small Companies. V Hayes N. (ed.). *Doing Qualitative Analysis in Psychology*. Hove, UK: Psychology Press.
- Hérbert, R., Bravo, G., & Prévile, M. (2000). Reliability, validity, and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging*, 19, 494–507.
- Hoffmann, F. & Rodrigues, R. (2010). *Informal carers: who takes care of them?* Policy Brief 4/2010. Vienna: European Centre. Retrieved from : [https://www.euro.centre.org/publications/detail/387\(1.10.2019\)](https://www.euro.centre.org/publications/detail/387(1.10.2019)).
- Huber, M., Rodrigues, R., Hoffmann, F., Gasior, K. & Marin, B. (2009). *Facts and Figures on Long-Term Care. Europe and North America*. Vienna: European Centre for Social Welfare Policy and Research.
- Kahlert, R., Boehler, C. & Leichsenring, K. (2018). *Monitoring and Evaluating Integrated LTC Models*. Vienna: Euro Centre Publication.
- Kindt, S., Vansteenkiste, M., Cano, A. & Goubert, L. (2017). *When is your partner willing to help you? The role of daily goal conflict and perceived gratitude*. *Motivation and emotion*, 41, 671–682.
- Mosquera, I., Vergara, I., Larranaga, I., Machon, M., del Rio, M. & Calderon, C. (2016). *Measuring the impact of informal elderly caregiving: a systematic review of tools*. *National Center for Biotechnology Information, U.S. National Library of Medicine*. Retrieved from : [https://www.ncbi.nlm.nih.gov/pubmed/26475138\(1.10.2019\)](https://www.ncbi.nlm.nih.gov/pubmed/26475138(1.10.2019)).
- Moya-Martinez, P., Escribano-Sotos, F. & Pardo-Garcia, I. (2014). *Estimating Total Informal Care Costs in Spain. Can Formal Care Reduce it?* *Ageing International*, 39, 403–420.
- Nagode, M. & Lebar, L. (2019). *Trends and challenges in long-term care in Europe*. *Revija za socialnu politiku*, 26, 1, 255–262.
- Naiditch, M., Trifantafillou, J., Di Santo, P., Carretero, S. & Hirsch Durrett, E. (2013). *User Perspectives in Long-Term Care and the Role of Informal Carers*. V K. Leichsenring, J. Billings in H. Nies (ur.), *Long-Term Care in Europe. Improving Policy and Practice* (str. 45–81). London: Palgrave Macmillan.
- Rodrigues, R., Schulmann, K., Schmidt, A., Kalavrezou N. & Matsaganis, M. (2013). *The indirect costs of long-term care. Research note 8/2013*, European Commission.
- Rosenfeld, J. M. (1989). *Emergence from Extreme Poverty, Paris: Science et Service*, Fourth World Publications.
- Santini, S., Socci, M., D'Amen, B., Di Rosa, M., Casu, J., Hlebec, V. & Hanson, E. (2020). *Positive and Negative Impacts of Caring among Adolescents Caring for Grandparents*. Results from an Online Survey in Six European Countries and Implications for Future Research, Policy and Practice. *International Journal of Environmental Research and Public Health*, 17, 6593, 1–16.
- Saldana, J. (2012). *The Coding Manual for Qualitative Researchers*. London: Sage.
- Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. & Vanhercke, B. (2018). *Challenges in long-term care in Europe. A study of national policies 2018*. European Social Policy Network. Brussels: European Commission.
- Tjadens, F. & Colombo, F. (2011). *Long-term care: valuing care providers*. *Eurohealth* 17 (2-3), 13-17. <https://silotips/download/long-term-care-valuing-care-providers>
- Verbeek-Oudijk, D., Woittiez, I., Eggink, E. in Putman, L. (2014). *Who cares in Europe? A comparison of long-term care for the over-50s in sixteen European countries*. Haag: The Netherlands Institute for Social Research.
- Tur-Sinai, A., Teti, A., Rommel, A., Hlebec, V. & Lamura, G. (2020). *How Many Older Informal Caregivers Are There in Europe? Comparison of Estimates of Their Prevalence from Three European Surveys*. *International journal of environmental research and public health*, 17, 24, 9531.
- Zigante, V. (2018). *Informal care in Europe. Exploring Formalisation, Availability and Quality*. Luxembourg: Publications Office of the European Union. Retrieved from: <https://publications.europa.eu/en/publication-detail/-/publication/96d27995-6dee-11e8-9483-01aa75ed71a1/language-en>.

