Sustainable tailored integrated care for older people in Europe (SUSTAIN project)

Lessons learned from improving integrated care in Estonia

Colophon

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Key points

- The results of the SUSTAIN project in Estonia have helped to raise discussion about tools for and ways of engaging clients in the planning and implementation of their integrated care service.

- The project confirmed that service user involvement is a long-lasting process in which existing habits and attitudes may need to change. To achieve that, certain objective (e.g. time management) and subjective factors (e.g. empowerment, preferences, and needs of older people) need to be considered when providing care and support.

- The client's psychological and mental resources need more consideration when developing an integrated care system.

- Long-term care should not consist merely of episodes of short-term care: future perspectives need to be included. Therefore, the caregiver should be seen as someone who supports and helps to create a future for the service user.

- In Estonia, negative stereotypes surrounding old age and poor health are prevalent. Such perceptions counteract attempts to help older people become more active in their integrated care. In addition to getting older people involved in their own care decisions, solutions for addressing the discriminatory conditions in society need to be developed.

- The well-known problem of overwork among health and social care professionals has an impact on clients' involvement, as illustrated by this quote from one respondent: "If professionals don't have time to listen, the patient doesn't want to talk." Therefore, a change in service standards or other solutions for the lack of labour should be incorporated into the development of integrated care.

- Integrated care requires the management of diverse person-centred information. To achieve that, cooperation between authorities and the financial system is needed. SUSTAIN was the first step in the process of creating a more complete and person-centred set of information about service users. Further efforts should focus on motivational aspects among the parties involved and ways of utilising data that are beneficial to all parties. The project investigated whether information sharing between health and social care professionals should be electronic or paper-based. Considering that (a) the tool is intended for a target group with reduced physical and mental capacity, and (b) there cannot be a person-centred solution without personal input from the service users themselves – the platform cannot be a 100% electronic solution. The record for each service user needs to include data obtained through a variety of media (audio, video, electronic, and paper-based data).

CONTENTS

1. INTRODUCTION

1.1 Integrated care in Estonia

In Estonia, **responsibilities** for the provision of integrated care are **divided between the health and social systems**. The health care system provides institution-based and home nursing care services, while the social care system offers personal care services such as day centre services, general care home services and home-based domestic services. Health care is the responsibility of the government-funded Health Insurance Fund, in which the family doctor is responsible for referring older people to nursing care services. Currently, personal care services are administered both at the central government level via the Social Insurance Board and by local municipalities, but the main responsibility falls on local governments. These different systems have caused fragmentation across care episodes, providers, settings and services. This fragmentation is multidimensional and exists at various levels, including the organisational, professional and policy levels. For example, local governments in Estonia are free to define their social service provision policy, but their willingness and resources to implement services are unequal. As a result, access to social services depends largely on the place of residence of the beneficiary.

With public funding for long-term care (LTC) at a low level, coverage of formal LTC is inadequate and inequitable and provides little financial protection. On the health side of LTC there is a shortage of nursing care beds. Regional accessibility to inpatient nursing care services is uneven, in part a consequence of the shortage of in-home nurses. On the social side of LTC, local governments' capacity to provide social benefits and services depends to a large extent on the budgetary resources available (World Bank, 2017).

In the absence of adequate publicly-financed coverage, the **burden of care falls disproportionately on informal carers**, giving rise to significant economic and social costs.

The National Audit Office is of the opinion that before providing assistance involving taxpayers' funds, local authorities should first make sure that a person in need of care, or his or her family, is not capable of providing care independently. The reliance on informal care is underpinned by the Constitution of the Republic of Estonia (Art. 27), which stipulates that the family is required to provide care for its members in need. This policy has led to a situation in which most social carers are informal (i.e. the family) and training offered to those informal carers is limited.

Health and social LTC services are also organisationally and professionally fragmented between two systems, each with their own cultures and modes of operation. Thus, although health and social care services coexist within the community (e.g., home nursing care and home help with daily activities) and within institutional settings (e.g., hospital-based nursing care and care social welfare institutions), they often lack adequate protocols for cooperation. This organisational separation also involves separate administrative procedures as well as IT/communication infrastructure. Similarly, at the professional level, there is fragmentation between health and social care in terms of differing professional norms and cultures, social statuses and prestige, employment terms and conditions, working time/shift patterns and training.

In January 2018, the Estonian Government launched local government reforms that are being applied to the country's 79 local governments. These large-scale, complex reforms focus on how to contribute to the more integrated and person-centred provision of support services to older people with high support needs. A local government must guarantee compulsory basic services for its residents, and one of the main focus areas is reducing dependency on informal caregivers, which has a significant health-related,

economic and social risk for individuals and their families. Integrated care has become an important policy priority in Estonia.

1.2 The SUSTAIN project

SUSTAIN, which stands for 'Sustainable Tailored Integrated Care for Older People in Europe' (www.sustain-eu.org), is a four-year (2015-2019) cross-European research project initiated to take a step forward in the development of integrated care. SUSTAIN's objectives were twofold: 1. to support and monitor improvements to established integrated care initiatives for older people living at home with multiple health and social care needs, and in so doing move towards more person-centred, prevention-oriented, safe and efficient care; and 2. to contribute to the adoption and application of these improvements to other health and social care systems, and regions in Europe.

The SUSTAIN-project is carried out by thirteen partners from eight European countries: Austria, Belgium, Estonia, Germany, Norway, Spain, the Netherlands, and the United Kingdom. With the exception of Belgium, two integrated care initiatives per country were invited to participate in the SUSTAIN-project. The initiatives were already operating within their local health and social care systems. Criteria for including these initiatives, also referred to as 'sites', were defined by SUSTAIN research partners and drawn from the principles of the Chronic Care Model and related models (Epping-Jordan et al., 2004; Minkman, 2012; Wagner et al., 2005). Accordingly, initiatives should:

- Be willing and committed to improve their current practice by working towards more person-centred, prevention-oriented, safe and efficient care, which, in line with the EC's stipulations, are SUSTAIN's four key domains;
- Focus on people aged 65 years and older, who live in their own homes and who have multiple health and social care needs;
- Support people to stay in their own homes (or local environments) for as long as possible;
- Address older people's multiple needs, in other words, they should not be single disease oriented;
- Involve professionals from multiple health and social care disciplines working in multidisciplinary teams (e.g. nurses, social workers, pharmacists, dieticians, general practitioners);
- Be established, i.e. preferably operational for at least two years;
- Cover one geographical area or local site;
- Be mandated by one organisation that represents the initiative and that facilitates collaboration with SUSTAIN research partners.

The fourteen initiatives selected according to these criteria showed great diversity in the type of care services provided (Arrue et al., 2016; De Bruin et al., 2018). Their focus ranged from proactive primary care for frail older people and care for older people being discharged from hospital, to nursing care for frail older people, care for people with dementia, and palliative care.

