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

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

Brief summary

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REPUBLIC OF SLOVENIA
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Evaluacija pilotnih projektov s področja dolgotrajne oskrbe

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# 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 of time 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 challenfsupportges 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 own 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 actually 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. We are facing the challenge of adopting a systemic law in the field of long-term care.*

*A uniform systemic regulation of the field of long-term care in the Republic of Slovenia is necessary.*

*The solutions proposed in the Long-Term Care Act draft 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, enable the active role of beneficiaries, strengthen support for informal carers, strengthen conditions to link health, social care and long-term care systems with the aim of continuous and integrated care, 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 OF 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 COVID19 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.*

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

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# EVALUATION OF PILOT PROJECTS AND METHODOLOGY

The subject of the Evaluation of pilot projects in the field of long-term care (2019-2020) is the project *Implementation of Pilot Projects That Will Support the Transition to the Implementation of a Systemic Law on Long-term Care* (2018-2020), which included activities in three pilot environments selected in a public tender[1]. The contracting authority of the evaluation is the Ministry of Health.

In the summary we present some key findings and messages which are substantiated in depth and more extensively in the individual chapters of the final report *Evaluation of pilot projects in the field of long-term care*.

The external evaluation of the pilot projects was implemented 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. Depending on the content, the present evaluation is a process and outcome evaluation[2,3]. Simultaneously with the formative process evaluation, we also performed *programme monitoring*. We evaluated whether the planned pilot activities were proceeding as planned, following the indicators[4] from the public tender for the implementation of the evaluation[5]. In the entire monitoring and evaluation process, we prepared an initial, four process, an intermediate and a final (synthetic) report.

As part of the evaluation, we assessed several objectives at four research levels: the effectiveness of new methods, the effectiveness of procedures in pilot projects, the effects of pilot projects on people, and the preparation of substantive and financial projections for the long-term care system.

The pilot projects we monitored and evaluated were complex, an experimental research plan was not possible. The evaluation was based on a comparison of 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 users, informal carers and employees has changed. Due to the rationalisation of data collection and to avoid burdening respondents, we measured some effects of projects only at the end of the project (for example, what was the experience of users, employees and informal carers with pilot projects, what was the perceived usefulness of services, etc.). The net effects of the intervention were therefore not accurately measured, as causality could not be established. We were therefore careful in attributing the effects of the pilot projects. However, the used research plan provided an appropriate basis for ongoing, process guidance of pilot projects as well as for providing guidance to the contracting authority in finding system solutions.

We used mixed research methods to support the findings and provide valid results. The main source of data was quantitative, among which was mainly data from the information system used by the employees in the pilot projects in their work where they recorded the implemented activities. We also used and developed a number

1 Ministrstvo za zdravje. 2018. Javni razpis za izbiro operacij »Izvedba pilotnih projektov, ki bodo podpirali prehod v izvajanje sistemskega zakona o dolgotrajni oskrbi«. Uradni list RS, št. 24/2018 z dne 13. 4. 2018.
2 CDC. 2011. Developing an 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.
3 Kustec Lipicer, S. 2009. Vrednotenje javnih politik. Ljubljana: Fakulteta za družbene vede.
4 Annex I to tender documents
5 Ministrstvo za zdravje. 2018. Javno naročilo za Evalvacijo pilotnih projektov s področja dolgotrajne oskrbe. Available at: https://www.enarocanje.si/Obrazci/?id_obrazec=280003.

of questionnaires for different target groups (users, informal carers, employees in the pilot environment, important stakeholders in the local environment). As part of the qualitative approach, we developed and used various methods and techniques or qualitative instruments, such as interviews, focus groups, employee reports and personal plans of users. We also held a democratic forum with assessors, a method that is not as yet very well known and widespread in the Slovenian research area. By using mixed research methods, we added depth or width to the results of the predominant method.

Due to objective circumstances related to the public procurement procedure, we started to establish the methodology at the time when the pilot projects were already in progress, which is considered one of the weaknesses of the evaluation, as we missed the starting point in the pilot projects, which is from the aspect of monitoring changes a key point of observation. Ideally, the methodology should be established before the start of user involvement in the project, and employees in pilot projects should be intensively involved in this process. Specifically, employees are an important factor in the evaluation. The involvement of employees and their participation in the vast majority of evaluation activities was extremely important for the evaluation, as they provided the conditions for the implementation of various evaluation activities (e.g. meeting space), they surveyed users, completed surveys themselves and wrote reports, provided data, participated in interviews etc. In addition to the employees, an important factor in the evaluation was, of course, the users and their informal carers, with whom the evaluators and employees in the projects conducted several questionnaires and interviews. In addition to the above, we also acknowledge the involvement of the Ministry of Health in the role of the contracting authority of the evaluation and the European Centre for Social Welfare Policy and Research, which advised in the preparation of the research methodology.

## Objectives of evaluation

### EFFECTIVENESS OF NEW METHODS

▹ To assess the suitability and applicability of the selected assessment tool for assessing eligibility for long-term care (LTC).
▹ To prepare proposals for amendments for personal planning and coordination of services in LTC.
▹ To prepare proposals for amendments for team work in LTC.

### EFFECTIVENESS OF PROCEDURES IN PILOT PROJECTS

▹ To prepare proposals for amendments to the procedures for assessing the eligibility of LTC, including an assessment of the options for reducing bureaucratic burdens.
▹ To prepare proposals for amendments for entire LTC process, from entry to the provision of services.

### EFFECTS OF THE PILOT PROJECT ON PEOPLE

▹ To develop guidelines for the provision of services that will enable a quality life for informal carers.
▹ To develop guidelines for greater support for informal carers.
▹ To prepare guidelines for the quality working life of formal care providers.

### PREPARATION OF CONTENT AND FINANCIAL PROJECTIONS FOR THE LTC 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 LTC entry point.
▹ To prepare proposals for amendments related to the electronic management of procedures and services in the field of LTC.
▹ To prepare a possible projection of financial and human resources in the LTC system (with the provision of approprate input data).
▹ To prepare guidelines for the development of organisational forms of cooperation and networking in the field of LTC and with other areas that will support the transition to the community forms of care.

# KEY MESSAGES

▸ It is important that several different actors participate in the evaluation, each with its own specific role: the contracting authority of the evaluation and the project, the consultative body (e.g. professional, research), project implementers or employees, other important stakeholders from the local or national level, participants or users in projects and their relatives, etc. Working together and co-creating can provide better conditions and circumstances and thus better project results.
▸ The evaluation of pilot projects was based on mixed research methods (linking qualitative and quantitative methods), which requires more research effort, but at the same time gives greater validity to the results. It also provides a rich set of different types of data that can be processed and displayed in various ways even after the end 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 in such projects, and we recommend it for use and testing in the future.
▸ It is important to start planning evaluation at the right moment: when setting up the model that is the subject of the evaluation, and in any case before starting the intervention.

# PILOT ENVIRONMENTS AND PROJECT ESTABLISHMENT

Public tender *Implementation of Pilot Projects That Will Support the Transition of the Implementation of the Systemic Law on Long-term Care (2018-2020)* has identified five key objectives:
▹ testing tools and procedures for assessing eligibility for long-term care (application, assessment scale, personal and implementation plans, informing the target public);
▹ testing new services and integrated treatment of the user in the home environment;
▹ testing new services and support mechanisms for providers of informal and formal care for the implementation of quality and safe treatment;
▹ testing coordination mechanisms and establishing effective coordination between social and health care providers and newly established entry points with the aim of providing an integrated service to the user;
▹ testing electronic documentation of procedures from the assessment of eligibility to recording the provision of services.

These objectives were pursued by three pilot projects selected through a public tender, which were also the subject of evaluation:
1. ***Establishment of systemic implementation of long-term care in the Celje region***, which was managed by the Celje Health Care Centre and took place in an urban environment;
2. ***Centre for integrated community long-term care services Koroška*** with the leading partner Residential Home for the Elderly Koroška in the semi-rural area; and
3. ***Integrated care in the municipality of Krško MOST***, managed by the Centre for Social Work Posavje, unit Krško, which represented the rural environment in the project.

**Long-term care pilot projects and project leading partners**

**CELJE**
*urban environment*

Establishment of systemic implementation of long-term care in the Celje region
—
ZD Celje

**DRAVOGRAD**
*semi-rural environment*

Koroška Centre for Integrated community long-term care services
—
KDS Dravograd

**KRŠKO**
*rural environment*

Integrated care in the municipality of Krško MOST
—
CSD Posavje, Krško unit

## The social context of pilot project environments

The pilot projects took place in environments with different social contexts in terms of geographical characteristics, population structure and population density, educational infrastructure and education of the population, state and local economy, accessibility of housing and also in terms of accessibility to services[6]. Thus, some pilot environments are less populated than others, mainly due to natural-geographical as well as socio-geographical characteristics, which provides important information for the organisation of long-term care services (e.g. especially from the aspect of organising and providing care at home). On average, in pilot environments, inhabitants receive salaries that are lower than the Slovenian average, and they mostly commute to work outside their place of residence. In all three statistical regions where the pilot projects took place, the unemployment rate is slightly higher than the national average, more people die from cardiovascular diseases, and there are more suicides. The latter indicates some health as well as social needs of the population of the pilot environments. It is also important to demonstrate the existing long-term care services in pilot environments and to assess their starting point in developing these services. With a better starting position, more established processes and greater coordination of contractors, it is easier to organise a project. The data show 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. The municipalities stand out due to their high proportion of both adults and older adults involved in home help, while Celje also stands out due to a lower average price of the service and a higher average proportion of co-financing from the municipality. 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 municipality of Krško 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.

## Establishment and organisation of pilot projects

The pilot projects were implemented in areas of different sizes, which was also a precondition for the public tender, which dictated differentiation in accordance with the degree of urbanisation of the environment. The pilot environments organised and established different organisational and operational structures and thus differed in terms of the number of project partners, the type of the leading partner (health centre, care home or social work centre) and the size of the pilot environment in terms of the number of involved municipalities (from one to four). Thus, in the urban pilot environment of Celje, the pilot project was led by a health care centre, in the semi-rural pilot environment of Dravograd by a care home and in the rural pilot environment of Krško by a centre for social work. As expected, the number of municipalities in which pilot projects were implemented was the largest in the urban environment (four municipalities) and the smallest in the rural environment (one municipality). The leading organisations of the

6 More in: Nagode, M., Črnak Meglič A., Dremelj, P., Istenič, A., Lebar, L., Rafaelič, A., Kobal Tomc, B. 2019. Evalvacija pilotnih projektov s področja dolgotrajne oskrbe. Začetno poročilo. Ljubljana: Inštitut RS za socialno varstvo.

pilot projects were those that in the existing system of long-term care operate within the health or social sector and provide various services – community nursing, institutional care and home help. Inversely proportional to the size and urbanisation of the environments, there were large "core teams" or pilot project motors in the pilot environments, as most consortium partners were situated in the rural pilot environment (five) and the least in the urban (three). In addition, the composition of the teams was heterogeneous. All pilot environments had a health care centre, a care home and a centre for social work in the core team, which is crucial from the aspect of providing integrated treatment, as they include organisations from the health and social sector. In addition, the teams in the rural and semi-rural environments also included a general hospital and a home help provider within the public service network. The absence of a home help provider in an urban environment was an obstacle for the implementation of pilot activities, especially from the aspect of work organisation and integrated provision of health and social care services. In the urban environment, the consortium specifically included an institution that provided social assistance to various population groups, in the semi-rural it included an intergenerational centre, and in the rural environment it included an occupational activity centre and a municipality. When testing various tools, methods, services, documentation, integrated treatment, etc. such heterogeneity in providers and services across different environments was important, as these differences may imply different outcomes and thus different solutions for the future long-term care system.