**ELECTRONIC MANAGEMENT OF  
PROCEDURES AND SERVICES AND  
INFORMATION SYSTEM SUITABILITY**

Boris Majcen  
Institute for Economic Research

Valentina Prevolnik Rupel  
Institute for Economic Research

## KEY MESSAGES

- ▶ The activities implemented within pilot projects were recorded accordingly and the data obtained was entered in the information system. The time lag between the data acquisition and the possibility of its entry in the information system, insufficient control of a complete capture of the data required for an individual form and insufficient control of the obtained data entry in the information system by the pilot project contractors were the reasons why certain data was not captured at the end of the project.
- ▶ The electronic recording system developed within pilot projects is suitable in the transition towards the implementation of the systemic act on long-term care.
- ▶ The experience of pilot projects demonstrated that a timely construction and operation testing of an information system before the start of operations of the new long-term care system is exceptionally important.
- ▶ We propose that, prior to a public call for the selection of the best bidder to develop and maintain the entire information system, the Contracting Authority prepares a detailed analysis of the required databases, their content, connectivity, manner of access and minimum extract requirements for the needs of ongoing monitoring of the functioning of the long-term care system, quality control and analysis of implementing services, including the implementation of scientific research in the field of long-term care based on the already obtained experience in the development of the information system within the framework of pilot projects.
- ▶ We propose that the solutions already drafted as part of the pilot projects be incorporated in the public call for the selection of the best bidder to develop and maintain the entire information system.
- ▶ It is mandatory to establish a suitable and continuous control system for collecting and entering the data required in the system.



## Introduction

Information support for long-term care processes connects providers of formal and informal care through digital communications tools and programme tools with data. These systems not only include data on the users' medical condition but are also intended to improve interaction between all care recipients and to place the care recipient at the centre of care (Kushniruk & Borycki, 2017). In long-term care, relations and the flow of information between users and doctors, nurses or carers are very important. Each change in the user's condition reflected by the data entered may lead to changes in the comprehensive treatment process; its quality is thus closely linked to accurate and timely entry of suitable data, accessibility, and interaction and communication with everyone involved in the comprehensive treatment (Krick et al., 2019). Digital infrastructure is recognised as one of twelve key components in the SCIROCCO Maturity Model for Integrated Care (Scirocco, 2021).

Within the framework of pilot project assessment, the evaluation of electronic management/recording of procedures and services in the field of long-term care takes place, including the evaluation of suitability of the information system developed through pilot projects as a basis for the development of a new system of long-term care in Slovenia. Throughout the entire project, the development of the programme tool was monitored, which enabled the recording of information collected through implemented activities in the electronic database. All options of data recording and monitoring which were subsequently developed in accordance with environment initiatives or in compliance with the needs displayed were simultaneously available to all three pilot environments. Information on the start of the individual module application in the system was not monitored by the software company Aleja Soft d.o.o., which developed the programme tool for all environments.

## Methodology

The evaluation objective was to monitor the course of electronic recording of the data collected about the activities implemented within the pilot projects, the suitability of the developed recording system for integrated provision of long-term care, and the preparation of adjustments regarding the electronic management of procedures and services in the field of long-term care. The following indicators were determined in the evaluation:

- ▷ the share of all data collected during the pilot activities, which were recorded accordingly and entered in the electronic database, whereby a 100% capture was considered the success standard. In doing so, we supervised the implementation of recording and entering of obtained information into the accordingly developed information system by the assessors, long-term care coordinators and service providers, which was collected on the basis of the activities implemented by pilot project contractors and service providers;
- ▷ the time lag from the acquisition to the entry of obtained information in the electronic database, whereby information on beneficiaries was entered in the database immediately or the option of using the databases created had to be provided, which were prepared by various providers when implementing pilot projects. The scope and time of entry of acquired information in the electronic database at the single entry point were checked for this indicator;
- ▷ the assessment of electronic data recording within the implementation of pilot activities, whereby we assessed whether the recording system developed within pilot projects was suitable for the transition in implementation of the systemic act on long-term care.

To obtain a better insight into the construction of the information system, we carried out a semi-structured interview with a representative of the software company on 18 November 2020. We first forwarded the starting points for the interview to the discussion partner, which referred to the review of chronology of

the information system construction within the framework of pilot environments, information on possible differences in the developed information system for an individual pilot environment and data accessing, and the assessment of suitability of the information system developed within pilot projects as a basis for the development of a new long-term care system throughout Slovenia. The interview was recorded, and the discussion partner also prepared written replies to the questions from starting points. Based on the information required, we were able to assess the suitability of the developed data documenting system. As explained below, it was impossible to assess the time lag from the acquisition to the entry of obtained information in the electronic database because the time lag was for the most part the result of an ongoing development of individual modules throughout the project and not the unsuitability of the already developed software (Aleja Soft, 2019; Aleja Soft, 2019a).