In the SUSTAIN-project, we adopted an implementation science approach using the Evidence Integrated Triangle (Glasgow et al., 2012), in which local stakeholders and research partners co-design and implement improvement plans. In the first phase of the project (starting autumn 2015), SUSTAIN-partners established working relationships with the different sites, and identified relevant local stakeholders related to the initiative (i.e. managers, health and social care professionals, representatives of older people and informal carers, local policy officers). Furthermore, they carried out baseline assessments of each initiative's principal characteristics and also worked with local stakeholders to identify areas of current practice in the initiative, which might be subject to improvement (e.g. collaboration between formal and informal care providers, involvement of older people in care processes). Findings from the baseline assessments were used as inputs for workshops with key stakeholders related to the initiative at each site. The purpose of the workshops was to discuss outcomes of the baseline assessments and enable sites to determine local improvement priorities.

In the second phase of the project (starting spring 2016), local steering groups were set up. Steering groups consisted of stakeholders who participated in the workshops together with additional local stakeholders considered relevant to the initiative. These steering groups were created to design and implement improvement plans, that is, sets of improvements that apply to local, site-specific priorities. Each steering group agreed to implement their plans over the 18-month period from autumn 2016 to spring 2018. In each initiative, implementation progress and outcomes were monitored by SUSTAIN partners using a multiple embedded case study design, in which each initiative was treated as one case study (Yin, 2013). A hallmark of case study design is the use of several data sources, a strategy which also enhances data credibility (Creswell, 2009). SUSTAIN partners therefore used a set of qualitative and quantitative data collection tools (see Appendix 10.1), allowing us to collect data from different data sources, being: surveys to users, surveys to professionals, interviews with users and carers, professionals and managers, care plans/clinical notes, field notes, notes of steering group meetings, and templates to collect efficiency data from local services, organisations or registries. Data were collected at agreed and specified times during the 18-month implementation period, using the same procedures and tools for all initiatives. In addition to a core set of data collection tools applied in all initiatives, sites were being encouraged to select site-specific tools tailored to their site-specific context and improvement priorities.

Data were analysed per site, guided by the principles of case study design. There were three steps in our analyses: 1. all data sources were analysed separately using uniform templates for analysis which were generated through a discussion among research partners; 2. for each data source, data were reduced to a series of thematic statements (qualitative data) or summaries (qualitative data); 3. an overarching site-specific analysis was done, in which all qualitative and quantitative data were coupled and underwent a process of pattern-matching across

the data. This is the approach of choice for evaluating complex community-based interventions which are context bound and noted for their differences in application and implementation (Billings and Leichsenring, 2014; Craig et al., 2008). In order to be able to do a site-specific overarching analysis, we created an analysis framework which was used by all SUSTAIN partners in order to create uniformity of approach.

is a medium-sized municipality-owned institution which operates on a different scale and in a different region of Estonia. Also, the service setting is different: Medendi is based in the community (home nursing care) and Alutaguse Hoolekeskus in an institutional setting (social care institutions). Medendi offers home nursing care services; Alutaguse provides integrated care service and round-the-clock home-care service.

1.3   SUSTAIN sites in Estonia

In Estonia, we identified two sites of innovative integrated care: Medendi and the Alutaguse Hoolekeskus Foundation. The reasons for including these sites are their ability to provide evidence and bring relevant stakeholders together. Both organisations have a supportive climate and are open to improving their current way of operating. They represent different organisational models: Medendi is a small private service provider, while Alutaguse Hoolekeskus

1.4   Reader's guide

The report is organised as follows: In Part 1 we describe the Alutaguse Hoolekeskus Foundation – first its characteristics and its improvement project (Chapter 2), followed by the main results of the improvement initiative (Chapter 3) and then a discussion of the main lessons learned (Chapter 4). Part 2 addresses Medendi, following a similar structure in Chapters 5-7. Part 3 (Chapter 8) reflects on the findings from a national perspective.

Table 1 - *Propositions and analytical questions against which SUSTAIN data were analysed.*

Proposition 1	Integrated care activities will maintain or enhance person-centredness, prevention orientation, safety, efficiency and co-ordination in care delivery.
Proposition 2	Explanations for succeeding in improving existing integrated care initiatives will be identified.
Analytical question 1	What seems to work, in what kind of situation, and with what outcomes when making improvements to integrated care?
Analytical question 2	What are the explanations for succeeding and improving integrated care initiatives?
Analytical question 3	What are the explanations for not succeeding and improving integrated care initiatives?
Analytical question 4	Are there any factors that are particularly strong in the analysis that could be seen as having an impact on integrated care improvements?
Analytical question 5	What factors can be identified in the analysis that could apply to integrated care improvements across the EU, and be transferable?

PART 1
Alutaguse Hoolekeskus

2. ALUTAGUSE: CHARACTERISTICS AND IMPROVEMENT PROJECT

2.1 General description of the site

Alutaguse Hoolekeskus (herein referred to as Alutaguse Care Centre) is located in the centre of Ida-Viru County in Estonia. It is in the small town of Mäetaguse (population: approx. 600), which is equally accessible from 20 villages in the municipality. It is located 20 km from Jõhvi, the county centre (population: approx. 12,000). The territory of the municipality is divided between oil shale mining and exploration fields. Mined areas constitute one-third of the municipality (approx. 10,000 ha). The nursing and health care services of the Care Centre are mainly intended for older people from Mäetaguse municipality and the southern part of Ida-Viru County. The services are cultivated based on the real needs of senior citizens and aim to be of high quality, accessible to the target group and available as close to home as possible.

The Care Centre has different stakeholders and their operations are closely linked. For example, Alutaguse is open to cooperation with health care institutions, local governments and many third-sector organisations. The most important everyday cooperation involving integrated services is with Mäetaguse municipality and local doctors. The services are well coordinated so that they (nursing and healthcare) can be provided prior to people coming to the institution so as to offer the best solutions depending on need. Service range development aims to provide more integrated services in the home.

Among other things, the Care Centre aims to be the integrating link between different target groups (old and young people), bringing together different parties by offering activities they can participate in together. The Care Centre has five different service areas: round-the-clock special-care services for adults with special mental needs; 24-hour care (nursing home service); care for persons suffering from dementia; day nursing/care; and nursing

treatment (health service). Each service is based on the need for services to be integrated, where the service is tailored to fit the older person's individual requirements (nursing treatment, care services, etc.).

Services are divided into general services, which are provided to all service users, and special services, which are available on request to every person receiving care. The everyday work of nurses and carers is process-based, the older person is at the centre of everything and staff teamwork guarantees the older person's care and safety as well as the expected quality of services. All provided services are documented. To protect privacy, only selected members of staff have access to personal data. The mental and physical activity of service users is regarded highly and different activities are organised by various specialists, including a physiotherapist and a social worker. The following services have been provided at the Care Centre for older people: physiotherapy; activation; activity therapy; hobby activities; modern accommodation; access to own kitchen; sauna; library; hairdresser; manicure; pedicure; rest areas; handicraft workshops; and access to a swimming pool. Alutaguse Hoolekeskus (herein referred to as Alutaguse) has 55 employees and approx. 250 clients per year with a capacity of 110 beds.

The service is funded by the National Health Insurance Fund the municipality and private payments made by users and their families. The centre was established in 2011. Alutaguse is a private corporate body, founded by Mäetaguse municipality. It is a well-run organisation which follows specifically laid out guidelines and regulations. In addition, the organisation has an in-depth quality handbook in which well-developed, specific roles and responsibilities are laid out for staff members on every level. Alutaguse's staff consists of experienced and knowledgeable health

care workers whose motivation is much higher compared to other similar institutions.