In the starting point, it was important to establish a single entry point in the project environments and to employ appropriate staff. Thereby, all environments faced certain challenges. For example, it happened that in Krško, due to objective reasons, they failed to establish single entry point by the scheduled date (1 February 2019), as it was placed in new premises and this process was longer than in the other two environments. In addition, in Krško, the team for activities of daily living and instrumental activities of daily living initially employed four professionals instead of the planned seven (they did not employ a nursing carer and social carer), as they already have well-developed[7] home help and did not need additional social carers. The biggest staffing challenges were faced in Celje, where during a significant part of the entire project they did not employ an adequate number of professionals (both at the single entry point and in the integrated care team), although the staffing needs were very high. They also had problems with employment in Dravograd, where they employed a sufficient number of professionals, but did not manage to employ a nurse among the profiles. They also failed to employ all the different profiles of assessors at the single entry point, even though they wanted to; a graduate occupational therapist and a graduate physiotherapist were missing. By the scheduled date, a long-term care coordinator was employed in all environments.

In addition to problems with the employment of suitable staff, especially in Celje, they also faced numerous terminations of employment or long-term absences due to illness or maternity leave. During the project, 25 employees terminated their employment, and another six were absent for a considerable period. In Dravograd, four employees stopped working on the project, and three were absent for a considerable period. In Krško, only the long-term care coordinator stopped working on the project. It should be noted that a larger number of employees (24) was envisaged in Celje than in the other two environments (17), so that a slightly higher fluctuation is expected to some extent, however, the proportion of employees who stopped working is significantly higher there than in the other two environments.

7 Nagode, M., Črnak Meglič A., Dremelj, P., Istenič, A., Lebar, L., Rafaelič, A., Kobal Tomc, B. 2019. Evalvacija pilotnih projektov s področja dolgotrajne oskrbe. Začetno poročilo. Ljubljana: Inštitut RS za socialno varstvo.

## Impact of different circumstances on the course of pilot projects

From mid-March 2020, project activities in the pilot environments were also strongly influenced by the situation related to the COVID-19 epidemic. Home services were temporarily provided only to users who desperately needed them and could not be provided by their relatives. There were not many such people, as many relatives stayed at home, either because of furlough or they were performing work from home and were thus able to provide assistance. Most of the employees in the projects also worked temporarily from home, and mostly employees from the care unit were active in the field. Assessors performed only emergency eligibility assessments in the field, and all environments provided support to users by telephone. There were no meetings between the project employees at that time, instead they communicated by phone and e-mail. Supervisions and training both for employees and informal carers were cancelled. A major problem in the environments was the lack of protective equipment and unclear instructions and protocols for operation. The situation began to calm down in May 2020, when environments began to re-establish the system of operation as it was before the epidemic, albeit subject to certain restrictions and measures to prevent the spread of infection.

The second wave of the epidemic then followed in the autumn. The epidemic was re-declared on 18 October 2020 and lasted until the end of the implementation of projects in Krško and Celje. According to the original plan, the projects should have ended on 30 June 2020, but (in agreement with the contracting authority) it was extended in Dravograd until 30 September 2020 and in Celje and Krško until 31 December 2020.

Through a public tender, the contracting authority determined the "model" (content and activities) of the pilot projects, but because it could not foresee in advance all the circumstances in which the pilot projects were implemented, the pilot environments adapted some activities to existing conditions, upgraded them or implemented them within different time frames. The characteristic of pilot projects in general is that they enable adaptation to the circumstances in which they take place, as testing something new is inevitably associated with unpredictable situations. In fact, pilot projects are intended to research and create new paths, solutions, and answers. And it is this flexibility that poses a challenge for evaluation, which must constantly reinvent ways and approaches adapted to new circumstances. In the case of the evaluation of pilot projects, the COVID-19 epidemic most affected the change and adaptation of measurement instruments and the methods of their implementation.

In projects where pilot activities have a direct impact on people's lives, in addition to discovering new solutions, it is also important that they do not worsen the situation of the people involved. In the challenges of adapting pilot activities and dealing with unforeseen situations (e.g. the COVID19 epidemic), a wider expert group (e.g. a project steering or advisory group or a national long-term care project council[8]) could play an important role in monitoring the course of pilot projects and provide expert bases and proposals for solutions

8 In preparation for pilot projects in the field of long-term care, the establishment of a national long-term care project council was planned, consisting of Ministry of Health, Health Insurance Institute of Slovenia, Pension and Disability Insurance Institute of Slovenia, Ministry of Work, Family, Social Affairs and Equal Opportunities, Association of Municipalities and towns of Slovenia, Slovenian Federation of Pensioners Associations, a representative of the local project council, and project leaders from pilot environments.

# KEY MESSAGES

▸ Pilot projects are intended to test the set solutions and create new answers, paths and good practices. As such interventions are demanding, innovative and complex, we recommend that as many different actors as possible relevant to the field undergoing testing be involved in the expert guidance. In this case, in addition to Ministry of Health and representatives of pilot projects, at least Health Insurance Institute of Slovenia, Pension and Disability Insurance Institute of Slovenia, Ministry of Work, Family, Social Affairs and Equal Opportunities, municipalities, etc.
▸ The pilot projects were implemented in different types of environments (urban, semi-rural and rural environment), with different social contexts and work organisation: the leading project partners differed depending on the type of organisation (health care centre, centre for social work and care home); consortia were also composed differently. The pilot projects thus provided insight into different structures and modes of operation and the organisation of long-term care in different environments and circumstances.
▸ The establishment of pilot projects and all planned structures and teams drew attention to the already known problem of staff shortages in the field of long-term care and provided insight into the challenges we will face in Slovenia in the future. All environments, some more and others less, had difficulties in recruitment, as some employment profiles were more difficult to employ or did not exist at all (e.g. nursing assistant, master of kinesiology). It will be necessary to make the care professions attractive.
▸ A particular challenge for the pilot projects was staff fluctuation, which was also due to the limited implementation time of the project and thus the inability to maintain the sustainability of employment.
▸ The course of the evaluation was influenced both by 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 our current experience in evaluating pilot projects, we conclude that significantly more time should be devoted to the final phase of the evaluation, especially to the final data harmonisation and data analysis and report preparation.

# EFFECTIVENESS OF LONG-TERM CARE METHODS AND TOOLS

A key element of the pilot projects were the methods and tools of long-term care, which were tested by the employees of the pilot projects and were defined in two objectives by the public tender for pilot environments: the first, *"testing tools and procedures for assessing eligibility for long-term care (application, assessment scale, personal and implementation plans, informing the target public)"*, and the fourth, *"testing coordination mechanisms and establishing effective coordination between social and health care providers and newly established entry points with the aim of providing an integrated service for the user"*. As part of the evaluation, we paid special attention to the eligibility assessment techniques and the methods of personal planning and coordination of services and teamwork.

## Eligibility assessment

A total of 2,031 applications were recorded in all pilot projects. As expected, most were in the urban environment of Celje (899), then in the semi-rural environment of Dravograd (631), and the least applications were received in the smallest, rural environment of Krško (501). Less than half (41.1%) of the applications were submitted by persons living in institutional care, with the proportion being the lowest in Krško (22.8%) and significantly higher in Celje (50.3%) and Dravograd (42.5 %).

The assessors made an eligibility assessment for the vast majority of all applicants (1972 or 97.1%): in Celje 885, in Dravograd 612 and in Krško 475. The pilot environments thus met and concretely exceeded the criterion of the public tender to evaluate at least 600 (Celje) or 300 (Dravograd, Krško) persons with the new eligibility assessment tool.

Of all those assessed, 81.1% or 1,599 persons were eligible for pilot project services. The proportion of eligible persons was the lowest in Dravograd (76.1%), while in Krško it was 82.1% and in Celje 84%. Of all beneficiaries living at home, 61.2% were involved in pilot project services. The proportion of service recipients among beneficiaries varies markedly between environments. It is the lowest in Celje (47.1 %), followed by Dravograd with 65.7%, and the highest proportion of eligible services was included in the care of the pilot environment Krško (76.1%). We can therefore observe a significant gap between the number of beneficiaries and recipients of services, which is the result of various factors, which are contextualised in more detail in the continuation of the summary in various chapters.

If we focus on the assessment of eligibility, according to the final results of the assessment, we find that in accordance with the scoring method adopted from the German assessment model (NBA-original)[9], which does not include the modules "course of everyday life and social contacts" and "ability to perform household chores in the environment where the person resides", more than 76% of the assessed persons are eligible for long-term care services. According to both proposed versions of scoring for Slovenia, approximately 80% would be eligible for long-term care services. We estimate that the modifications of the modules, as shown in the following table, are appropriate and we suggest their continued use.

9 Learn more about the eligibility assessment tool in: 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.

The analysis of the identified categories of eligibility for care with the new assessment tool for residents of the care homes and the assigned categories of care in accordance with the translation table from Article 157 (Item 3) of the Draft Long-Term Care Act from 2020 revealed large differences and thus showed the necessity that consideration also be given to implementing an eligibility assessment for those living in institutional care. Of course, this also raises the question of the adequacy of the current care categorisation regime, which has not been the subject of this evaluation.

According to the assessors, the assessment tool covers all areas relevant to the eligibility assessment, but they also emphasise the need to maintain the seventh and eighth modules of the assessment form.

It has also been demonstrated by an explanatory model of factors influencing the categorisation of eligibility that the assessment tool is generally suitable for assessing eligibility. Thus, we did not find statistically significant differences in the probability of ranking in a higher category according to gender and expected significant differences according to age, education, receiving assistance and attendance allowance, living in an institutional environment or receiving some form of long-term care, reasons reflecting more specific problems (compared to age-related weakness). The analysis results showed that in people living in a semi-rural or rural environment, the probability of being placed in a higher category of care is on average not statistically significantly different from the probability in an urban environment.

In order to ensure the appropriate quality of assessment and also to provide appropriate profiles in the employment of new staff who will implement the eligibility assessment in the new long-term care system, it was necessary to determine whether the different profiles of the assessors in the pilot projects assessed individual applicants differently and therefore the assessments were also a consequence of the

**Eligibility assessment scoring variants (proportion of total assessment)**

| | NBA - original | REDUCED M4 | REDUCED M5 |
|---|---|---|---|
| **M1** Mobility | 10 % | 10 % | 10 % |
| **M2+M3** Cognitive and communication abilities + Behaviour and mental health | 15 % | 15 % | 15 % |
| **M4** Self-care | 40 % | 35 % | 40 % |
| **M5** Ability to deal with illness-/ therapy-related demands and burden | 20 % | 20 % | 15 % |
| **M6+M7** Managing everyday life and social contacts+ Activities outside the house | 15 % (only M6) | 10 % | 10 % |
| **M8** Household maintenance | 0 % | 10 % | 10 % |

profile of the assessor. The obtained results did not confirm statistically significant differences. At the democratic forum, the assessors also agreed that the educational profile of the assessor can be in the field of both health and social care, but it is desirable that one or the other profile has the pre-education or additional education of the other profile. They also agreed that it was important for the team of assessors at the single entry points to be as heterogeneous as possible with regard to the education of the assessors.

The concept of eligibility assessment used in the pilot projects is based on a changed paradigm in which the user's independence versus their dependence is at the forefront; we are therefore looking for the user's strengths and ways to adequately support them when they need assistance. At the end of the implementation of the pilot projects, the assessors at the democratic forum agreed that evaluating the independence of individuals is an appropriate way to assess the eligibility of applicants. Thereby, the assessor assesses the applicant according to their current state and does not consider the broader context of receiving assistance (e.g. assistance from informal carers). The assessor must assume that the applicant lives alone and, on this basis, assess how much assistance they need to carry out individual activities. The starting point for the assessment is the needs of the applicant. The assessment of the applicant's eligibility must be implemented in the same way, regardless of where the applicant lives. In the event of a major change in the user's living circumstances, which we believe may affect the amount of assistance the user needs, we propose a reassessment of eligibility.