## Results

Table 1 displays a timeline of the development and possibilities of applying individual modules in the information system for long-term care monitoring. As evident, the majority of requested functionalities of the information system was roughly developed by the end of August 2019. The fact that the provider was selected only after the pilot projects had already commenced further contributed to the delay in the development of the suitable programme tool. The pilot environments chose the software company on their own, which had already initially led to the delay in the software development as the pilot environments had already started their work. The first application was established in January 2019 (the Oskrba.online application), which enabled:

- ▷ the creation of a database or a list of users with personal records and a list of employees;

- ▷ monitoring of the employees' labour calculations, and
- ▷ entry of the visits conducted, and work implemented by providers and users.

The system functionalities were then regularly upgraded, which in practice caused delays in the entry of data in individual modules.

From the viewpoint of evaluation, irregular development of individual modules prevented the assessment of time lags from the acquisition to the entry of obtained information in the electronic database.

The next major module set, "List of Users", "List of Employees" and "Statistics" followed, which the provider established on 22 February 2019. These modules were regularly upgraded by the provider with new options (for further details, see table 1), while simultaneously creating new tabs/modules as per the needs. Such a work method was the result of the fact that the public call (Ministrstvo za zdravje, 2018) failed to define in detail all functionalities which the information system was to provide, since the monitoring of "all" electronic procedures was anticipated, but it was not clear which procedures were meant. The need for updating the information system occurred over time, and the employees in pilot environments and the system developer resolved them during the course of the project; the information system was also being piloted in the project. In the interim period until the development of a suitable module or solutions, certain data was collected manually by the employees in pilot environments and entered in temporary Excel files.

As part of the project, the software company developed a package of two applications, i.e. the OSKRBA ONLINE web application and the OSKRBA MOBILE mobile application, a programme tool to support the entire long-term care process.<sup>95</sup> By the end of the project, the software company developed numerous modules within these two applications (Aleja Soft, 2019a). The Oskrba Online web application has the following modules:

<sup>95</sup> The description is based on the material, Presentation of the programme package by Aleja Soft d.o.o., which was prepared by the software company.

Application receipt, Eligibility assessment for long-term care and personal implementation plan, List of Users, Work review, List of Employees, Statistics, Report for the Ministry of Health, Data for evaluation of the Social Protection Institute of the Republic of Slovenia and Exports. The Oskrba Mobile mobile application has the following modules: Reports, Calculations, Employee accounts, Code list, Retroactive signing, Observations, Work organisation, Synchronisation.

The applications enable: a) receipt of the application to enforce the right to long-term care, b) preparation of an eligibility assessment regarding long-term care with the help of an assessment tool, c) preparation of a personal implementation plan, d) preparation of all subsequent eligibility assessments and electronic recording of implementation of long-term care services, e) preparation of various reports, statistics and evaluation studies. Since January 2019, the system has been available and applicable in all three pilot environments and is undergoing a continuous process of updating and adjusting. Both applications have five levels of application users with arranged rights and restrictions regarding access to content and application functions: administrator, long-term care manager/project coordinator, long-term care coordinator, single entry point and long-term care providers. The latter have fewest rights and may record visits and tasks, notes, observations and particularities, and may later review work which they performed.

## The OSKRBA ONLINE web application

The employees of the single entry point may generate a Personal record of a user in which they enter: a) user's personal data from the application on enforcing the right to long-term care, b) data on the user's related persons, and c) data for statistics (marital status, monthly net income, education, number of people in the household, housing situation, reason for long-term care, type

of services on the assessment day, benefits and services being already received by the user). Each entered user is allocated a registration number by means of which they are managed without their name in reports, statistics and exports. This number is also the only piece of information written on the NFC sticker through which the visit is electronically recorded.

The application enables employees of the single entry point to make an eligibility assessment regarding long-term care with the help of an assessment tool which has been integrated in the application since 14 August 2019. Before this date, the assessments were made in Excel and each assessment was saved individually. The application also enables incorporation of a life story and drafting of an electronic report on eligibility or ineligibility of long-term care.

The applicant eligible for services is transferred to the List of Users tab, which enables the formation of a list of users, monitoring the use of the starting scope of service hours in an individual category of eligibility for long-term care, entry and reviewing the notes or observations relating to a certain user. The list is equipped with a number of filters – search filter for users, buttons for displaying Active, Inactive and All users, filters logically linked to the users' status group, filter of municipality (includes permanent and temporary residences), selection of an observed time period and further filtering of users by various dates. On a relevant user level, it is possible to edit, complete and delete data.

The Review tab gives an insight into the current situation in the field (completed visits and visits underway), including the review and edit of past visits and other tasks and the entering of new ones. Completed visits include information on the user, provider of LTC services, date of the visit, start/end and duration of the visit, types of performed LTC services, manner of entering the visit, type of LTC service, status of the visit, information on notes and the user's signature. The recording of other tasks, which are part of the employees' work obligations, is also possible.

The List of Employees is also formed within the application. By registering in the database, an employee receives an identification number by means of which they are featured without their name in reports, statistics and exports. In addition to basic data, the list also includes contact data, data on education, profession, workplace, level of access to data, daily work obligations and other data. When recording visits and tasks, the application also enables the calculation of an employee's work. When entering rates of salaries, allowances, benefits and sick leave, a summary table with all employees is available with accounting data for further processing by the accounting service.