Alutaguse complies with the requirements of nursing hospitals concerning facilities, with 110 beds, service content and health care and nursing equipment/accessories (Health Care Administration Act, requirements of types of hospitals, Social Welfare Act, etc.).

2.2 Rationale for improvement project

Lacking a clear-cut, unambiguous and systematic approach to the care planning process, as well as a documenting process, is often a barrier to achieving higher quality in long-term care. Another rationale is that the routine involvement of older people and staff is an essential facet of optimising and increasing users' quality of life. The planning process requires more involvement and cooperation from older people and staff.

A comprehensive approach adapted to the needs and expectations of long-term care service users focuses not only on the physical domain of life, but also on the psychological, social and environmental domains. Security, comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality and spiritual well-being are essential to the quality of one's life. . Attention to psychosocial environments and efforts to bring about a cultural change in nurshing homes will emphasize the person-centred aspect of care services.

Therefore, it is vital to identify the methods used in working with older persons and staff together. Service providers should seek to empower, support and extend the authority of older persons to increase their participation and cooperation with the staff within the care plan. The improvement project sought to address this by implementing new procedures and improving procedures in place for involving older people in identifying their needs and staff in planning and evaluating the services provided to them.

2.3 Aims and objectives of improvement project

After identifying the main areas for improvement, it was decided that a broader approach which engages older people and a multi-professional team (social worker, nurse and professional carer) in the process of defining the care plan will be developed.The care plan will provide an overview of the nature of cooperation between the team and the older people.

A critical element of success was introducing organisational systems and procedures that enable efficient information exchange between the multi-professional staff. One key

aspect of the project, therefore, was conducting a person-centred assessment of the older person's health and social care needs upon entering the service and how to keep the user needs-focussed process alive during long-lasting relationships in institutions.

2.4 Explanation of improvement project

The purpose of the SUSTAIN improvement project is to enhance the sharing of information and communication in Alutaguse.

The SUSTAIN project cooperated with the initiatives "Talk to Me" in Alutaguse. It represented efforts to improve the collecting and sharing of information on what influences users' quality of life, and a new concept of the nursing care plan was implemented. The initiatives provide care that is tailored specifically to users' needs.

The intervention required a change in organisational systems and procedures to ensure that staff are acquainted with users and that users are engaged in a systematic way so as to set up and keep alive the individual care plan in a long-lasting relationship in an institution.

To enable this process, the improvement project team needed to:

1. define the approach of person-centred care. The project team decided to give all users a care plan that includes key information about the person's life, interests, abilities and challenges and that defines the development goals for the older person; and
2. further cooperate with the family of the user to find out more about the user's life.

Steps to be taken:

1. develop a questionnaire to collect information about aspects of older people's lives (background, hobbies, etc.);
2. make the questionnaire accessible on the Alutaguse website;
3. require older people's families to fill in the questionnaire before signing the service contract;
4. establish indicators to assess the effects of the proposed individual care plan system; and
5. develop the questionnaire system and monitor it regularly.

Steps to be taken to enable efficient information exchange between multi-professional staff, the user and their family:

6. develop the necessary ICT system;
7. hold regular meetings;
8. keep an events calendar (distributed to older persons and families as well as information about leisure activities);
9. upon the arrival of a new service user, have a meeting with everyone associated with the patient; and

10. regularly monitor the outcome in order to understand whether the implemented system is operational and gives better result in terms of engaging the older person and keeps the process of updating his/her needs alive.

A summary of the key aspects of the improvement project and key requirements for implementation is shown in Figure 1.

Alutaguse

Current

| Hospital or Family Physician | → | Admission to the care service | → | Patient health data fragmented | | Patient care plan fragmented | | Uncoordinated implementation of the plan |

Improvement

| Developing digital data recording system | Introducing new ways of admission of the patient: patient needs assessment and care plan development with the patient | Introducing new ways of information exchange among staff | Improvement of internal communication exchange between multi-disciplinary team | New integrated care plan | Care provided according to the new plan | Care plan follow-up at home |

0   6   9   12

Preliminary activities

| Shared network drive | → | Shared agenda in outlook calendar staff | → | Phones for nurses and carers | → | Recepionist interview template |

Outcomes

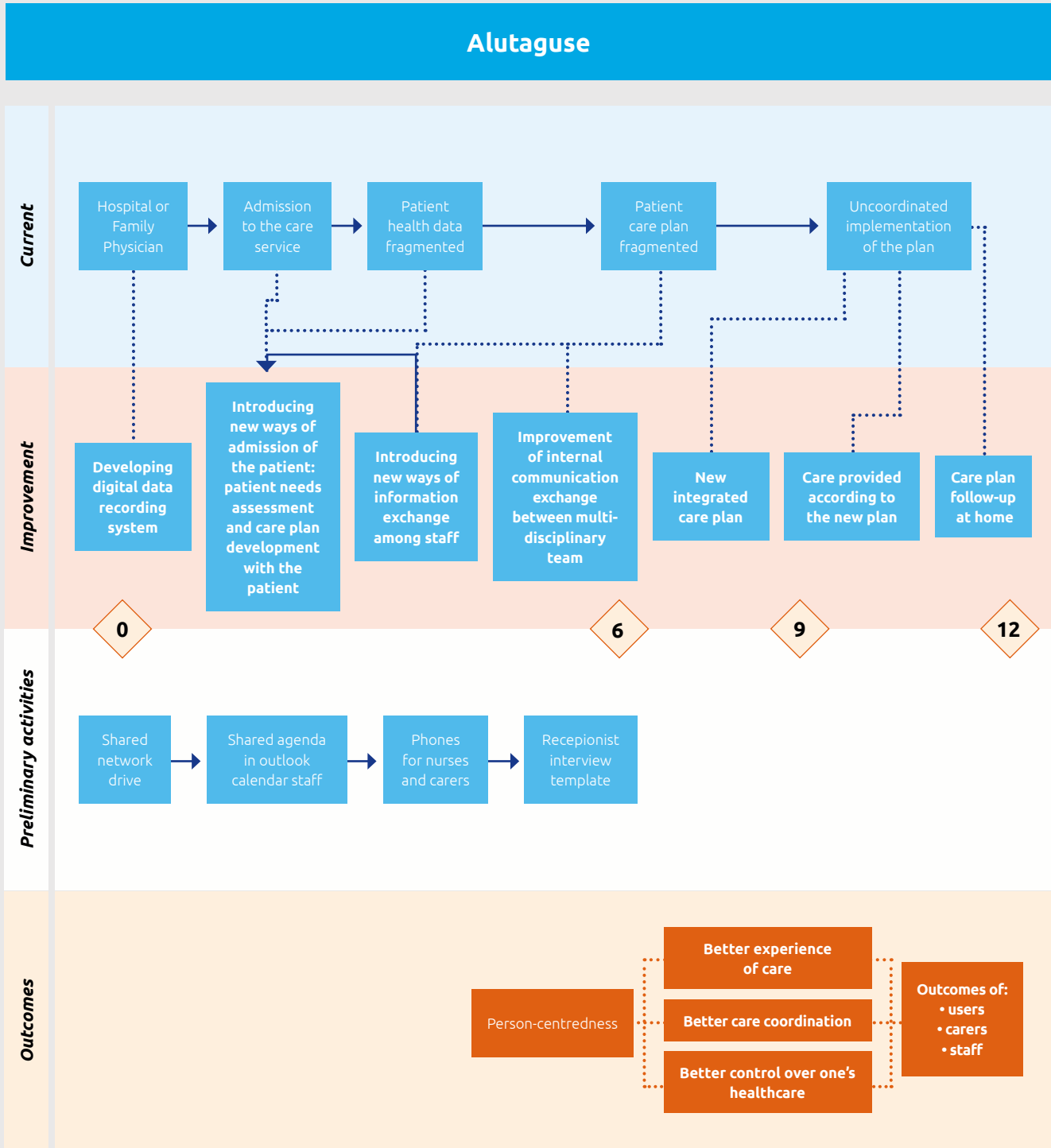| Person-centredness | Better experience of care | Outcomes of: • users • carers • staff |
| | Better care coordination | |
| | Better control over one's healthcare | |