The assessors consider that they are relatively well trained to assess the eligibility for long-term care, but they nevertheless emphasised the need for additional, especially substantive training. The necessary training that assessors should receive is additional training in the field of health and social care, workshops (e.g. recording of living circumstances), training in the field of communication, training in the field of dementia, intellectual disabilities, addiction, and use of medical technical devices. It is essential that, during the initial period, eligibility assessments are implemented by expert assessors together (at least ten joint assessments), that they are provided with regular evaluation and supervision meetings, and that they have the option of mutual and additional expert consultation.

Although the assessors assessed themselves (assessment in pairs was implemented only at the beginning of the pilot projects and in the evaluation of applicants together with expert assessors), they mostly believe that in the future it would be more appropriate to perform assessments in pairs. The advantage of two assessments in assessing applicants is reflected in the technical sense of the assessment implementation, greater professionalism and objectivity of the assessment, as well as in the sense of security of the assessors themselves.

## Applicants, assessed, beneficiaries and users of pilot project services

| | **Total** | Celje | Krško | Dravograd |
|---|---|---|---|---|
| **Applicants (N)** | **2031** | 899 | 501 | 631 |
| **Applicants in institutional care (N)** | **834** | 452 | 114 | 268 |
| **Applicants living at home (N)** | **1197** | 447 | 387 | 363 |
| **Assessed (N)** | **1972** | 885 | 475 | 612 |
| **Assessed living at home (N)** | **1147** | 434 | 361 | 352 |
| **Beneficiaries among the assessed (N)** | **1599** | 743 | 390 | 466 |
| **Beneficiaries among the assessed living at home (N)** | **897** | 378 | 289 | 230 |
| **Recipients of services (N)** | **549** | 178 | 220 | 151 |
| **Applicants from institutional care (%)** | **41,1** | 50,3 | 22,8 | 42,5 |
| **Applicants from home environment (%)** | **58,9** | 49,7 | 77,2 | 57,5 |
| **Assessed (in %)** | **97,1** | 98,4 | 94,8 | 97,0 |
| **Assessed from home environment (%)** | **95,8** | 97,1 | 93,3 | 97,0 |
| **Beneficiaries among the assessed (in %)** | **81,1** | 84,0 | 82,1 | 76,1 |
| **Beneficiaries among the assessed in home environment (%)** | **78,2** | 87,1 | 80,1 | 65,3 |
| **Ineligible among the assessed (in %)** | **18,9** | 16,0 | 17,9 | 23,9 |
| **Recipients of services among beneficiaries living at home (in %)** | **61,2** | 47,1 | 76,1 | 65,7 |

# KEY MESSAGES

▸ Eligibility assessment is a novelty in Slovenia and was tested for the first time in pilot projects. The experience and results of pilot projects assessing eligibility are therefore extremely important.
▸ Statistical analyses showed that the eligibility assessment tool is appropriate, and the statistical adequacy of the proposed module scoring adjustments was confirmed.
▸ It is also important to note that the structure of applicants according to the category of care was very similar regardless of the type of environment and that different profiles of assessors did not affect the classification of the applicant in a particular category.
▸ Assessors also confirmed that the eligibility assessment tool is appropriate and recognised the concept of evaluating the independence of persons as an appropriate way of assessing the eligibility of applicants.
▸ Eligibility assessments must be implemented in the same way, regardless of where the assessment is carried out. The assessor must assume that the person lives alone and, on this basis, assess how much assistance they need to carry out individual activities. In the event of a major change in the person's living circumstances, which we believe may affect the amount of assistance the person needs, we propose a reassessment of eligibility.
▸ The educational profile of the assessor can be in the field of both health and social care, but it is desirable that one or the other profile has pre-education or additional education pertaining to the other profile. It is recommended that teams at single entry points be as heterogeneous as possible regarding the assessor's education.
▸ In introducing new profiles such as an assessor, ongoing training, both theoretical and practical, is important.
▸ Assessors who were employed in pilot projects can form an important learning base for further eligibility assessment training.

## Personal planning and coordination of services

Personal planning began to develop abroad in the 1980s, when it was necessary to organise and coordinate the implementation of care in the community[10]. In Slovenia, the method began to be used in the early 1990s, when it was presented in Slovenia by David Brandon (1994)[11]. Today, personal and individual planning in Slovenia is also prescribed by various laws (e.g., Mental Health Act, Personal Assistance Act). International guidelines on long-term care emphasise that the purpose of a personal plan is to ensure coherence between what a person needs, how they want to live and what support they want to receive[12].

Personal planning in long-term care was also tested in pilot projects. Specifically, the public tender for the implementation of pilot projects defined one of the activities as *"the assessment of the eligibility for long-term care with a single assessment tool and the preparation of a personal and implementation plan"*. Furthermore, it defined one of the goals of the evaluation process as *"the creation of a personal plan with the active participation of the user and his relatives, considering the user's social network and the possibility of including volunteers and other services in the community"*. Personal planning was implemented by the long-term care coordinator, who also implemented *"team coordination and coordination between social and health care and the newly established entry point and informal carers, including organised volunteers"*. The public tender further defined the coordination as follows:

▹ *"Coordination between the integrated care team and the entry point for long-term care (cooperation with professionals of the single entry point when the user enters the long-term care system, participation in monthly meetings of long-term care coordinators employed by the formal care provider and entry point professionals, notification of the entry point about the change of the user's implementation plan);*

▹ *coordination of the long-term care team for the implementation of integrated care (planning visits to users in formal and informal care and coordination of the provision of services for users in both formal and informal care);*

▹ *coordination between all partners in the pilot environment (establishment and implementation of cooperation protocols to ensure integrated care with health and social care providers) and coordination of the involvement of informal carers, including organised volunteers in care (recording the form and frequency of participation/contacts with each user, number of involved volunteers and recording the number of volunteer hours worked)".*

The coordinator of long-term care in the pilot projects was therefore the professional profile that took care of maintaining the central role of the user both in the planning and implementation of the personal plan. The basis for this work was a personal plan with an implementation plan. As can be seen from the definitions of tasks in the public tender, they performed a large number of different tasks.

Regarding the public tender, the position of coordinator of long-term care could be filled by either a graduate social worker or a graduate nurse, but in practice the social-worker profile prevailed among the coordinators of long-term care. The experience of the pilot project has shown that long-term care coordinators can be both social workers and nurses, but it is good that the profiles complement each other and combine the principles of operation of both professions. The long-term care coordinator needs knowledge from both the health and social care systems, and must know both well, since only thus can they perform this role comprehensively and in a unifying way.

10 Flaker, V., Mali, J., Rafaelič, A. and Ratajc, S. 2013. Osebno načrtovanje in izvajanje storitev. Ljubljana: Fakulteta za socialno delo.
11 Brandon, D. in Brandon, A. 1994. *Yin and yang of the planning of psychosocial care.* Ljubljana: High School for Social Work.
12 European Expert Group on the Transition from Institutional to Community-based Care. 2012. Common European Guidelines on the Transition from Institutional to Community-based Care (Guidance on implementing and supporting a sustained transition from institutional care to family-based and community-based alternatives for children, persons with disabilities, persons with mental health problems and older persons in Europe). Brussels.
Available at: https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf. (4 October 2019)

As part of the evaluation, we paid special attention to the analysis of personal plans and annexes which were prepared by seven different long-term care coordinators together with users. We received a total of 576 personal plans (181 in Celje, 159 in Dravograd and 236 in Krško) and 71 annexes to personal plans (35 in Celje, 9 in Dravograd and 27 in Krško). All three pilot environments used the same personal plan template (prepared by the contracting authority), which included the following information: personal and contact details of the beneficiary and his/her legal representative, living conditions of the beneficiary, long-term and short-term goals, possible proposals for additional professional goals and measures and the connection or involvement of other services/providers or the involvement of organised volunteers. This was followed by an implementation plan in which, in accordance with the individual goal, its implementation was recorded together with a description of the service and the dates of implementation, as well as the date of the beginning and end of the service. It was also possible to include in the personal plan how other health and social care services, volunteers or informal carers were involved, what was the scope of informal care in hours and the content of informal care services received and any additional comments for consideration in long-term care. The personal plan was signed by the beneficiary and the long-term care coordinator, thus confirming its validity. Thus, it became the basis for the launch of long-term care services in pilot projects.

Through the evaluation, we found that long-term care coordinators recorded living conditions in the personal plan only as an abbreviated version of the living conditions record from the eligibility assessment written by the assessors. These two parts of the procedure should be separated in more detail, as the analysis shows that the pilot project lacked a precise definition of what life circumstances or conditions are and what a life story is. The demarcation could be such that the assessor records life circumstances and conditions in the eligibility assessment, for example in accordance with the model of the personal assistance eligibility record, and the long-term coordinator records them more broadly, in the form of a life story. It transpired that the life story was the weaker aspect of personal planning – the reviewed personal plans did not clearly reflect the wishes and goals of the user. In most cases, the implementation plans included the services that users received in the pilot projects, as well as the services of other providers (e.g. assistance at home, NGOs, informal assistance). The long-term care coordinators recorded the goals in a rather structured way: very short, written in a similar way for different users, connected to assistance from the aspect of the user's health condition. Most of the goals written were short-term; sometimes long-term care coordinators found it difficult to distinguish between short-term and long-term goals. By introducing a goal implementation timeline, we could bridge the division into short-term and long-term goals, and thus write only about goals.

In practice, not all objectives covered by a life story may necessarily be related to the provision of services classified as long-term care services, but they should nevertheless be written down and a definition established concerning who will realise them or what other services or organisations will be included to make the goals a reality. If we do not do this, the care remains fragmented, and we cannot talk about service integration or integrated care.

In order to meet the trends of modern long-term or integrated care, which emphasises a holistic view of life and needs of the user, the appropriate form of recording a personal plan that will be used in the long-term care system should be in accordance with the method for which long-term care coordinators were trained in pilot projects: a personal plan describing the user's life story from which his/her goals derive and from the goals the services provided within and beyond long-term care as defined in the implementation plan. Such a personal plan is broad enough to cover all aspects of the user's life and all persons involved in the provision of care can draw

information from it to begin working with the user. This also eliminates the need for the user to repeat the same thing with different professionals who work with them. We emphasise that it is essential that the personal plan is made in the presence, and with the participation, of the user, who must have insight and control over all steps of planning. If the user does not feel competent enough to design his/her personal plan, he/she must be encouraged by the personal plan recorder and his/her relatives and informal carers should be involved in the creation of the personal plan as well.

Personal planning thus represents a great challenge and a deviation from established patterns of operation, which has also been shown in pilot projects. Specifically, the long-term care coordinators warned and emphasised that they need more training and constant support in their work. We find that the implementation of a method such as personal planning requires quality training that would offer tools and knowledge to long-term care coordinators so that they can produce in-depth and well-defined personal plans. They need to learn the skills of working with the user, whereby the user is in the centre and the position of power is transferred from the expert to the user.

As one of the long-term care coordinators called it, the work of the long-term care coordinators was "multifunctional". In addition to personal planning, they also coordinated various actors and activities in the project, and their work was highly team-based. However, the extensive set of different tasks was the main reason why long-term care coordinators in the pilot projects felt overburdened and undernourished in the scope of direct work with users.

The significant impact of the pilot projects, which was also highlighted by the long-term care coordinators and could be seen in all three pilot environments, was reflected in the strengthened relationship and cooperation between health and social care services and profiles in the field of community-based care. Despite this important shift, we noticed in the evaluation that there is still some room for improvement.