Under the Statistics tab, the application supports three sets: a) Logs (monthly log of care of an individual user, total in a selected period – total of all users, total in a selected period – all providers), b) Report for the Ministry of Health (semi-annual reporting from pilot environments), and c) Data for evaluation (exports of data on users, employees, visits, tasks and messages on work organisation). All three sets were updated according during the project as per the needs of the pilot environment, the Contracting Authority and assessors.

## The OSKRBA MOBILE mobile application

The OSKRBA MOBILE mobile application is intended for long-term care providers for electronic recording of completed long-term care services and other tasks. The application has the following modules: a) *Reports*, which enables the recording of visits and tasks through the NFC sticker or a manual entry (user's name and surname, date of visit, start, end and duration of the service conducted, option for recording the delivery of lunch, entering of possible notes and observations and the user's signature, daily review of conducted visits and tasks in the current month), b) *Calculations*, which displays total time of conducted visits, tasks and kilometres

in the current month displayed by users, days and individual tasks, c) *Employee accounts*, which enables a review of the work done by the employee – option for a review of calculation for the last two months, d) *Code lists*, which include several codes: codes of users (surname and name, registration number, address and phone number, contacts of related persons, agreed long-term care services, frequency of signing, date and assessment category, whether the user uses e-care and date of the start of inclusion and completion), codes of employees (enables making of phone calls directly from the mobile application without exiting it while the provider is making a visit), codes of services (displays a list of services of long-term care with information on required minimum education, environment of implementation, name and description of service, restrictions and exclusion between services), codes of tasks (all tasks used by a certain organisation are displayed), e) *Retroactive signing*, f) *Observations*, g) *Work organisation*, and h) *Synchronisation* (enables the transmission of new data or changes from a remote server to and from the mobile application and mobile application updates).

## Discussion with key messages

Experience obtained by the software company during the development of the information system reveals a difference in understanding the applicability of the information system in individual pilot environments. The Krško pilot environment was thus consistently very interested in the development and suitable content of the software tool and, as a result, it intensively cooperated with the provider, while the remaining two environments usually followed the development passively and accepted new functionalities of the information system. On the one hand, this made the provider's work easier because they only followed the requirements of one environment and the development of the information system was

subsequently uniform and completely identical for all three environments. On the other hand, the system may have only represented a necessity and obligation for the passive environments, thereby failing to encourage in those environments a consideration of the possibility of using the system for their own needs and possible further analyses.

During the pilot projects, we determined that some data on the applicants regarding their enforcing the right to long-term care was not entered in the information system until the end of the project or certain data on individual applicants was missing. This points to the fact that the control of data entry into the information system was deficient. Deficiencies were also revealed in the inconsistent completion of the Application for enforcing the right to long-term care or the form for the Eligibility assessment for long-term care or inconsistent entering of data into the information system, i.e. certain important pieces of information were not entered: level of education (18.1%), income (23.9%), number of people in the household (5.3%), marital status (6.8%), housing situation (27.2%), year of birth (4.3%), reasons for needing long-term care (12.2%) and the type of care the applicant chose (57.6%). The reason for the insufficient completion of the application under certain variables was that the applicant was already receiving institutional care, and the resultant application was thus not considered incomplete as the desired data was simply not selected.

At the end of the project, we can assert that the activities within the implementation of the pilot projects were recorded and entered accordingly. The reason why certain data was not captured could be attributed to the time lag regarding the data obtained and the option to record it in the information system. Reasons could also be sought in insufficient supervision of a complete capture of required data in an individual application and the supervision of the entry of acquired data in the electronic database by pilot project providers.

To ensure optimal data monitoring and documenting, the software company carried out a series of training sessions for individual pilot environments concerning the application of the software tool and separate sessions for individual users. Training sessions for five persons at the single entry point (2 hours), two coordinators (3 hours) and 14 long-term care providers (4 hours) were implemented for the Dravograd pilot environment. Training sessions for seven persons at the single entry point (2 hours), two coordinators (3 hours) and 15 long-term care providers (4 hours) were implemented for the Celje pilot environment. Training sessions for four persons at the single entry point of the Krško pilot environment took place by e-mail. Sessions were also carried out for one coordinator (3 hours) and eight long-term care providers (3 hours). Instructions for the use of both applications were also produced.

As mentioned above, a simultaneous development of the information system enabled the evaluation of the second indicator, i.e. a time lag from the acquisition to the entering of obtained information in the information system.