Figure 1 - *Flowchart of Alutaguse Care Centre improvement project and requirements for implementation.*

3. FINDINGS OF THE IMPROVEMENT INITIATIVE IN ALUTAGUSE

3.1 Introduction

Researchers worked with the SUSTAIN project team from October 2015 to identify stakeholders, form and support a steering group, specify the improvement project and plan its implementation. The service was implemented in April 2017. Evaluation data were collected between April 2017 and April 2018. The study proposal was not reviewed by the ethical committee.

A summary of the data is given in Table 1. The remainder of this section is based on an analysis of these data. One manager and ten professionals participated in the study. The manager was a 44-year old female with high education and employed full-time. 90% of professionals were female, which reflects the gender demographic profile in caring professions. The age range was 18-54 years, which is quite unusual in Estonia in this sector. The most common age group was 35-44 (20%). Usually, we have a lack of professionals in the youngest age group. Most of them are Estonian (60%), and full work time (90%). Half of the professionals have attained a high level of education, and 30% middle and 20% low level of education. The majority of the professionals (50%) are caretakers, social workers or, activity instructors, 20% are nurses, and another 20% are administrative staff.

In total, 28 users participated in the study. More than two-thirds of the participants were female, and approximately half of the users are 85+ years, and one-third are aged 65-74. Two-third of users did not attain a high level of education (primary school or lower/none), and only 18% achieved a high level of education. 64% of the users were widowed, and 18% married. The users were either living alone at their homes (35%) or at an institutional care home for the final stages of their lives (46%) or with a spouse/partner (10%). Users reported having between 2 to 12 different chronic conditions, the average was

6.25 conditions per user. Vision problems (61%), hearing problems (54%), back pain (46%), dizziness with falling (43%), heart failure (36%), diabetes (25%), and depression (36%) were the most prevalent conditions; whereas broken bones (32%), stroke (21%), joint issues (21%), osteoporosis (18%) were less frequent. 57% reported other medical conditions, such as Parkinson's disease, movement disability, neck radiculitis, arrhythmia, high blood pressure.

The sample of informal carers was small (6). Two informal carers were spouses, one was a son, and two were a sons-in-law and one was a daughter-in-law. Half of the carers were women, and half were men. One informal carer was an elderly person, aged between 65-74 years, but half of the carers were middle-aged (45-54 aged). Four carers had intermediate education levels, and two had a high level of education. Two carers lived with the users, one away from the user (more than 5 km), and three lived close by. Four informal carers had a paid job, and one was retired. The average amount of time spent on caregiving activities was 13,5 hours per week, ranging from a minimum of 2 and a maximum of 20.

3.2 What seems to work?

Coordination
The new shift in services in Alutaguse consisted of developing a template for the new integrated care plan based on commonly defined goals. While the plan was to be created on an electronic platform, the final result was the designing and implementation of a paper-based plan. Every older person received a paper-based plan that was also available to his/her informal carer and all professionals related to his/her care. In addition to the main change in

Table 2 - *Summary of data collected for Alutaguse.*

Surveys	N = Total
P3CEQ (Person-centred Coordinated Care Experience Questionnaire)	28
PCHC (Perceived Control of Health Care)	27
TCI (Team Climate Inventory)	22
User Demographics	28
Carer Demographics	6
Manager Demographics	1
Professional Demographics	10
Care Plan Data	26
Interviews	
Dyad interviews (user + carer)	6
Professional/manager interviews	2
Steering group notes and reflective notes	
Meetings (steering group, intervention meetings)	6

service, weekly multi-professional team meetings were implemented as well as the introduction of topics on person-centredness.

Improvements in coordination and cooperation in care delivery were not entirely evident. Professionals tended to share information about service users, but professionals' ability to contribute to a patient's care plan was limited (with an average score of just 0.78 in P3CEQ, of a maximum of 4). On one hand, the older persons felt that they do not need to repeat information for different members of staff (the average score of 2.27 (of a maximum of 4) being the highest of all the indicators in P3CEQ, although the value of the score is a moderate one). The same applies to the indicator "I am considered as a 'whole' person" (2.1). Nevertheless, only 25% of older persons indicated that a nurse and social workers were involved in their care process.

In the new care plan, advice given by professionals was documented in only 75% of cases, and only eight care plans (57%) contained records of falls (42% by the end of the data collection period). This shows that the organisation still tends rely on oral exchanges between people without recording them.

Person-centredness
In the interview with the manager, she acknowledged that the enhanced mindset of professionals' person-centredness, as well as prevention orientation and safety was achieved through active engagement of professionals in all project activities. The implementation of the integrated care plan has improved the quality of integrated service because all professionals observed and followed

the complete list of indicators essential for the older person's well-being and there were fewer possibilities to forget certain aspects. Also, professionals have approved following the same care plan if they have it (in the P3CEQ 3.67).

According to the initial idea, older persons needed to be engaged in setting goals for his/her care services and recovery activities. Nevertheless, the theoretical concept and what the survey reflects are somewhat contradictory. Most of the respondents indicated they either did not have a care plan or did not know whether they had one as indicated in the interviews and P3CEQ survey. The older people also stated that they had difficulties understanding the questions asked of them during the interviews. Analysis of the content of the care plans supported these results. Initially, only five care plans included the roles of informal carers (36%) and just nine (64%) care plans described which activities needed to be done by the older person to achieve these goals. These two indicators positively changed over time (65% and 21%)[1] but shares still remained relatively low. The results indicated poor engagement of older people and their informal carers. It is likely they see little point in becoming involved in planning and implementing their care when there is no chance of improvement. This conclusion is based on the interviews.

[Sighs] …The issue was and is to this day completely undiagnosed (by the specialist). So there cannot be some sort of just-give-it-to-us program, can there? They have simply ascertained her/his level of abilities and made sure it does not deteriorate. Sure, they said it was an issue of old age but my grandparents lived very long lives so in my opinion saying it's an age-related thing when you're 73, well, that's too early. (Carer 1)

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[1] Not the same respondents.