***"I estimate that there is simply too much work for a single coordinator for such a large number of people."***
***"I may have had unrealistic expectations. I really wanted to do more social work."***

*Long-term care coordinator*

# KEY MESSAGES

▸ The use of the personal planning method would require more training 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 broader personal plans.
▸ Personal plans should record the user's life story, which offers broader knowledge of their context and more clearly reflects their wishes and goals than do the life circumstances from the eligibility assessment used by the long-term care coordinators in personal planning.
▸ In order to avoid fragmentation of individual care, we suggest that all goals from the life story should be written in the personal plan together with a plan of who will realise them or what other services/organisations will be involved in their implementation.
▸ For the future use of the personal planning method in long-term care, it should be defined what form of personal plan and life story recording should be used – a broad 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 role of long-term care coordinator has proven to be meaningful and crucial for further work with users. We suggest that the norm of the number of users with whom an individual long-term care coordinator should cooperate be set low enough to enable the coordinator to follow the method of personal planning and coordination of services for which they were trained.
▸ The pilot projects confirmed that the long-term care coordinator is the central profile of long-term care, and their work is distinctly team-based.
▸ In accordance with the warnings of long-term care coordinators from pilot environments, in the future we propose the introduction of the possibility of providing a "transitional service package" or "initial service package", which the user would receive after the assessment of eligibility, during the creation and adaptation of the personal plan and the connected implementation plan pertaining to their needs.
▸ We propose the systematic acquaintance of long-term care coordinators with the social model of cooperation with the user, as envisaged by the method of personal planning.

## Teamwork

Several teams worked in the pilot projects: a team of assessors at the single entry point and an integrated care team consisting of an independence maintenance team and a care team. The teams in the pilot environments consisted of about the same number of members, connected and coordinated by the long-term care coordinator.

The analysis of the teamwork of employees was performed through the dynamics of their operation and connection or mutual cooperation. In the analysis, we mostly relied on the questionnaire of social support networks. We find that information related to work and the work process, as well as advice on solving work challenges, was mostly given by management staff, especially care coordinators and project managers. In the pilot environments of Celje and Krško, employees turned more to other employees than to management staff, specifically in the pilot environment of Celje, where the central role was played by the employee at the single entry point, and in Krško by the employee in the independence maintenance unit. In the Dravograd pilot environment, the long-term care coordinator played the central role. An overview of the dynamics of team work shows that this changed during the pilot project and at the end of the project took on the character of teamwork, i.e. cooperation between employees within individual teams as well as between employees from different teams. Changes in the modes of operation are especially noticeable in the pilot environments of Dravograd and Krško. The reasons for this can also be found in the dynamics of meetings between employees in individual pilot environments. In the pilot environment of Celje, these were relatively few (26), as they were mostly held once a month, and in some periods even once every two months. There were almost no meetings within individual teams. In Krško, numerous meetings were organised (83), most of which were separated into meetings of the integrated care team and meetings of the single entry point assessors. Also in the Dravograd pilot environment, there were many meetings during the project (63), mostly between single entry point assessors and the long-term care coordinator, which was also due to the fact that the assessors and the long-term care coordinator were at different locations. Several meetings of the integrated care team and assessors were also organised in the environment during the project.

The results certainly show the central role of the care coordinator in all three pilot environments, both in the exchange of information related to work and the work process, as well as in the provision of expert advice in solving work challenges. In addition to the long-term care coordinator, the project manager is also an important source of such support. In the event of problems at the work post, employees talked to various co-workers, in which case the role of management staff was somewhat smaller. As this is a conversation, employees are most likely to turn to people who are close to them not so much professionally as humanly. It is therefore noticeable that the long-term care coordinator had a distinctly connecting role between the employees and that the employees connected with each other both within the teams and between them.

*TEAMWORK*

# KEY MESSAGES

▸ The dynamics of team operations varied in the pilot environments. While in the pilot environments of Dravograd and Krško at the end of the project we observed mutual cooperation between employees within individual teams as well as between employees from different teams, in the pilot environment of Celje such cooperation was not established. The reasons for this can also be found in the smaller number of formal meetings among employees in Celje compared to the other two pilot environments.
▸ The long-term care coordinator has a central and connecting role in all three pilot environments, both in the exchange of information related to work and the work process, as well as in the provision of expert advice in solving work challenges.

# EFFECTIVENESS OF LONG-TERM CARE PROCEDURES

The evaluators monitored the process of providing long-term care in pilot projects, which was tested by pilot environments and included the following steps: submitting an application for exercising the right to long-term care, determining eligibility, involving the long-term care coordinator in work with the beneficiary and creating a personal plan providing services, reassessing the eligibility and redefining the scope of services. We paid attention to the structure and content of the procedures, which were largely the same in all three pilot environments. Different practices within each environment occurred only at some points in the process.

The pilot environments used various forms and letters as part of the long-term care procedures described below:

▹ Application for exercising the right to long-term care within the project "Implementation of pilot projects that will support the transition to the implementation of the systemic long-term care act";
▹ Consent form for the collection and processing of personal data;
▹ Views of the personal doctor or treating specialist on the relevant health condition of the insured person;
▹ Assessment scale;
▹ Assessment of eligibility for long-term care within the project "Implementation of Pilot Projects That Will Support the Transition of the Implementation of a Systemic Law on Long-term Care" for persons in an institution;
▹ Assessment of eligibility for long-term care within the project "Implementation of Pilot Projects That Will Support the Transition of the Implementation of a Systemic Law on Long-term Care" for persons in an institution;
▹ Personal plan for implementing long-term care within the pilot activities "Implementation of Pilot Projects That Will Support the Transition of the Implementation of a Systemic Law on Long-term Care";
▹ Annex to the personal plan for implementing long-term care within the pilot activities "Implementation of Pilot Projects That Will Support the Transition of the Implementation of the Systemic Law on Long-term Care";
▹ Letters on eligibility or ineligibility for long-term care were sent in pilot environments as an attachment to the eligibility assessment form;
▹ Forms, letters, applications and contracts for e-care and e-health;
▹ In the pilot environments, the employees in the independence maintenance unit created forms for what they called individual kinesiological, physiotherapeutic, or occupational therapy treatments.

Some forms were compiled and coordinated with the pilot environments by the contracting authority of the pilot projects. Due to the needs of evaluation or practical experience, some forms (application for long-term care, form for personal plan) were changed by the contracting authority and pilot environments even after the start of pilot activities (especially in January and February 2019). Some forms and letters were created by the environments themselves and used in the implementation of pilot projects after coordination and approval by the contracting authority.

The following figure schematically shows and briefly summarises the sequence of individual steps of the entire procedure for exercising long-term care rights in pilot projects, which began with the submission of an application for exercising long-term care rights to a single entry point. Although the pilot projects provided only

services at home, institutional care residents were also able to apply, as one of the purposes of the projects was to test the tool for assessing eligibility in various forms of care, including institutional care. If the application was complete, the applicant was visited by an assessor and assessed for eligibility for long-term care services. If they were deemed eligible, they were visited by a long-term care coordinator with whom they drew up a personal plan. At the same time, communication between employees and preparations for the implementation of care have already started. By confirming the personal plan, the user could start receiving services. After six months, part of the procedure was repeated, as the assessor re-assessed the user's eligibility for long-term care services within the pilot project. If the user was also assessed as eligible at the re-assessment, they were re-visited by the long-term care coordinator to prepare a revision of the personal plan. What the other possible outcomes in the individual steps of the procedure were is illustrated by the plan of the procedure on the next page.

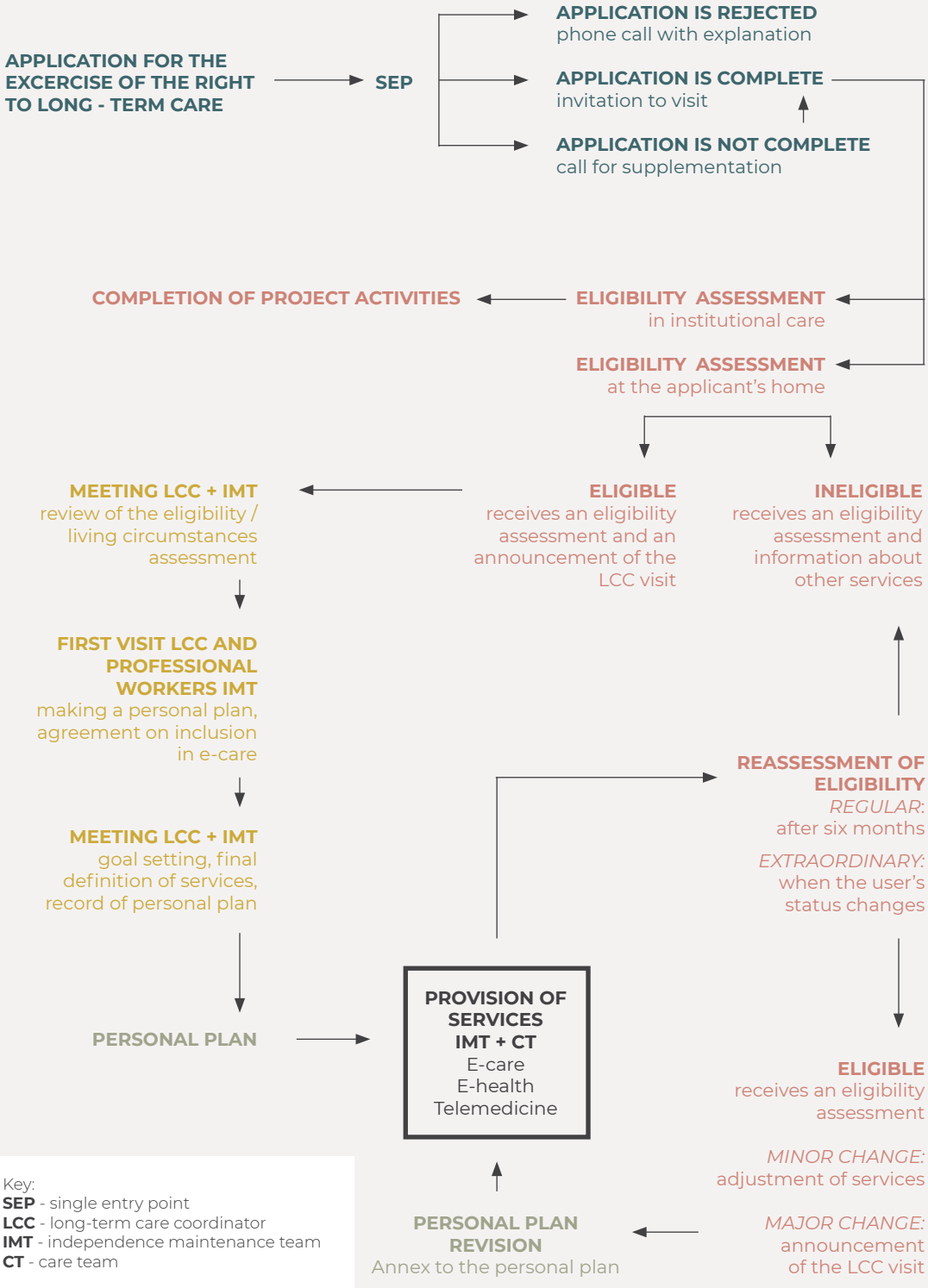
Among the procedures within the implementation of pilot projects of long-term care, it is necessary to emphasise innovation – assessment of eligibility at home, which brought experts significantly closer to the user and their living space, which we have not known to this extent in the Slovenian social care area so far. Assessing eligibility at home is a practice that should be maintained and encouraged.

A special feature of the procedure, which we recorded in the framework of pilot projects in the field of long-term care, is the waiting list. This was created in Celje soon after the start of services (February 2019) and was maintained until the end of the pilot project. The need for services was therefore higher than the number of staff provided within the pilot project, so the space for receiving a new user was vacated only with the departure or termination of the care of another user. In Dravograd, they had no problems with the waiting list, while in Krško they avoided it by hiring two more nursing technicians when the number of users increased. The creation of waiting lists, which are a general feature of social and health care services in Slovenia and not an isolated experience of pilot projects, must be prevented and possible pitfalls of their creation must be anticipated.