Information regarding the installation of the system in pilot environments and the start of application of individual modules is scarce; all three environments were enabled simultaneous access to new functionalities of the information system and the software company did not specify when application users in the individual pilot environments should have actually started using the individual modules. Their experience reveals significant differences between providers in individual environments regarding the entry and application of the system. They further added that the Krško pilot environment was the first to start using the system to the largest possible extent. In the Dravograd pilot environment, the recording of activities by means of manual entries lasted in certain cases until the end of the project.<sup>96</sup>

96 Two further added services were managed manually in the Dravograd pilot environment (music therapy and delivering food to the users involved in the project – the Municipality of Ravne in cooperation with a Lions Club). They obtained the consent of the Ministry of Health for the services agreed on and implemented separately, which were a particularity of the pilot environment, while other LTC services were entered in the information system.

**Table 1: Description of milestones in the development of individual modules and additional application possibilities in the Oskrba Online application**

| Date of establishment | Tab                                                                           | What                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|-----------------------|-------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| January 2019          | First functionalities and launching of the application                        | Creation of a database or a list of users with personal records is enabled<br>Creation of a database or a list of employees is enabled<br>Employee accounts can be monitored<br>Enabled entry of conducted visits and tasks; enabled preparation of Reports/Calculations/Extracts on conducted visits and work done by providers and users                                                                                                                                                                                              |
| 21 February 2019      | Users                                                                         | Option for entering assessment results, assessment date, eligibility for assessment, long-term care category and marking of an e-care use                                                                                                                                                                                                                                                                                                                                                                                               |
| 21 February 2019      | Employees                                                                     | The levels of a single entry point and a long-term care coordinator are activated<br>Profession of a registered nurse is added<br>Determining care units and independence maintenance units at the level of a provider                                                                                                                                                                                                                                                                                                                  |
| 21 February 2019      | Statistics                                                                    | Report for the Ministry of Health may be generated                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| 22 March 2019         | Users                                                                         | Related persons tab is added to the personal record                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| 22 March 2019         | Employees:<br>Levels of a single entry point and a long-term care coordinator | Expansion of rights to work at the level of a single entry point: entry of a new user, editing of the entry, deleting and completing of a user's personal record is enabled<br>Editing of the user's personal record is also enabled at the level of the long-term care coordinator                                                                                                                                                                                                                                                     |
| 22 March 2019         | Lists of Users and Employees                                                  | Display of registration numbers of employees and users (data on/off) is enabled – Manager, project coordinator and long-term care coordinators see identification numbers of all employees, while the providers see only their own identification numbers                                                                                                                                                                                                                                                                               |
| 26 March 2019         | Users                                                                         | Under the "Statistics Data" tag in the personal record, it is possible to tag a user who is already using home assistance services                                                                                                                                                                                                                                                                                                                                                                                                      |
| 28 May 2019           | Users                                                                         | The Observations tab is added, which enables the generation of new ones and reviewing of observations by date levels<br>The system for tracking more than two assessments is introduced in the personal record                                                                                                                                                                                                                                                                                                                          |
| 7 June 2019           | Users                                                                         | Various search and classification filters are activated on the List of Users                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| 13 June 2019          | Printing                                                                      | Printing directly from the browser is enabled: from the user's personal record, the List of Users, the List of Employees, the Employee accounts, review of visits and tasks                                                                                                                                                                                                                                                                                                                                                             |
| 20 June 2019          | Users                                                                         | A separate Assessment tab was added in the personal record by entering:<br>- first assessments (all three categories)<br>- repeated assessments (all three categories)<br>- in the "LTC category", the programme automatically selects the highest category among the assessments of module 4 and module 5 as per the NBA assessment tool<br>- under the selected "special provision", all three assessments change into the highest<br>All observed statistical items are added under the "Statistics Data" tag in the personal record |
| 20 July 2019          | Users                                                                         | Multi-level filters and "Quick information" with the option of displaying the assessor's name, number of performed assessments, display of a warning regarding a required regular repeated assessment are added on the List of Users                                                                                                                                                                                                                                                                                                    |
| 25 July 2019          | Review of visits                                                              | Display of a total sum of services carried out by types of services and care units or independence maintenance units is enabled under the Review of visits                                                                                                                                                                                                                                                                                                                                                                              |