The interviews with users revealed that person-centredness as a principle tends to be implemented only at the admission to the service. For long-term service users, a non-personalised service is perceived as more common and the initiative to change the established routine tends to come from the user.

"But have they asked you as well? Sure, they did at the beginning, but, well, that was at the beginning. I've got used to things here now, so there's no need [...] And they know that if I need something, I'll ask for it". (User 1)

The low level of person-centredness could be improved upon through incremental change and better time management. Therefore we conclude that it would be relatively easy to raise the level of older people's satisfaction by offering more personalised care. To this end, more thorough knowledge of older persons needs to be accumulated.

In general, service users felt that they wanted to retain control of their own care (the mean score in PCHC for "Keeping control of health care" being 6.8 on the 10-point scale, with 48% of respondents considering themselves to be the person who controls their health care). Nevertheless, older people admit difficulties in doing so: the maximum score of related indicators was 3.5 for "knowing when it is time to request professional care". The ability to find information, aids and services and arrange care were rated 2.9 or less (on a 5-point scale).

According to P3CEQ, moderate evidence of efficiency was found as a result of the survey. The respondents did not often discuss what was most important to them in managing their health and well-being (with a mean score of 0.54 in P3CEQ, q1). The older persons expressed more profound negative thoughts and fears; desires seem to be hidden.

"But do you think that if you're under emotional strain or you get in a bad mood that that's something you could tell your carer about as well? - No, I don't want any trouble. I just want to live my life quietly, by myself". (User 2)

Since staff members only tend to ask family members (informal carers) about a service user's preferences and abilities and the old person themselves tends to be excluded from such inquiries, we cannot talk about person-centredness or possibilities to maintain or enhance independence.

"Have health care workers given you an assessment or asked you about the things you're still capable of doing on your own? Well, I don't know. I don't think I've ever been asked anything like that. Perhaps they do ask, though – they've definitely asked my son". (User 3)

Efficiency
With regard to efficiency, it is not apparent whether this improved as a result of the project. Efficiency was not specifically addressed in the interviews with the managers nor the professionals. As mentioned in Chapter 2, the idea was for the project to improve the understanding of the service users' needs and preferences, which was in turn expected to improve their quality of life through incorporating this knowledge to the refreshed nursing care plans. Although the project helped to create awareness of the necessity to have such information (which was indeed collected at the beginning of the project), the knowledge was rarely used to enhance care.

Alutaguse, as an institution providing integrated services, inevitably reduces the care burden of those close to older people. Accordingly, institutions like Alutaguse provide carers with the opportunity to carry out fewer routine duties related to the service users, giving them the chance to engage them in the integrated service in ways other than physical care.

Prevention orientation
During the steering group meeting, both the professionals and managers expressed that prevention is important as it influences users' quality of life and that a new concept of the nursing care plan had been implemented. It is still too early to conclude anything about the outcomes of the project at the time of writing this report as they may not yet have taken effect.

Safety
Professionals expressed the view that safety was a natural part of their work, encompassing adapting the environment, mobility aids, fall prevention programmes and the possibility of having a personal alarm. However, rather than engaging the service users into improving their own safety, their carers merely inform them of the arrangements. For example, employees warn service users about a slippery floor or whether the blood pressure readings indicate that they are allowed to take part in an exercise class.

The nursing home may be a safe environment compared to the home, but this is passive in nature which may deteriorate service users' self-efficacy. Thus when service users express the wish to return home, they may have lost the ability to manage their lives on their own.

Moreover, the carers mentioned that they supervised the medication their relatives were taking and some indicated that the medication distribution rolls provided by the pharmacy were very helpful. In these rolls, medication is distributed in separate "tear-off" compartments which clearly indicate the amount and time of the day the medication needs to be taken. However, medication reviews by professionals, as an important component of the safety of older people, were not mentioned in the six care plans studied. Furthermore, the interviews with users and carers indicated that some of them had concerns about the medication prescribed. They wondered whether the medication was still necessary or were concerned about the side-effects. Most users and carers stated that as far as they knew a medication review had never been performed. Moreover, another important aspect of safety is that falls do not seem to be recorded routinely in care plans.

With regard to safety instructions, service users are given recommendations when they ask for them, but often the instructions tend to entail very general advice, e.g. recommendations are not linked to the person's current circumstances. For example, suggestions like "you need to walk" and "you need to exercise" could be inutile in cases where it is painful for the person to move. At the same time, professionals and other staff members (and even room-mates) may have much more of an insight and thus a more motivating effect on older people to remain physically and mentally more active. Thus, interpersonal relationships could be used more to help maintain the integrity and self-efficacy of the service users.

3.3 What are the explanations for succeeding and improving integrated care initiatives?

In the steering groups, the professionals suggested that the **supportive climate** of the organisation promotes the implementation of changes. The Alutaguse manager makes people feel comfortable enough to express themselves without fear of being criticised. The staff members involved in the improvement process felt free to say no: they could explain why they did not want something to change and how they saw their everyday work and opportunities to do things in a better way. They also expressed doubts on whether most clients would ever begin using their care plans or set goals for their lives.

The project had a solid start. The implementation of activities was led by the manager and key social worker. All of the scores presented in TCI were relatively high, especially in the beginning, indicating a positive team climate and readiness for change. The lowest score, 4.3, was given to "the team's objectives are achievable" in the first phase of data collection. Staff members prepared for change as part of **regular meetings** at which the need for and nature of person-centredness were clarified.

Periodic pressure from the steering group ensured that the improvement project was implemented, as it insisted on regular updates on progress. There was also the positive impact of having a small working group of dedicated key persons who could take decisions and make the improvement process smooth and quick.

In 2016 **a new occupational safety and health management strategy was introduced and successfully implemented** in Alutaguse. It created a good basis for further service improvements, and the team was ready for this. It was also mentioned by the Alutaguse management during the steering group that leadership from a third party (Praxis), especially in the early phase of the project (up to month 6), helped them to keep in mind all of the aspects of integrated care. The involvement of the local GP and the local social affairs official contributed to understanding the broader picture and the needs of different parties (primary health,

home nursing and municipal social services).

Moreover, they said that the **local government contributed** to the improvement process, making it easier. They were involved in discussions and gave an overview of local older persons' needs. For example, they discussed barriers to the sharing of delicate medical and social information and how it could be safe and responsible whilst giving older people timely and appropriate help. The social worker from the municipality was involved in the improvement initiative, giving feedback based on her experience with a person-centred way of working. Support and cooperation from the local government will help to resolve integrated care issues at the local level.

Service users recognised staff's enormous workload and tried to support them in fulfilling their tasks. This meant that the older people went along the new initiative and did what was asked of them.

"Sometimes a nurse will say there's no need to measure my blood pressure right now, we'll measure it in the morning, I've got a lot to do. And I said, well, if you've got a lot to do, then by all means, let's measure it in the morning. Because my blood pressure's high in the mornings. And then a nurse brings me a tablet and I take it and I get the help I need. It's fine". (User 6)

Because of this buy-in from the service users, the implementation of the integrated care approach is more likely to depend on whether the frontline staff embrace and drive the change. **The service users are likely to support the staff in the rearrangements.**

3.4 What are the explanations for not succeeding and improving integrated care initiatives?

Since there were no direct instruments with which to ascertain reasons for failure, the following chapter presents interpretations of the results – thus possibly a more subjective account.