In the pilot projects, complaint channels were defined, but the experience of pilot projects showed that the complaint route should be defined in more detail and transparency, and the user complaint procedure should be presented in detail to the user. The user must be informed of all internal and external complaint channels, be provided with complaint forms and be supported in filing a complaint. It is essential that the applicant/beneficiary/user receives the documents and the corresponding forms, as the involvement and familiarity of the user with all steps of the procedure is crucial – we perform procedures and services with them and not in place of them.

In general, on the basis of the collected data, we estimate that the procedure according to which the activities of the pilot projects were implemented was appropriate and that the activities mostly proceeded smoothly. The pilot projects had their peculiarities in that the activities were newly established, so a huge amount of innovation and ingenuity was needed in their implementation, which led to various challenges, as well as to many new solutions. The procedures could, of course, be shorter; the length of procedures and the greater workload of employees were in this case also affected by the considerable volume of evaluation activities they had to implement. From this we can conclude that the procedures in the future long-term care system, if implemented as in the pilot project, could be sufficiently fast and efficient, considering the written proposals.

**Procedure for exercising long-term care rights in pilot projects**




Key:
**SEP** - single entry point
**LCC** - long-term care coordinator
**IMT** - independence maintenance team
**CT** - care team

# KEY MESSAGES

▸ We believe that the procedures within the implementation of the pilot project were appropriate and that the activities mianly ran smothly.
▸ 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 for several different experts in the context of procedures.
▸ Forms used in long-term care procedures should be adapted as much 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 should be maintained and encouraged.
▸ The annexes ("changes" or "revisions") of the personal plan should show changes in the scope of services, as they follow each other chronologically.
▸ In the future long-term care system, it is necessary to ensure that waiting lists are created as rarely as possible.
▸ Users must be made aware of the complaint procedures and be provided with the option of support in the event that they wish to file a complaint.

# EFFECTIVENESS OF LONG-TERM CARE SERVICES

The public tender for pilot environments emphasises *"testing new services and integrated treatment of the user in the home environment"* as the second key goal of the pilot projects. As part of the projects, services were provided to users at home by two teams: a care team and an independence maintenance team. In the first team, the services of activities of daily living, instrumental activities of daily living and nursing care were provided by a social carer, a nursing assistant and nursing technician, each in accordance with their competencies. The second team, i.e. the independence maintenance team implemented new services for users. Team members were a physiotherapist, occupational therapist, master of kinesiology and/or social worker. The services they provided are called "new services for maintaining independence" (also: new services) and are intended to prevent falls, raise awareness of better health, take care of the health of users, counsel for greater independence in living spaces, advise informal carers on the correct approaches to working with the user, prevent burnout of informal carers, and prevent and manage mental distress. A special set of services that we monitored within the project were also assistive technologies, which include e-care and e-health services.

## Activities of daily living, instrumental activities of daily living and new services for maintaining independence

At least one of the services, which are divided into four sets (activities of daily living, instrumental activities of daily living, services for maintaining independence and nursing care), included 549 users within the project (178 in Celje, 220 in Krško and 151 in Dravograd). They received a total of 100,028 services in a total of 37,182 visits. The user thus received an average of 182.2 services within the project.

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. We find that within the project the largest number of nursing services was performed (36,016 or 36.0%), followed by instrumental activities of daily living (24,722 or 24.7%) and activities of daily living (21,731 or 21.7%), the smallest number represents the independence services (17.6%). The mentioned distribution of types of services varies between environments and is mainly a picture of the situation in the local area; pilot environments adapted to local capabilities and needs and strengthened those services that were most lacking in the environment (e.g. health care in Krško and home help in Celje).

The analysis recorded large differences between the activities envisaged in the implementation plans and the activities actually implemented. Based on the available data, we can conclude that the providers mostly did not follow the personal plan closely or changed it during the implementation phase. We propose a stricter formulation of the implementation plan (recorded full set of services that each user needs in accordance with the category of care and identified restrictions, a specially marked set of services that the user already receives in the form of informal and/or formal care, including information on

frequency and scope of implementation and the provider), which would also provide better quality data and the possibility of more detailed projections and analyses. Specifically, although we were able to prepare basic analyses, the obtained data did not allow for more extensive projections. We could not make estimates based on the set of services in the pilot environments, as the obtained data reveal an important fact that the set of services in the pilot project depended not only on the category of care of each user, but also on the environment in which they live and on the possible receipt of informal or formal forms of care.

Given the fact that not all services that an individual user is supposed to receive in the new long-term care system were included in the measurement, the measurement of the duration of the implementation of an individual service, which was performed in the Krško pilot environment, enabled the comparison of average times according to gender and the category of care with the proposed times of implementation of an individual service in the draft long-term care act from 2020, Annex 4. The obtained results are much higher than the proposed duration of an individual service written in the draft act, so in the future more attention will have to be paid to measuring implementation times and setting appropriate average times in the draft long-term care act[13].

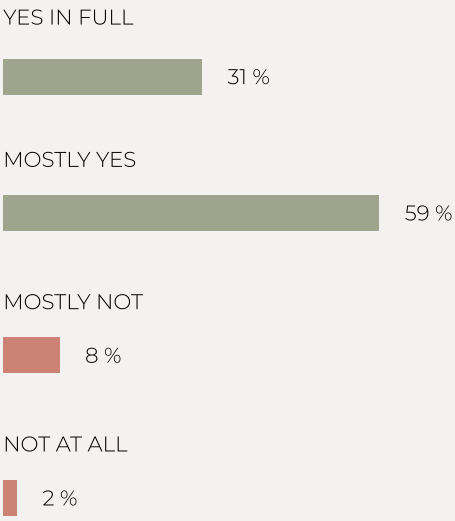
We analysed the new services in more detail. Most of the users who received services as part of the pilot projects were also involved in at least one of the new services. Summaries of the opinions of professionals and user responses show that the introduction of such services (especially services provided by physiotherapists and occupational therapists) is necessary, desirable, needed in the field and the employees emphasise the need to expand and strengthen them and they at least partially bridge current systemic differences between accessible formal care for users at home and in a care home.

We find that users express very high satisfaction and recognise the usefulness of all services and positive effects, especially in the partial increase of independence and quality of life. They are most satisfied with services for maintaining and improving motor independence and motivation services for learning to live independently. The vast majority of users (90.3%) mostly or completely agreed that they had received the services they wanted within the pilot project. Despite the general satisfaction with receiving new services, only a good third of users (35.1%) thought 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 actually received in the framework of new services.

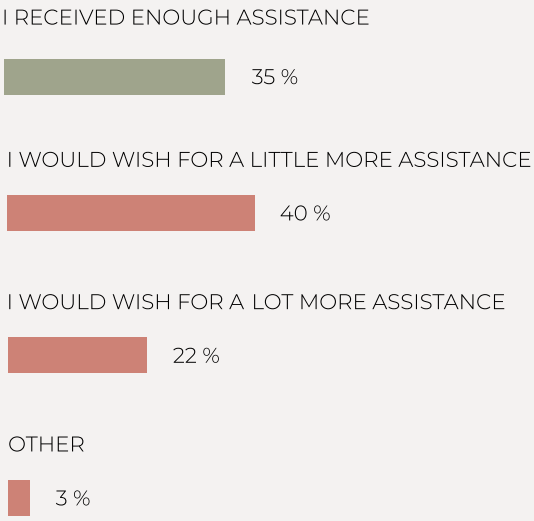
The pilot projects also highlighted the challenge of urgently determining the adequacy of the proposed set of services – i.e. whether it covers all the necessary services and, if not, which services should be added. Specifically, we find that the services of prevention, counselling and strengthening the user for independent living and programmes for strengthening health and a healthy lifestyle, counselling the user and informal carer, counselling and teaching informal carer and counselling for managing chronic non-communicable diseases were, according to team members, somewhat vaguely defined, as they overlap according to the description. We also found that (especially social workers) implemented activities which could not be recorded within the scope of services within the pilot project, which unjustifiably reduced their effective time. Therefore, in Krško they proposed additional services that were not in the initial proposed set of services (e.g. short and long telephone conversations, informing formal providers, support for users and informal carers upon the transition to institutional care or hospitalisation, user support upon discharge from hospital, work with volunteers).

13 The Ministry of Health of the Republic of Slovenia. 2020. Draft Long-Term Care Act.

**Did you receive the services you wanted within the pilot project?**




**How would you assess the amount or scope of assistance you received within the pilot project?**



# KEY MESSAGES

▸ In three pilot environments, users received a total of more than 100,000 services in more than 37,000 visits. By introducing new services for users living at home, 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 challenge 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 it during the implementation phase.

# Assistive technologies

Assistive technologies are a common term for ICT-based systems that support older people and their informal carers. They include e-care and e-health services.[14] In the project, a total of 152 users tested assistive technologies, 131 of these users tested only e-care services, 9 e-care and e-health services and 12 only telemedicine. A total of 6.9 % of eligible applicants in the community were involved in testing support services. We estimate that the proportion of those involved was high, and it was undoubtedly influenced by the possibility of free testing of the service.

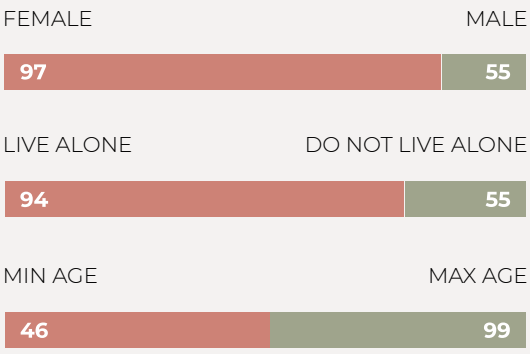
We evaluated the use of Telekom Slovenije's services (Basic package in all three environments, as well as the Premium package, the package of monitoring vital functions at home and additional equipment in the Krško and Celje pilot environments). In addition, in Dravograd, they tested the In Life smartwatch service developed by the Institute "Jožef Stefan", and telemedicine support provided by MKS Electronic Systems, in collaboration with the Remote Health Centre (CEZAR Centre).

Based on combinations of different measurement instruments, we determine high satisfaction with, and recognition of the usefulness of, e-care services among users and informal carers. In focus groups with providers (long-term care assessors and coordinators) we recognise an increase in knowledge of such technologies and insight into their advantages. The results of the survey show that 74.4% of users estimate that the overall quality of e-care services is high or very high, and 75.6% of users are satisfied or very satisfied with its use. Comparable with this or even more pronounced is the level of satisfaction

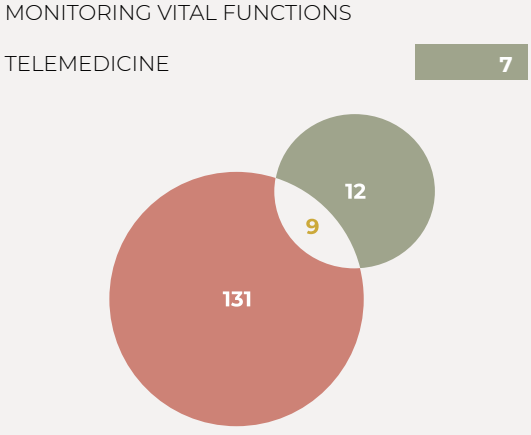
14 E-care and e-health enable the provision of health and social care services at a distance, in users' homes. E-care assistive systems refer to a range of smart technologies that are connected with 24-hour accessible services. These include personal alarms (a small device triggered upon adverse event – the need for assistance), environmental sensors (e.g. gas leaks, smoke), mobility monitoring devices (e.g. fall detector), and a GPS system for positioning or tracking. E-health refers to the exchange of physiological data between a patient at home and healthcare staff at a distance in order to facilitate the diagnosis and monitoring of the vital signs.