| Date of establishment | Tab                | What                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|-----------------------|--------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 29 July 2019          | Statistics         | <p>Several logs are added under the Logs tab:</p> <ul style="list-style-type: none"> <li>- Monthly log of user's care in the PDF format (review of services implemented within care units or independence maintenance units)</li> <li>- Monthly log of user's care in the XLSX format (detailed breakdown by services, by units)</li> <li>- Calculations for selected periods (total of all users) in the PDF format displays visits conducted by workdays, Sundays and holidays. In the XLSX format, visits by services and units are further displayed.</li> </ul> |
| 29 July 2019          | Users              | Activation of the Use of hours: enables the monitoring of the use of hours from the fund by users Option of switching between annual (independence maintenance unit) and monthly (unit for care) use of hours                                                                                                                                                                                                                                                                                                                                                        |
| 2 August 2019         | User/assessment    | <p>Added dates:</p> <p>FIRST ASSESSMENT (application date, date of visit without an assessment (reason), date of visit, date of assessment drafting, date of letter)</p> <p>REPEATED ASSESSMENT (date of visit, date of assessment drafting, date of letter)</p>                                                                                                                                                                                                                                                                                                     |
| 1 August 2019         | Users              | <p>Users' personal records enable:</p> <ul style="list-style-type: none"> <li>- Entry of another phone number</li> <li>- Selection of more than one reason for the need of long-term care</li> <li>- Selection of gender when PIN is not entered</li> <li>- Renaming certain fields</li> <li>- Added option of Care category 0</li> <li>- Introduction of quick information (badges) in the header of the personal record ("User of HH", "Eligible for LTC", "User of e-care", etc.)</li> </ul>                                                                      |
| 1 August 2019         | Single entry point | The SEP level is enabled access to necessary Statistics and Logs                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| 1 August 2019         | Statistics         | Added log Calculations for selected period by providers in PDF and XLSX formats                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| 5 August 2019         | Statistics         | Export of data for evaluation by the IRSSV is enabled. It may be accessed by the levels manager, project coordinator, long-term care coordinator and single entry point.                                                                                                                                                                                                                                                                                                                                                                                             |
| 7 August 2019         | Single entry point | <p>From the single entry point, it is possible to:</p> <ul style="list-style-type: none"> <li>- enter one's Tasks</li> <li>- generate and edit Observations</li> </ul> <p>All levels can enter past observations.</p>                                                                                                                                                                                                                                                                                                                                                |
| 14 August 2019        | Assessment tool    | <p>Incorporation of the NBA assessment tool in user's personal record under the Assessment tab:</p> <ul style="list-style-type: none"> <li>- all assessment modules are included</li> <li>- calculation of the NBA assessment of module 4 and module 5</li> <li>- extract of Report on eligibility assessment</li> <li>- extract of Application</li> </ul>                                                                                                                                                                                                           |
| 19 August 2019        | Assessment tool    | <p>Updates and improvements when working in the assessment tool:</p> <ul style="list-style-type: none"> <li>- "living circumstances" may be entered subsequently when editing assessment</li> <li>- Free switching between modules is enabled until the assessment completion</li> </ul>                                                                                                                                                                                                                                                                             |
| 21 August 2019        | Assessment tool    | <ul style="list-style-type: none"> <li>- Subsequent entry/edit of replies with mandatory entry of a reason for changing replies is enabled</li> <li>- Preparation of a significant number of repeated assessments is supported</li> </ul>                                                                                                                                                                                                                                                                                                                            |

| Date of establishment | Tab                           | What                                                                                                                                                                                                                                                                                                                                                                                               |
|-----------------------|-------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 22 August 2019        | Statistics                    | Added under the Exports tab, which enables exports of data on: <ul style="list-style-type: none"> <li>- Users (personal data, related persons, observations)</li> <li>- Employees</li> <li>- Visits</li> <li>- Tasks</li> <li>- Messages on Work organisation</li> </ul> Access to Exports is enabled to levels manager, project coordinator and long-term care coordinator.                       |
| 22 August 2019        | Users                         | The "Personal plan" tag is added in the user's personal record with functions for adding, editing and deleting the plan. Preparation of the Personal plan report is enabled.                                                                                                                                                                                                                       |
| 29 August 2019        | Users                         | <ul style="list-style-type: none"> <li>- Added fields in the personal field</li> <li>- In addition to the assessment date, the List of Users also includes a category of long-term care (quick info)</li> <li>- Added reason for concluding "Personal assistant"</li> </ul>                                                                                                                        |
| 6 September 2019      | Statistics                    | Supplement to the Report for evaluation of IRSSV Document with three tabs <ul style="list-style-type: none"> <li>- Data from the table template</li> <li>- Applicants (the "year of birth" column is added at the request of IRSSV)</li> <li>- Living circumstances</li> </ul>                                                                                                                     |
| 11 September 2019     | Assessment                    | A selection of two assessors is enabled in the assessment tool.                                                                                                                                                                                                                                                                                                                                    |
| 1 October 2019        | Users                         | In the List of Users, the levels of manager, project coordinator and long-term care coordinator can obtain the list of informal providers.                                                                                                                                                                                                                                                         |
| 1 October 2019        | Independence maintenance unit | Access to the latest assessment permitted                                                                                                                                                                                                                                                                                                                                                          |
| 1 October 2019        | Assessment                    | When editing and viewing the implemented assessment, it is possible to freely switch between steps.                                                                                                                                                                                                                                                                                                |
| 1 October 2019        | Users                         | User's personal record: a list of personal plans is a table with expandable rows in which short-term, long-term and other objectives are added; it is also possible to add other data which may be viewed without entering the personal plan form.                                                                                                                                                 |
| 5 November 2019       | Users                         | In the personal record, it is also possible to edit Related persons for Inactive users. In the most modules, the assessment scale receives a questionnaire in the form of a survey matrix, questions are in alternating colours, the module title is bolder                                                                                                                                        |
| 6 November 2019       | Users                         | The Notes field for the long-term care coordinator is introduced under the Service tab of the personal record; these notes are entered and edited by the long-term care coordinator and are visible to the levels of manager, project coordinator and single entry point.                                                                                                                          |
| 18 November 2019      | Users                         | New additions on the List of Users: <ul style="list-style-type: none"> <li>- new filters classifying the range of those who were not assessed to those waiting, those waiting with a signature, those waiting without a signature, visits with no assessment</li> <li>- new column for the care category</li> <li>- the Address column enables filtering by permanent/temporary address</li> </ul> |
| 21 November 2019      | Users                         | Annex to a personal plan may be drafted                                                                                                                                                                                                                                                                                                                                                            |
| 5 December 2019       | Users                         | The Records of interviews tab is enabled in the personal record.                                                                                                                                                                                                                                                                                                                                   |
| 9 December 2019       | Users                         | Functionality for collecting and returning keys is added.                                                                                                                                                                                                                                                                                                                                          |