There were several reasons for this fundamental change in plans, starting with the restrictions of **data protection regulations,** which need more time to be implemented in integrated care systems, and ending with employees' insufficient e-skills. But the most important reason stems from the fact that the tool is intended for a target group with a great deal of reduced physical and mental capacity. Retaining the idea that there cannot be a person-centred solution without input from the person themselves, the platform for collecting data cannot be a 100% electronic solution.

The primary **challenge was to involve all employees in the improvement process.** The immediate digital plan was cancelled because of uncertain needs (including for testing), IT development costs and low levels of IT knowledge

among staff. The central question which was raised pertained to implementation processes and work flow, and how to meet staff members' and users' needs smoothly. They discussed which language to use, which method to adopt and when to implement it so as to precisely and efficiently make it clear to both sides what the possible purpose of the care service was and what realistic action would have to be taken to meet clients' needs.

Staff members expressed that the objectives of organisation were worth the effort but they were slightly doubtful as to whether the team's objectives were achievable (TCI indicators 4.3 and 3.9, of a maximum of 5).

The interviews showed that **a more prevention-oriented approach is needed** but is hindered by the reluctance of the service users to express their needs and to take up services offered.

> *"S/he² is the kind of person who's ashamed to admit they're unwell. And in fact s/he is ashamed that s/he is feeble. All the more when people fuss around and do things for him/her. S/he gets quite embarrassed about that".* (Informal Carer 2)

> *"Do you need any physio or some gymnastics or a massage? Meaning, are there any other services that would help you? No, I've not used any of them. But have you been offered them? Yes, they've been offered to me. I just haven't wanted to use them".* (User 4)

In such a case, the assistance that ensues is inevitable. Assistance, however, reduces the possibility to maximise a person's efforts to remain independent.

In general, institutional care settings in Estonia tend not to direct older people to make a real effort in managing an independent life back home. Often it is taken for granted that the nursing home is the final destination. An older person's lack of sense of the future may be a crucial feature in being a relatively passive agent in their own integrated care system.

> *"Well, I still feel that I'm better off here. I can't cope on my own at home, with keeping the fire going and all. But everything's very nicely organised here. I'm not in need of anything. I've even laughed at the eat, sleep, eat, sleep routine!"* (User 5)

The analysis of the user interviews revealed that their relatively inactive participation in planning and implementing their integrated care may indicate **a lack of future prospects among older people.** This may lead to low motivation in making plans (setting goals) and for the staff to encourage the service user to do so. Still, long-term care should not be a series of episodes of short-term care, even if the users themselves expresses the wish to live a day at a time.

Those who live in a care home admit that the staff face an enormous workload and acknowledge **the lack of employees** in the health and care sectors. To be forthcoming, the service users wants to trouble the carers as little as possible. This could explain why older

people seldom discuss what is most important to them in managing their health and well-being. Instead, they avoid disturbing the professionals and turn to them only with topics of great importance, i.e., issues related to material things and physical suffering.

Family members seem to be a relatively untapped resource in nursing homes while many of them have expressed the willingness to be more engaged. This could help to relieve the workload of the staff and enhance the well-being of the service user(s). For proposals for the roles the family members could take in, see (Part 3).

The family of the service user may notice the shortcomings in the way their relative's needs are addressed and thus take it up with the staff. This may start a cycle where the **service user themselves is not included**, and thus remains passive, in discussions on their needs and preferences – **the conversation takes place between a family member and the professionals**.

Although staff members were prepared for change, the service users were not willing to actively engage in goal-setting and recording individual data on an everyday basis. To counter such disengagement, more emphasis may need to be placed on supporting service users' self-worth and on explaining the benefits of these practices. Another hypothesis is that frail people, often suffering from an acute disease or pain that uses up much of their energy, find it **difficult to think beyond their immediate needs without a systemic approach to support them**. The service users may fall into passivity and prefer to trust other people's decisions. However, in the interest of supporting and enhancing their wellbeing, it is vital they are asked.

Furthermore, the service user engagement should be adapted as an approach more widely not just in the care homes. For example, the many service user have had unpleasant experience with the Emergency Medical Care Department (EMCD). The participants in this study described **ageist and dehumanising behaviour by the medical staff,** which may have undermined the attempts at empowerment at the care home. Low self-esteem and self-stereotypes of inadequacy among older people and their informal carers reduce overall readiness to be active partners in an integrated care service.

There is some evidence that the staff found it **difficult to maintain the momentum of the change and thus may have fallen back to their previous procedures.** In the second phase of data collection the average of all TCI scores was lower than 4 for six indicators, among which "Preparedness for basic questions" had the lowest score (3.3) followed by "the team's objectives are clearly understood" and "time taken to develop ideas" (both 3.7).

Although the manager of Alutaguse is known as a change-oriented leader who values direct contact with service users and understands that to form new habits you need to understand old ones, the current project was likely too brief to get to know how older people think and their role

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² *The Estonian language does not distinguish between the two sexes in the third person, thus we cannot be sure which the carer meant.*

in care in light of their health and vulnerable psychological state. Older persons tend to need much more time than professionals can afford to discuss the factors involved in their well-being. **Staff need to be ready to provide more encouragement to service users**, and **empowerment needs to precede all other measures taken by staff**. Also, staff members need to embrace the responsibility to influence older people whenever possible.

4.   MAIN LESSONS LEARNED FROM ALUTAGUSE

From the analysis of the Alutaguse case, some key factors have emerged which have had an impact on the extent to which the organisation has been able to achieve its aims of an integrated and goal based **person-centred** care service.

4.1 Working towards integrated care improvements that could have an impact

There were several particularly influential factors affecting the implementation of planned efforts to improve collecting and sharing information in-house and a new concept of the nursing care plan. The SUSTAIN project has highlighted the complexity of the integrated service. The project had a solid start, with the Alutaguse management stating that **leadership** from a third party (Praxis), especially in the early phase of the project (up to month 6), **helped them keep in mind all of the aspects of integrated care.** At the same time, a new occupational safety and health management strategy was introduced and successfully implemented that created a good basis for further service improvements.

Also, both service users and informal carers highly appreciate the work the professionals and staff members do in Alutaguse. This emerged in comparison with other service providers.

The cooperation with the integrated service involves Mäetaguse municipality and local family doctors. They have linked operations to provide nursing and health care services before people come to the institution, so as to offer the best solution for what they have. Service range development aims to provide more integrated services in

the home. The involvement of the local GP and the local social affairs official in the project contributed to understanding the broader picture and needs of different parties (primary health, home nursing and municipal social services).

In addition to a wide range of partners with direct links to the integrated service, we also identified external players who are not directly related to the particular partnership of integrated care that influences the person's and their family members' ability to be an active agent in their integrated care. One such external player with a negative effect in the Estonian context is Emergency Medical Care Departments. **Ageism and dehumanising behaviour** need to be eliminated from the system before establishing a new type of service in which patients are expected to take an active role.