**Users of assistive technologies**

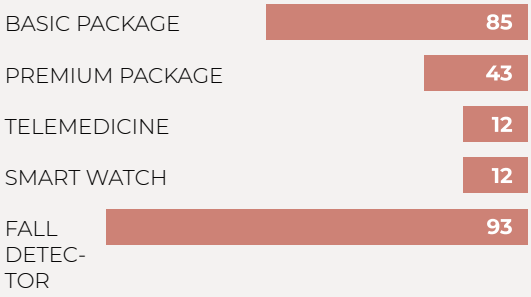
**152 ACTIVE USERS**




**E-HEALTH**




**E-CARE**



with e-care services of informal carers. Users and informal carers also rate the usefulness of e-care services very highly, recognising the high usefulness for both target groups, and referring mainly to the usefulness for people living alone and having past experiences with falls. The majority of users (74.4%) and especially informal carers (86.1%) also expressed an intention for further use, which is often conditioned by subsidising the costs of use.

We find that both long-term care users and their informal carers have reported positive effects of using e-care services and a higher perceived quality of life. Users observe the greatest positive change in the area of their independence (AM = +0.8[15]), sense of control (AM = +0.8) and quality of life (AM = +0.7). The analysis of the qualitative data shows mainly psychosocial outcomes, namely positive (stronger sense of security, peace of mind, reassurance, relief and general well-being) or (less frequently) negative effects (increased anxiety and fear, especially users' fears of breaking or destroying the technology) and a sense of greater autonomy for users. Among the negative aspects, they also point out that the use of the equipment is potentially disruptive (impractical) or inappropriate for the user, there were also technical problems (e.g. automatic triggering of a false alarm either after a sensor error or a user error), which can be stressful for the user.

We found that users of assistive technologies were more often even slightly more vulnerable compared to the overall sample of long-term care users living at home. Although they had fewer needs for activities of daily living and instrumental activities of daily living and were included in lower categories of care, older people were widowed more often than average, lived alone more often, were on average less educated and received lower net household income. Access to these services also has some limitations, as most are only available if the users have an informal carer who is contacted by the assistance centre (or the ICT-supported service itself) in case the user needs help. This paradoxically means that services are not available to those who may need them most. Thereby, it is worth emphasising the good practice of the Krško pilot environment, in which informal carers were replaced by on-call staff from the pilot project. Given all the positive effects reported in relation to assistive technologies, we appeal to decision-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.

Although there were few e-health users involved in the project, they should not be overlooked in the system provisions. Remote health monitoring makes sense especially for people with chronic diseases. In the project, these were most often people with heart failure and type 2 diabetes. E-health users were very active in the project; a total of 12 users thus performed over 6000 measurements of vital functions during the eight months of monitoring. We also emphasise e-health and e-care services in the light of the COVID-19 epidemic. In the project, users also replaced contacts with formal care providers with technology, mainly telephone conversations. 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 1000 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 did not use them. Telemedicine treatment of already involved persons was uninterrupted even during the epidemic and proved to be one of the key services and a successful method of support, which took place despite less accessible health care institutions.

15 AM stands for arithmetic mean. The PIADS-10 measuring instrument was used to determine whether the use of assistive technologies 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.

# 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.

# QUALITY OF LIFE

The effects of long-term care pilot projects on key target groups – users, informal carers and project staff – are in fact key project results. As part of the evaluation, the effects on people were observed through a change in two time points (at the beginning and at the end of the project), and we must emphasise that the quality of life, well-being and satisfaction with individual aspects of (working) life at the end of the project was also affected by the COVID-19 epidemic, which stopped the provision of many services or limited them to only the most urgent ones. In the pilot environments, the work of employees had to be adapted, and the users' needs for services or their circumstances also changed (for example, some relatives were able to provide more care than before the epidemic and thus took over part of the required care, while some could provide less care and, in these cases, users needed more formal assistance than before the epidemic). Also, many processes in the project, such as education and training for employees and informal carers, supervision for employees, meetings of local project councils, etc., were stopped during this time or were implemented less intensively.

## Quality of users' lives

The effects of pilot projects on users' lives were measured with two standardised questionnaires for measuring quality of life[16]: CASP-12 and EQ-5D. The latter is more focused on self-assessment of health status. The results of the EQ-5D measurement showed that users faced a number of health problems: more than 90 % of them reported at least moderate walking difficulties at the first assessment, the largest proportion of these users was in the Dravograd pilot environment (95.5%); 83.8 % had at least moderate problems with washing and dressing, the largest proportion of these users was in Krško (92.5%), the smallest in Dravograd (68.2%); 93.1% of users reported at least moderate difficulties in carrying out usual daily activities, most in Krško (93%), and in Celje and Dravograd 88.2% and 86.4% respectively; more than 83.3% of users experienced at least moderate pain and discomfort, and a good half of users (54.0 %) experienced anxiety or depression.

When evaluated after one year of involvement in pilot activities, the proportions of users with at least moderate difficulties in walking, performing daily activities, and with at least moderate feelings of pain and discomfort in all pilot environments together decreased. The largest positive difference between the first and last assessment is seen in the feeling of pain and discomfort, and the greatest negative change in anxiety or depression. The change in anxiety and depression of users shows that it increased only in Celje (from 56.3% to 69.1%), while it decreased in Krško (from 60% to 51.3%) and Dravograd (from 36.4% to 28.6%) during the involvement of users in the project. The result can also be partly attributed to the impact of the COVID-19 epidemic; almost half of all users reported feeling anxious and uncomfortable because of the epidemic[17], and urban environments were probably more exposed to these effects than rural or semi-rural ones. For example, a study in France[18] showed that older

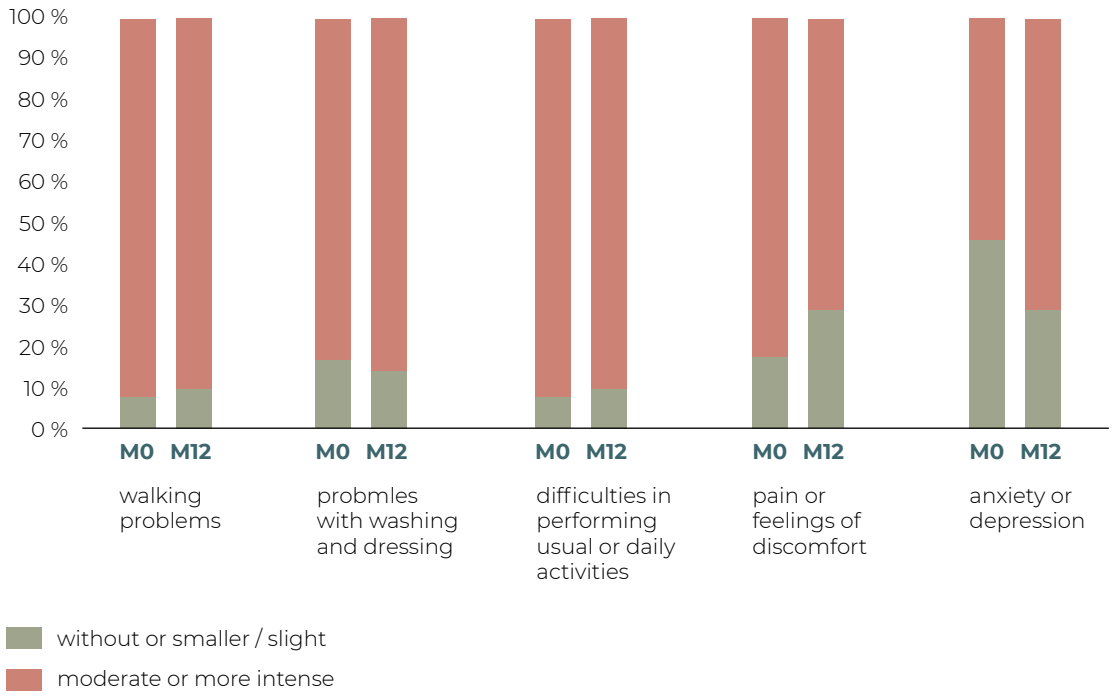
16 In the preparation and selection of measurement instruments, we followed the guidelines and recommendations of the European Centre for Social Welfare Policy and Research, which had an important external consultative role in the project.
17 Anxiety and discomfort were measured with a control question.
18 Peres, K., Ouvrard, C., Koleck, M., Rascle, N., Dartigues, J-F., Bergua, V., Amieva, H. 2021. Living in Rural Area: A Protective Factor for a Negative Experience of the Lockdown and the COVID-19 Crisis in the Oldest Old Population? Available at SSRN: https://ssrn.com/abstract=3803358 or http://dx.doi.org/10.2139/ssrn.3803358.

people from rural areas had a better experience of the first lockdown during the epidemic than those from urban areas, as they had better social support, more family members nearby, less frequent feelings of captivity, a garden, fewer symptoms of depression and a lower level of anxiety.

The index of health status of users averaged 0.201[19] in the first assessment, which means poor health, and in the second assessment it increased slightly compared to the first (0.241), but the difference is not statistically significant. We also find in individual pilot environments that the health status index of users increased slightly at the last assessment compared to the first. This is indicated by the fact that when joining the pilot project, 83.5% of users had poorer health than average, and after one year of participation in the project, the share of such users decreased (76%). The pilot projects therefore had this impact on improving the health of users.

We need to be more careful when interpreting the results regarding the quality of life of users measured by CAPS-12, as some users may not have given valid answers due to misunderstanding and sensitivity about the questions. The complexity of the questionnaire was reported several times during the project by the assessors who interviewed the users. The results showed that the users had a moderately high quality of life at the time of the first assessment (30.1)[20] and that after one year of involvement in the project it had hardly changed (30.3), so it remained at approximately the same level as at the first assessment.

**Proportion of users according to the level of walking difficulties (mobility), self-care (washing and dressing), usual activities (household chores, family, leisure) and the level of pain/discomfort and anxiety/depression (N = 130)**




19 Here, the value 0 means a medical condition equal to death, and 1 a perfect medical condition.
20 The minimum is 12, the maximum is 48.

# KEY MESSAGES

▸ The self-assessment of the health status of users, as measured by the EQ-5D questionnaire, increased on average at the end 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 have also contributed to this.
▸ The average quality of life of users did not change significantly during the intervention. It is a subjective assessment of the quality of life of users, which was obtained on the basis of the questionnaire for measuring the quality of life of older people (CASP-12). Despite the adaptation of the questionnaire for the older people, we find that the questions were incomprehensible and sensitive for some users; therefore, 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 health or well-being. Large changes in the self-assessment of health status as well as in the quality of life of users cannot be expected in a relatively short period of pilot activities, as the effects of such social concepts are usually manifested only after longer periods of intervention. It would therefore make sense to observe the pilot activities for a longer period of time.
▸ From the methodological aspect, we estimate that the use of the CASP-12 questionnded in long-term care is not the most appropriate, while the EQ-5D questionnaire is recommend.

## Quality of life of informal carers

Informal carers are an important partner in long-term care, because, as we know from the scientific and professional literature, a large part of care is provided by them. Informal care is very widespread which is illustrated by the fact that three quarters of the persons assessed in the pilot project have at least one person who provides them with informal care and assistance. The incidence of informal care in pilot projects is thus high, which is also a general feature of long-term care in other European countries.