| Date of establishment | Tab                 | What                                                                                                                                                                                                                                                                                                              |
|-----------------------|---------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 16 December 2019      | Users               | Numbering of contact persons by priority order is enabled in the Related persons tab in the user's personal record.                                                                                                                                                                                               |
| 19 December 2019      | Statistics          | Export of personal plans with annexes is enabled                                                                                                                                                                                                                                                                  |
| 20 December 2019      | Users               | All levels can access and review the Use of hours                                                                                                                                                                                                                                                                 |
| 20 December 2019      | Statistics          | All users and employees, including providers within the independence maintenance unit, can access the Monthly calculations log                                                                                                                                                                                    |
| 10 January 2020       | Users               | Under the Assessment tab in the personal record, the proportions of long-term care modules are displayed graphically.                                                                                                                                                                                             |
| 13 January 2020       | Users               | WARNING and FILTER for "Six months has passed since the last repeated assessment" were added on the List of Users.                                                                                                                                                                                                |
| 15 January 2020       | Statistics          | Report for the Ministry of Health: new Date of reporting field is introduced. The "number of users" field in the report is linked to the date of reporting.                                                                                                                                                       |
| 27 January 2020       | Users               | Two fields to be completed, i.e. Telemedicine (has/does not have) and Smartwatch (has/does not have), are added under the Service tab in the personal record. Ticked field ("has") appears in the form of a badge in the header of the personal record. The fields also appear among the filters of active users. |
| 27 January 2020       | Service code        | A location can also be determined for a service (which is observed in the Employees' accounts).                                                                                                                                                                                                                   |
| 17 February 2020      | Statistics          | New Report for the Ministry of Health with five tabs is available.                                                                                                                                                                                                                                                |
| 2 March 2020          | Users               | Personal record:<br>- Deletion of a selected answer in matrix questions is enabled in the assessment tool<br>- Assessment tag: it is not necessary to enter the assessment tool to review and edit "living circumstances"                                                                                         |
| 17 March 2020         | Documents           | New module which consists of generated reports, documents, logs, applications, etc.                                                                                                                                                                                                                               |
| 25 March 2020         | Review of visits    | Entry of visit cancellation for a longer period is enabled                                                                                                                                                                                                                                                        |
| 27 March 2020         | Review of tasks     | Recording of extraordinary absences is enabled<br>- Covid-19 – furlough<br>- Covid-19 – childcare                                                                                                                                                                                                                 |
| 29 May 2020           | Recording of visits | Entry of duration for each selected service is enabled                                                                                                                                                                                                                                                            |
| 29 June 2020          | Users               | Attachments tab is added in personal record with the option of adding PDF documents                                                                                                                                                                                                                               |
| 10 September 2020     |                     | Speeding up functioning of the application when opening the user's personal record                                                                                                                                                                                                                                |
| 8 October 2020        | Users               | The Assessments sub-tab is activated with a list of all conducted First and Repeated assessments Different sorting and filtering is enabled Data regarding total calculations based on filtered data is added                                                                                                     |
| 19 October 2020       | Review of tasks     | Recording of extraordinary absences is enabled<br>- Covid-19 – quarantine                                                                                                                                                                                                                                         |

Due to the ongoing development of the information system and the activities being carried out in individual environments, time lags between the data being obtained and it being entered into the information system were evident. The data already obtained was entered into the system in the pilot environments (i.e. retrospectively). An example of this is the assessment tool which, by means of its incorporation into the system, enables among other things an automatic calculation of the eligibility category. As a result, the software company added the option of importing the eligibility assessments already prepared in Excel so that the assessment forms drafted in individual pilot environments were gradually incorporated into the system; such an option would not have been required when preparing information solutions before the start of project implementation.