Family members are a relatively untapped resource in nursing homes. The individual scores from the survey indicate the need to engage family members more in the life of the nursing home. They can prepare for the integrated care service as partners equal to staff members.

Alutaguse recognised the need for better **staff training in the area of maintaining clients' physical fitness.** They need to be able to provide detailed and personalised preventive instructions instead of general advice like "you need to get moving" or "do more exercise". For example, in the case of a client's inability to walk, the professional needs to know and recommend what type of activities are available to the person to maintain their physical fitness.

More detailed client feedback needs to be collected in the form of a more in-depth face-to-face conversation, because formal ways of assessing individual needs do not reach into clients' more profound negative thoughts and fears, and desires seem to be hidden. For such in-depth regular interviews "senior field researchers" could be used in the

future – older local people who are specially trained for such tasks.

Underestimation of the emotional condition of older people is an overwhelming phenomenon and needs public discussion. We saw that patients only dare to discuss material things and physical suffering with staff; emotional concerns are not considered worth raising. One reason for this is that older person acknowledge **the enormous workload of staff members**, as well as the lack of professionals in the health and care sector. Older people seek to trouble professionals as little as possible. This could explain why patients seldom discuss what is most important to them in managing their health and well-being. Instead, they avoid disturbing professionals and turn to them only with issues of great importance, i.e. related to material things and physical suffering. One underused **resource is engaging family members** so as to **increase attention to psycho-social environments.**

For integrated care, **representatives from all relevant organisations need to be engaged**. Therefore GPs and care providers need to be included as well as hospitals, Emergency Medical Care Departments and family and community representatives. This must take place **via an information-sharing system in Estonia** – for example, **the e-health system** enables secure and timely connectivity across social and health services and between health and social professionals, but also between older people and their families. Such connectivity facilitates information-sharing and can support staff in making informed decisions in real time, encouraging all health and social services and policy initiatives to preserve and protect older people's sense of dignity and independence.

4.2 Working towards integrated care improvements that could be transferable across the EU

Findings from the Alutaguse case study demonstrate that features of **leadership and involvement** of service users, municipality, family doctors, and other wide range of professionals and family members **are key in service transformation.** Empowerment needs to take place at the administrative, legal and the individual level. It is a multidimensional social process through which service users and all counterparts gain better understanding of older people's needs which enables old people to gain better control over their lives. For an individual, empowerment is an important element of life quality. Greater participation among older people, family members or other informal carers requires more time for discussing the well-being of older people. The process of taking control and responsibility for actions leads to self-reliance, participation in decisions, dignity and respect belonging and contributing to a wider community.

4.3 Reflections and keypoints

This pilot project for planning and implementing a goal-based integrated care approach in the framework of a care home setting has huge potential in the context of ageing societies. The paper-based tool for information sharing was tested, and recommendations for the better engagement of all parties were provided.

The paper-based tool, the structure of which was developed during the project, helped to improve the quality of service in Alutaguse by enhancing the professionals' mindset regarding person-centredness, prevention orientation, and safety. The plan operates as a tool for keeping the essential aspects of person-centredness in mind when delivering care. However, this tool should be utilised repeatedly throughout the care spell to re-assess the needs of the service user.

There is further need for procedure development to achieve better engagement of patients and their family members.

It was also recognised that a **general shift in attitudes towards old age and quality of care form the prerequisites** for the implementation of the integrated care plan. Tools alone — whether paper-based or electronic — cannot guarantee the quality of a goal-based integrated care system.

4.4 Methodological reflections

It was difficult to find older people to participate in the process because of their conditions and their lack of ability (or motivation) to use the new integrated plan. This is a problem with a short-term project. In the case of an established, permanent integrated service, most older people obtain their plans when in a better condition. Hopefully the low motivation experienced by older people exists only in the context of the project.

All tools need to be designed taking into account users' limited vision and other reduced abilities by implementing principles of universal design.

The structure of an integrated, goal-based care plan should probably also have a special section for the implications of ageism perceived and recorded by older people or their family members.

PART 2
Medendi

5. MEDENDI: CHARACTERISTICS AND IMPROVEMENT PROJECT

5.1 General description of site

Medendi is a small private company which has been in business for 15 years. Home nursing aims to help service users who are recovering from operations, the elderly, the disabled and anyone who is in need of care for some other reason. Medendi provides individual processes that are mainly driven by coordination between medical providers and the locations of the persons served. Its services are delivered through a multi-agency partnership with other service providers. Primarily in cooperation with physiotherapists, family doctors and palliative nurses the best solution is found, and the task of home nurses is to efficiently help the people at home. There are 14 home nurses, three of whom are also involved in management. The organisation has an average of 180 service users in Tallinn and Harju County. All of the nurses have received specialist training and have years of experience in the medical field. All staff, including the manager and owner, do home nursing work. The company functions like a family firm. The team is united in a shared vision and shared values. However, quality rather than quantity of services has been the Medendi strategy. The company has become particularly effective at linking health and social services for users. Management argues that one of the main reasons for this is that they place high value on the role of nurses in delivering their services and are increasingly expanding their roles. This implies good cooperation within the health care sector and between the health and social sectors.

The main target group for home nursing care consists of people who do not need active treatment and are discharged from hospital. People over the age of 85 and then those in the 65-85 age bracket are the most common groups using home nursing in Estonia. Fewer than half of all service users are functionally independent and manage to take care of themselves, while half are partly dependent and around one-tenth are entirely dependent.

Hence a person using home nursing care in Estonia is typically elderly, chronically ill and with no prospect of recovery. Most service users have problems arising from a combination of illnesses.

The home nursing team consists of a home nurse and nurse manager. The home nurses meet with the manager once a week to discuss and analyse cases that are more problematic. The manager coordinates the nurses' activities, assigns nurses to service users (taking into account their workload and skills and the user's needs) and organises substitutions, work during holidays, etc.

The home nursing service as a primary-level nursing service needs to be available to every service user in need. It is necessary to attend an appointment with a family doctor to assess the need for home nursing. A family doctor or specialist can assess the need for home nursing and refer a person to the service. An older person, their family or social workers can also request home nursing. The service is funded by the National Health Insurance Fund.

5.2 Rationale behind improvement project

The fragmentation in health and social care results in inefficiencies in the provision of integrated care. This fragmentation is multidimensional, existing at the financial, organisational, professional and policy levels, and across care episodes, providers, settings and services (Paat-Ahi, G., Masso, M. 2018). Considering needs and expenditure, Estonia requires efficient coordination between health and social care to ensure the effective provision of tailored integrated care.

At the current level of development, the most appropriate model of integrated care for Estonia is that of a coordinating network. This network model implies that the people and institutions in the network have focussed their activities clearly on cooperation, but their ties are not necessarily firm, and the partners may change. In the case of such integration, relationships are formed on the basis of actions and contracts.

All parties need to understand that quality is defined as a multidimensional concept encompassing the effectiveness of care, service users' safety, responsiveness (or person-centredness) and the coordination of providers (Dandi, R., Casanova, G. 2012). The improvement project sought to address this by implementing and improving cooperation between the health care and social systems.