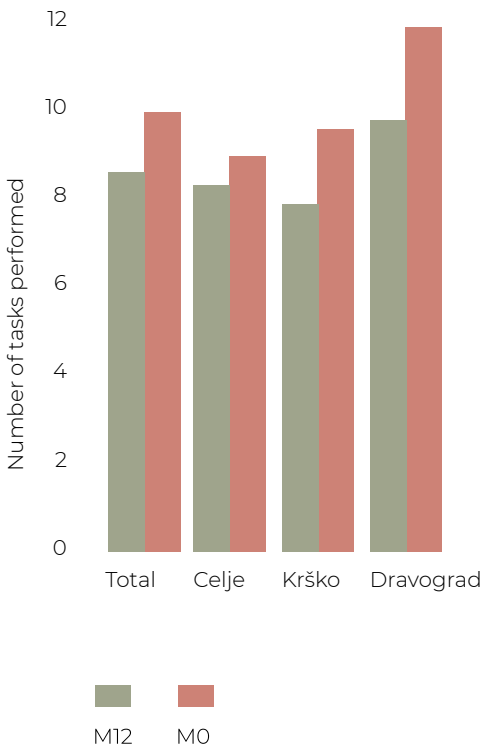
In the pilot projects, therefore, informal carers were one of the target groups in addition to users and employees. Although they were not at the forefront of the project as users, certain activities within the pilot projects were nevertheless intended for them. The pilot projects paid special attention to the education of informal carers, supported them in finding information on care and with advice on the proper implementation of care.

Nearly two-thirds of informal carers in pilot environments were female. Their average age is 63 years, three-tenths of them are older than 70 years. Most informal carers are married or in a partnership (79.8%), about half of them are retired, and a third are employed part-time. A good two-thirds offer help to a person living in the same household. Most of them help their parents (47.7%), slightly fewer help their partner (33.2%). They mainly perform instrumental activities of daily living (e.g. washing dishes, cleaning kitchen, helping to prepare meals or delivering food, making beds, cleaning living spaces, helping to buy and take medicines), but less often also activities of daily living (e.g. dressing, undressing, lying down in bed and getting up, use of toilet and bathroom, maintenance and care of care aids). On average, they perform nine different tasks per day.

In the sample of informal carers, we find that the number of tasks they perform daily decreased on average by one task[21] during their participation in the pilot project. The decrease was most significant in Dravograd (2 tasks).

The objective burden (measured by the number of hours of care per week) of informal carers also decreased during the pilot project, which can confirm the positive impact of pilot projects on the lives of informal carers. The reduction of the objective burden also indicates that, in the current system of long-term care, the formally organised care does not relieve informal care intensively enough or that cooperation between the two types of care is insufficient and that intensive cooperation shows positive effects in the objective burden of informal carers. Pilot activities had this impact.

**Number of tasks performed by the surveyed informal carers per day (M0 = at the time of joining the project, M12 = after one year of joining the project) (N = 58)**




21 The difference is on the border of statistical significance (t = 1.953, p < 0.056).

**Relieving and burdening factors of care**

**SELF-CARE AS MOTIVATION**

▹ altruistic attitude
▹ a sense of duty to help
▹ self-relief (method of relaxation, formal care assistance, assistance of family members)

**CARE FOR THE CARE RECIPIENT AS MOTIVATION**

▹ satisfaction of the care recipient with care and gratitude for it
▹ connection with the care recipient
▹ spending time together and a loving and emotional relationship
▹ visible effect of the assistance
▹ physical and mental health of the care recipient
▹ providing home care, preventing institutionalisation

**SELF-CARE AS BURDEN**

▹ risks associated with one's own health
▹ lack of (free) time and adjusting their time to the care recipient
▹ abandonment of own activities
▹ constant presence with the care recipient
▹ reconciling private (family) and/or professional life
▹ performing activities of daily living and instrumental activities of daily living
▹ distance
▹ financial condition
▹ reduction of social contacts, social exclusion

**CARE FOR THE CARE RECIPIENT AS BURDEN**

▹ health problems of the care recipient
▹ disturbing behaviour or traits or changes in the care recipient's mood
▹ feeling powerless (the effect of help is not visible or they do not have the competencies to care)
▹ ignorance of forms of assistance
▹ difficulties in cooperating with the formal assistance network

Organised formal care in the homes of users is thus seen as an opportunity to relieve informal carers both in terms of net relief (the formal provider performs certain tasks previously performed by the informal carer) and in terms of providing support to informal carers by being instructed by an expert in how to properly perform certain tasks (transfer of actionable knowledge).

If we look at the quality of life of informal carers in terms of the subjective burden, we cannot generally say that it has improved for informal carers in the year of the pilot activities. However, we can understand many of the stressing and relieving factors (see Figure 8) that are reported and detected by various measurement instruments within the evaluation.

Thus, in addition to the very concrete provision of formal help at home (additional hours of formal care), the evaluation finds that for informal carers the option of using leave (e.g. at least 14 days) is shown as an important relief factor, while for the person they care for, alternative care in an institution or at home is provided. We do not have data on how many informal carers actually used substitute care or day care within the pilot project, but based on the available materials, we find that there were very few of them.

For informal carers, occasionally, a few hours of alternative care is also extremely important, so that they can perform certain tasks uninterruptedly during this time or, for example, attend education, training or self-help groups that they need and appreciate, but often experience as a burden. In this respect, informal carers need support in transport, adjusting appointments, providing alternative care and organising these events in their vicinity. Informal carers are often older people who take care of their partners, and they would urgently need transport to attend the training, or it would be easier for them to attend the events if they were organised in their local community. On the other hand, for those informal carers who are employed, flexible timing of events is also important.

*QUALITY OF LIFE OF INFORMAL CARERS*

# KEY MESSAGES

▸ Informal care is the backbone of long-term care, and its high frequency has also been confirmed by pilot projects.
▸ Informal care is primarily in the domain of women, which puts them in an unequal position with men.
▸ The subjective burden of informal carers did not improve during the time of involvement in pilot projects, but we can find many relieving factors (option of alternative care, use of leave, transport, time flexibility, etc.).
▸ The pilot projects had a positive impact on the lives of informal carers in terms of objective relief, which further reinforces the call for better support for informal carers. Measures in this area are therefore necessary, as formally organised care currently does not relieve informal care intensively enough, or cooperation between the two types of care is too weak.
▸ Organised care at home and in the community is an opportunity to disburden informal carers, either as a relief from certain tasks or in terms of support and teaching how to provide care (transfer of actionable knowledge).

## Quality of working life of employees

For the successful implementation of pilot projects, those who implement the pilot activities, i.e. employees, and the circumstances in which they work are particularly important. Accordingly, we monitored how employees feel about their work, where they see the advantages and disadvantages of the work they perform, and what the working conditions are. We used an online questionnaire for employees, which we conducted in two time points so we could assess the change in the quality of working life of employees during the course of the pilot activities.

Measuring the organisational climate in pilot environments, which shows how employees perceive their work environment, showed at the end of the project that employees see belonging to the organisation, i.e. the pilot project in which they performed their work, internal relations, attitude to quality (contributing to the quality of work, responsibility for the quality of their work) and innovation and initiative (awareness of the need for change, options for making suggestions for improvements, willingness to take risks in implementing initiatives, etc.) in the best light. Compared to the first survey, knowledge of the objectives of the pilot projects, which was rated below average in the first survey, and clarity of work organisation and the role of employees increased at the end of the project.

For the pilot environments, the results of the assessments of individual categories of organisational climate are primarily a guide to try to improve their work in areas where the assessments are lower (challenges for pilot environments). In the Celje pilot environment, the assessments of individual categories of organisational climate were lower at the end of the project than at the beginning, except for the organisation of work (clarity of certain roles and work). Lower assessments at the end of the project could be associated with high staff fluctuation in the pilot environment. Many employees entered the project during its implementation (even in the later stages), so they may not have received sufficient information about and the objectives of the pilot project or did not participate in the initial stages of the project, when the project guidelines and objectives are usually formed. Due to staff fluctuation, the perception of the work environment at the end of the project is different than it would be if it were assessed by the same employees at the beginning. In the Krško pilot environment, the perception of the working environment did not change significantly at the beginning and end of the project; however, positive changes in affiliation, internal relations, organisation and knowledge of goals are noticeable. In the Dravograd pilot environment, in which employees assessed individual categories of the organisational climate at the beginning of the project the lowest compared to the other two pilot environments, the assessment of the working environment in all observed categories increased at the end.

Regarding satisfaction with individual aspects of the working life of employees, we find that employees were less satisfied with the working conditions and their immediate superiors and more with the work they perform, working hours and their jobs in the project. An important aspect of satisfaction with working conditions is also satisfaction with payment for performed work. In all pilot projects together, at the beginning of the project, just under half of the employees were satisfied with the payment for the performed work, and at the end of the project, a little more than half. Looking at individual pilot environments, the proportion of employees who are satisfied with the payment for performed work increased in Celje and Dravograd, while this proportion in Krško decreased slightly, but still remained high and much higher compared to other pilot environments.

If we look at the satisfaction with the payment for performed work between individual types of employment in the pilot environments and in both points of the survey together, we find that

on average the employees in the care unit (social carers) were the least satisfied with the payment for their work and the most satisfied were the employees in the independence maintenance unit.

In their reports on activities within pilot projects in the field of long-term care, the employees stated differences in pay grades between pilot environments as the main reason for dissatisfaction with payment for the performed work. Pilot environments classified employees differently into pay grades, usually depending on whether they were employed in health or social care. The latter, on the one hand, had a bad effect on work motivation, and on the other hand, on mutual cooperation and networking between employees of different professions.

The option of supervision for employees in pilot projects proved to be an important element of working life. It was provided by all three environments; however, its implementation was suspended during the stricter measures imposed due to the COVID-19 epidemic. The pilot environments organised it in different ways and for different teams, but it nevertheless turned out to be an important acquisition in the project. Employees were thus given support to resolve dilemmas at work.

We find that working in pilot projects was quite stressful for employees, especially at the beginning, as almost half of them reported that they could not do some household chores at home due to fatigue. Approximately a fifth of employees, however, spent too much time at work, making it difficult for them to meet their family obligations. The workload decreased slightly at the end of the project, but it is not possible to determine from the data whether the reason for this decrease is due to the better-established work in the project, fewer applications than at the beginning of the project or whether the reduction would be greater if the COVID-19 epidemic had not occurred during the survey and project completion period.

# KEY MESSAGES

▸ The employees in the pilot environments were satisfied with the individual aspects of their working life, a little less satisfied with the working conditions and their immediate superiors and more with the work they perform, working hours and their jobs in the project.
▸ They were dissatisfied mainly with the payment for the performed work. Pilot environments classified employees differently into pay grades, usually depending on whether they were employed in health or social care. The latter, on the one hand, had a bad effect on work motivation, and on the other hand, on mutual cooperation and networking between employees of different professions. The result shows that the dispersion of long-term care between different subsystems (especially health and social) has a negative impact on cooperation and integration, and that the integration of services is necessary from this aspect, as it will increase the joint competence of different sectors.
▸ Among all employees in the pilot environments, social carers expressed the highest dissatisfaction with the payment for the performed work, specifically in accordance with the uniform salary system of the public sector they are ranked in the 16th (social carer III), 19th (social carer II) and 22nd (social carer I) starting salary grade. The results of the pilot project can trigger an appeal to improve their working conditions at the systemic level, as the pilot projects are another proof that the profession of social carer needs to be made more attractive and be (at least) equated with comparable professions (e.g. personal assistant).
▸ Supervision proved to be an important element of working life and an important gain for employees in pilot projects.

# TRANSITION TO COMMUNITY FORMS OF CARE

The interconnection and cooperation of various stakeholders in this field, both at the local and national level, is important for the effective implementation and organisation of long-term care. Integrated care contributes to easier access to services, their higher quality and efficiency, and consequently to greater user satisfaction. Experience in Slovenia shows that coordination between services that provide long-term care services is not good[22]. Assuming that coordinated action is necessary for the development

of community-based care, we monitored how the pilot environments connected more broadly with the local environment and key stakeholders and how they were included in the project.