The information system developed within the pilot projects covers databases which will be of key importance in the long-term care system. The developed software includes a web application accessible anywhere and fully adjusted to the work in long-term care; it is thus not an adaptation of a general application which could also be used for long-term care. All functionalities were developed specifically for the long-term care application, and the entire system was verified and established in practice.

Due to the need for analyses that would enable higher quality decision-making by competent decision-makers regarding long-term

care, it is necessary to add data collected when carrying out the eligibility assessment with the new assessment tool to the records mentioned in the act on long-term care. On the other hand, certain records as per the selection required by law are missing and will have to be added before transitioning to the new long-term care system: a) internal control system (indicators of quality and safety, adverse events and those that could have occurred when implementing services and persons responsible for work processes at contractors) and b) records on the occupancy of capacities and number of reservations.

From the very start of the development, application and upgrading of individual modules, which may represent one of the significant sections of the new integrated long-term care information system, the Contracting Authority, i.e. the Ministry of Health, should have been actively involved in the supervision of system operation and application. Unfortunately, it was not planned that the Contracting Authority would be able to access data. Similarly, the fate of the information system developed within the pilot projects after the completion of those projects was not planned. Six months after the completion of the pilot projects, the software company will cease maintenance of the system. It would be regrettable if a system developed specifically for use in the long-term care system and which has also been verified in practice was simply dismissed as it represents a suitable foundation for the development of a long-term care information system in Slovenia.

## BIBLIOGRAPHY

- Kushniruk, A.W., & Borycki, E.M. (2017). *Usability of Healthcare Information Technology: Barrier to the Exchange of Health Information in the Two-Sided EHealth Market?*. V Vimarlund, E. (ed.). *E-Health and Two-Sided Markets*. Academic Press London, 33–41.
- Krick, T., Huter, K., Domhoff, D., Schmidt, A., Rothgang, H. & Wolf-Ostermann, K. (2019). *Digital technology and nursing care: a scoping review on acceptance, effectiveness and efficiency studies of informal and formal care technologies*. *BMC Health Serv Res.*, 19:400.
- Scirocco exchange, Maturity model. (2021). Retrieved from <https://www.sciroccoexchange.com/digital-infrastructure>
- Ministrstvo za zdravje. (2018). Javni razpis »Izvedba pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi«. Retrieved from <https://www.uradni-list.si/glasilo-uradni-list-rs/vsebina/2018002400003/javni-razpis-za-izbor-operacij-izvedba-pilotnih-projektov-ki-bodo-podpirali-prehod-v-izvajanje-sistemskega-zakona-o-dolgotrajni-oskrbi-st-303-1201816-ob-198618>
- Aleja Soft d.o.o. (2019). *Dolgotrajna oskrba – Spletno orodje Oskrba Online v 1.0. Navodila za uporabo*. Interno gradivo Aleja soft d.o.o., Ljubljana.
- Aleja Soft d.o.o. (2019a). *Predstavitev programskega orodja Aleje soft*. Interno gradivo Aleja soft d.o.o., Ljubljana.

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**Long-term care – a challenge and an opportunity for a better tomorrow.  
Evaluation of pilot projects in the field of long-term care**

**Editors:** Mateja Nagode, Klavdija Kobal Straus

**Technical editors:** Aleš Istenič, Mojca Počič

**Reviewers:** doc. dr. Nikolaj Lipič and dr. med Mircha Poldrugovac

**Language review:** Translation and Interpretation Division,  
Secretariat-general of the Government of the Republic of Slovenia

**Design:** Kolektiv DVA Urška Bavčar s.p.

**Publisher:** Ministry of Health, Štefanova 5, 1000 Ljubljana

**Publishing year:** 2022

**Publication is available at:** <https://www.gov.si/drzavni-organi/ministrstva/ministrstvo-za-zdravje/o-ministrstvu/direktorat-za-razvoj-zdravstvenega-sistema/sektor-za-dolgotrajno-oskrbo/>

*Monograph was created as part of the Evaluation of Pilot Projects in the Field of Long-Term Care. The investment is co-financed by the Ministry of Health, the Republic of Slovenia and the European Union from the European Social Fund.*

*Supported by the EU Health Programme Co-funded project SCIROCCO Exchange as part of its Knowledge Transfer Programme.*

Kataložni zapis o publikaciji (CIP) pripravili v Narodni in univerzitetni knjižnici v Ljubljani

COBISS.SI-ID 101728003

ISBN 978-961-6523-80-6 (PDF)



INSTITUT RS ZA SOCIALNO VARSTVO



Co-funded by the European  
Union's Health Programme  
(2014-2020)

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