Stakeholder networking and participation in pilot environments were monitored using various indicators. Above all, we were interested in how many employees in the pilot projects met with partners in the local environment and how they were informed. The data shows that in all environments, an event was held in the first months of the projects at which the project was presented to local stakeholders in the field of long-term care. Local project councils were established in all pilot environments in which project partners were involved, and in Krško, stakeholders (12) who were not project partners were also included. There were not many meetings of local project councils (Dravograd 4, Krško 3 and Celje 2), but the reason for this is also the COVID-19 epidemic, as physical meetings were not possible most of the time in 2020, and virtual ones were not chosen except in Krško. In the environments, they planned to hold meetings of the local project council twice a year, but they did not establish other organisational structures between the partners in the environments. In the pilot environments of Celje and Dravograd, regular communication and cooperation took place mainly with obligatory partners, while in Krško a wide range of stakeholders from various fields were involved in various activities, although fewer stakeholders were involved in the project than in the other two environments. In the Celje pilot environment, the point was made that it was difficult to coordinate meetings with several stakeholders, and in the future, it will be necessary to consider the use of technology and organisation of online meetings, which proved to be an effective mechanism for cooperation during the COVID-19 epidemic.

In the project, with the help of a questionnaire addressed to stakeholders in pilot projects after 18 months of pilot activities, we also obtained their opinion on various segments of long-term care in their local environment. Due to the small number of units of analysis (Celje 9, Krško 12 and Dravograd 14), because the response of stakeholders was relatively poor, we must interpret the results with methodological caution, and above all we must not generalise them. Stakeholders included in the survey were identified by leading project partners based on their role in long-term care in the local environment and mostly involved project partners.

The results show that stakeholders are generally fairly well aware of the various challenges of long-term care and are sensitive to them. They recognise e.g. the advantages of community-based care over institutional care, emphasise the importance of formal care, strengthening and empowering informal carers, and believe that providers perform quality work in the local environment. At the same time, they

22 Nagode, M., Zver, E., Marn, S., Jacović, A., Dominkuš, D. 2014. Dolgotrajna oskrba – uporaba mednarodne definicije v Sloveniji. Zbirka Delovni zvezki UMAR, letn. 23, 2, Ljubljana: UMAR.

## Establishing an organisational form of cooperation and networking in pilot projects

| Pilot environment | Celje | Krško | Dravograd |
|---|---|---|---|
| **Presentation of the project to all stakeholders in the environment** | 15/10/2018 | 10/09/2018 | 27/11/2018 |
| **Establishing regular communication with stakeholders in the environment** | ✓ | ✓ | ✓ |
| **Local project council** | Established: 20/02/2019<br><br>No. of partners involved: 18<br><br>No. of meetings: 2 | Established: 21/12/2018<br><br>No. of partners involved: 23<br><br>No. of meetings: 3 | Established: 27/11/2018<br><br>No. of partners involved: 33<br><br>No. of meetings: 4 |
| **Establishment of stakeholder participation protocols** | Established in the second half of 2019<br><br>Amendments to the protocol during the project: NO | Established in October 2018<br><br>Amendments to the protocol during the project: YES | Established in January 2020<br><br>Amendments to the protocol during the project: NO |

recognise that users are insufficiently informed about such services, and that field providers are insufficiently connected and coordinated. At the end of the project, only a good quarter of respondents said that users in need of long-term care are sufficiently informed about possible forms of assistance, although many activities in the project were aimed at informing potential users about possible forms of assistance. When stakeholders assessed "general and not situation-based" topics in the questionnaire, their average agreement was high, while in specific topics (in individual cases) their agreement decreased. For example, stakeholders agreed that if the existing form of assistance is no longer sufficient for the user, it should be smoothly transformed to a more appropriate form of care. However, when they specifically assessed discharge from the hospital, perceptions changed and most assessed that the transition from hospital to home care in the environment is not regulated. We can therefore observe that at the declarative level, respondents perceive and assess the situation in the field of long-term care differently than at the actual, concrete level.

If we compare all three pilot environments, the Krško pilot environment stands out, which indicates that it is slightly more sensitive to the challenges of long-term care (e.g. they recognise the importance of community-based care even for individuals with a larger scope of needs, and they support formal care somewhat more), but the differences are mostly rather vague and cannot necessarily be generalised. One of the differences stems from the initial state of the project, as the leading partner in the project is the home help provider and the discourse is more likely to focus more on the importance of strengthening home care services. However, we also noted in the initial report that the municipality of Krško 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. At the same time, the interviews with the municipalities show that the municipality of Krško was very interested in applying for the project and was actively involved in the application process, and at the end of the pilot project, it made an agreement on further cooperation with the pilot environment, which it will co-finance. The development of community-based care is based primarily on the commitment and sensitivity of the municipality in regulating this area; therefore, its role and cooperation are crucial. Only with the active role of the municipality could the Krško pilot environment ensure, even if only partially, the sustainability of the project.

Finally, it should be noted that the surveyed stakeholders in the open answers direct all their hopes to the future long-term care act, which they believe must necessarily be based on the experience gained in the pilot project.

# KEY MESSAGES

▸ Integrated care contributes to easier access to services, their higher quality and efficiency, and consequently greater user satisfaction; therefore, it is necessary to connect and cooperate with various stakeholders in this field.
▸ Cooperation between stakeholders must reflect a common interest in identifying and meeting the needs of the local population, which is reflected in active and effective cooperation in providing long-term care.
▸ In the pilot environments, a wide range of different stakeholders were involved in the project, but regular meetings were held mainly with consortium partners, while cooperation with other stakeholders took place only occasionally or rarely.
▸ The vast majority of stakeholders in the environments believe that long-term care must consist of integrated and coordinated social and health care services.
▸ Just under half of stakeholders agree that the various organisations involved in the provision of long-term care are well interconnected, and just under a third that the transfer of information between different long-term care providers is effective. This means that cooperation between stakeholders in environments needs to be improved.
▸ Stakeholders recognise the importance of pilot projects and believe that systemic solutions for long-term care should be based on the experience gained from pilot projects.

# EFFECTIVENESS OF DATA RECORDING

As part of the evaluation, we also examined the effectiveness of data recording in terms of electronic support for procedures and services in the field of long-term care, suitability of the information system developed within pilot projects as one of the bases for developing a system for the new long-term care system throughout Slovenia and the option of using the collected data to try to assess the financial and human resources of the new long-term care system.

Only one contractor was selected for implementation in all three environments, which eliminated the problem of coordination of individual solutions for the development of the information system in the event of the selection of different contractors in individual pilot environments. Such an approach would not make sense in the implementation of a public procurement for the development of the entire information system for the needs of the implementation of the new long-term care system. The selection of at least two or more providers would maintain the competitive behaviour of individual providers and thus maintain efficient and quality development and maintenance of the information system in the future.

Most of the required functionalities of the information system were established in all three environments by the end of August 2019. Important is the fact that the contractor was selected only after the start of the pilot projects, which further contributed to the delay in the development of the appropriate software tool. It is also important to note that all added functionalities were accessible to all three environments at the same time. The first application was prepared in January 2019 (Online Care application). The functionalities of the system were then regularly updated, which in practice caused delays in the entry of data into individual modules.

This way of working was necessarily due to the fact that not all the functionalities that the information system was supposed to provide were precisely defined in the public tender. The public tender stipulated that all procedures had to be monitored, but given the pilot nature of the projects, not all procedures could be precisely defined in advance. The need for additions to the information system thus arose on an ongoing basis, and employees in the pilot environments and the system developer addressed them during the course of the project. Some data was therefore entered following a delay or subsequently or when the possibility of entering data into the information system was provided. In the interim period, the data in the pilot environments was collected manually and entered into temporary Excel files.

The gradual development of the information system made it impossible to evaluate the time lag from the acquisition to the entry of the acquired data into the electronic database. Regarding the proportion of all activities within the pilot activities that were properly recorded and entered into the information system, with the success standard set at 100% coverage of all implemented activities – we can conclude that they were properly recorded and entered. However, it should be added that some data was not captured at the end of the project, which may also be due to the time lag in the obtained data and the possibility of recording them in the information system. The reasons can also be found in the lack of control over the full coverage of the required data in the individual form as well as the control over the entry of the obtained data into the information system by the pilot project providers.

We can conclude that the recording and documentation system developed in the framework of the pilot projects is suitable for use in the transition to system use. In any case, this is an important part of the records that will be collected under the new long-term care system. The system, which was developed as part of the pilot projects, actually covers databases to be collected and managed by long-term care providers. It is a web application that is accessible everywhere and is completely adapted to work in long-term or integrated care. All functionalities were developed specifically for use in long-term care and the system itself was tested and implemented in practice. However, it should be noted that the pilot environments only collected data on the care provided in the pilot projects and not on the total care that the individual user receives or should receive according to the identified needs. This enabled the calculation of the prices of individual services provided, for which we measured the duration of implementation in the project, but the data did not allow us to prepare estimates of total expenditure by individual categories, nor an analysis of the number and structure of services by category of care. The data needed to implement these analyses is still to be collected as part of an additional project or a specific project focusing on the financial estimate of expenditure.

From the very beginning of the development, use and upgrade of the information system, which can be one of the important parts of the new information system of integrated long-term care, the contracting authority, the Ministry of Health, should actively participate in controlling the operation and use of the system. However, it was not planned for the contracting authority to access the databases themselves and it is not planned what will be the fate of the information system developed in the framework of pilot projects after the end of the projects. It is possible that due to the lack of a plan, the contractor will stop maintaining the system after the end of the pilot projects.

***The pilot projects in the field of long-term care were a complex and demanding innovation. Their evaluation, which gave important and numerous results, was also demanding and complex. The results of the pilot projects and their evaluation can therefore be read as an important tool for both policy makers and social and health care professionals in finding better solutions to bridge the gaps and meet the challenges of the current long-term care system regulation.***

*EFFECTIVENESS OF DATA RECORDING*

# KEY MESSAGES

▸ Data on services recorded by the pilot environments in the information system allowed the estimation of costs only for services performed in the framework of pilot projects, which could not be used for evaluation at the aggregate level of the new long-term care system. In order to assess the adequacy of the scope of services in individual categories of care in the Long-Term Care Act draft (2020), to assess the adequacy of services in individual categories of care, to assess the staffing needs of individual employee profiles and, last but not least, to assess the aggregate costs of the new long-term care system we would require data on the full range of required services as well as the times of their implementation.
▸ This data could be collected in the framework of a new or additional project which will focus on the financial assessment of expenditures of the entire system.
▸ We find that most of the activities within the pilot projects were properly recorded and entered in the information system. The reason that some data was not captured at the end of the project is due to the time lag between data acquisition and the possibility of recording them in the information system and the lack of control of full coverage of required data for each form as well as control of data entry in the information system by pilot project providers.
▸ The recording and documentation system developed in the framework of pilot projects is suitable for use in the transition to system use.
▸ Experience gained from pilot projects has shown that the timely development and testing of the information system before the start of operation of the new long-term care system is extremely important.
▸ We suggest that the contracting authority, before publishing a public tender for the selection of the best bidder for the development and maintenance of the entire information system, based on the written data collection requirements for long-term care and experience gained, prepares a detailed analysis of required databases, their content, connectivity, access method and minimum printout requirements for the needs of ongoing monitoring of the operation of the long-term care system, control and analysis of the quality-of-service provision as well as the implementation of scientific research in the field of long-term care. It is also necessary to establish an appropriate and permanent system of control over the entry of the required data in the system.

**Long-term care – a challenge and an opportunity for a better tomorrow. Evaluation of pilot projects in the field of long-term care**

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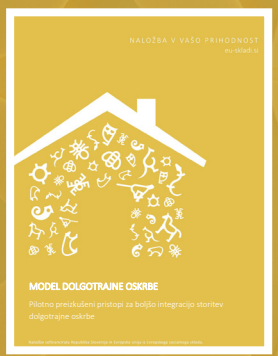
NALOŽBA V VAŠO PRIHODNOST
eu-skladi.si
MODEL DOLGOTRAJNE OSKRBE
Pilotno preizkušeni pristopi za boljšo integracijo storitev dolgotrajne oskrbe