5.3 Aims and objectives of improvement project

During the problem-defining and needs assessment phase, the main problem was identified as a lack of cooperation between the health care and social systems, which is partly related to strict medical data protection regulations.

The plan was to develop a common IT platform accessible to the multi-professional team involved in home care. This intervention would actively involve older people in setting their priorities and making decisions about how they wish to support their health.

The project's goal was to increase the engagement of older people, their families, formal and informal carers and other specialists in the development of a goal-directed common care plan in order to deliver an individualised service. The target is to provide older people with access to the type of care they need efficiently, without any overlap or duplication.

5.4 Explanation of improvement project

The intervention required stringent legislation, interest and motivation among the participating parties and sufficient financial resources. This could be achieved by offering versatile cooperation, strong leadership and public agreements.

To enable this process the improvement project team needed to:
- identify the necessary steps to achieve the user's goals in a collaborative manner; and
- start working with users, their family members, caregivers and other professionals.

Steps to be taken:
- improve cooperation between health and social providers and informal carers;
- adjust the system to include all relevant information despite the system not yet being set up for this at the state level;
- establish an information interchange system (by setting up a digital information exchange system);
- divide tasks between participating parties i.e. between health and social providers such as family doctors, family nurses, social workers, hospitals, specialists and palliative care services; and
- reach agreements and make sure they are kept.

A summary of the key aspects of the improvement project and the key requirements of its implementation is shown in Figure 2.

The main risks associated with the project are not achieving consensus regarding what kind of information to share and with whom, and information flow becoming so extensive that it is not adequately comprehensible. These risks could be reduced through constant feedback and monitoring.
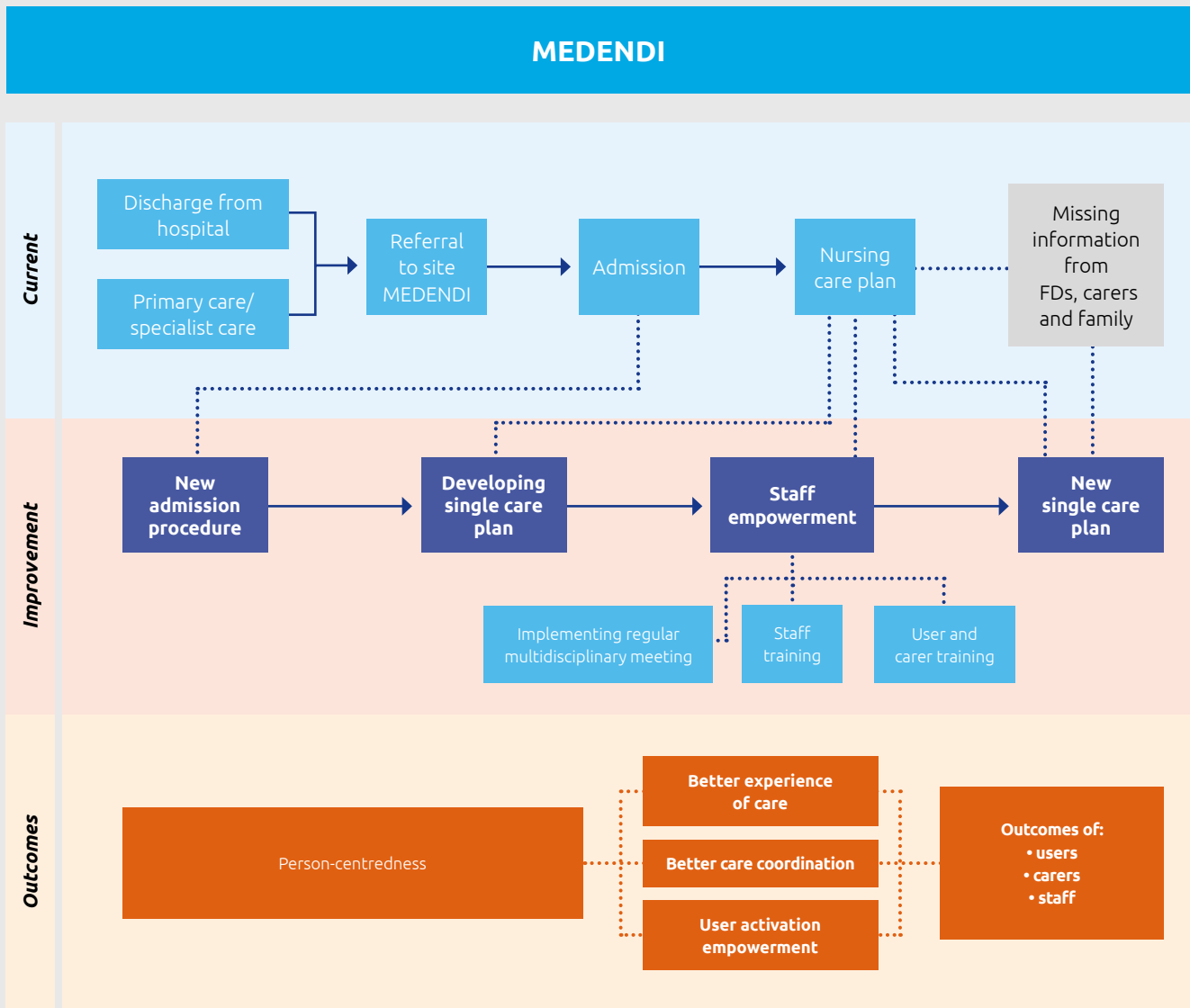
Figure 2 - *Flowchart of Medendi for improvement project and requirements of implementation.*

6.   FINDINGS OFTHE IMPROVEMENT INITIATIVE IN MEDENDI

6.1 Introduction

Researchers worked with the project team from October 2015 to identify stakeholders, form and support a steering group, specify the details of the improvement project and plan its implementation. The service was implemented in April 2017. Evaluation data were collected between April 2017 and April 2018. A summary of the data is shown in Table 1. The remainder of this section is based on an analysis of said data.

Our study included a female manager with high school education aged between 45-54 and the 13 female professionals, which reflects the gender demographic in caring professions. The manager was employed full-time as a member of management board Medendi Ltd. The manager worked for a private Healthcare organization (primary care).

The professionals' age range was 25-65 years, with no professionals in the youngest or oldest age groups. The most common age group was 45-54 (38%). Usually, we have a lack of professionals in the youngest age group. Approximately half of them are Estonian and another half Russian, work full time (69%), and all have a permanent employment contract. Majority of professionals have attained a high level of education (69%). All professionals represent the nursing staff, except the CEO who is also an active nurse and head of Medendi.

It was a small sample of eight informal carers. In Estonia, The Family Law Act provides a description of responsibilities children have for their elderly parents. The law does not regulate informal care, and there are situations in which the workload for carers is too high or simply unmanageable. In general, informal care is provided at home by the family and hence free of charge. Three informal carers were spouses of the users, and three informal carers were

daughters, one was a son, and one another family member. Seven of the carers were women, and only one man. The two informal carers were elderly, aged between 65-74, and one carer between 25-35. One carer had a low level of education, six had middle education, and one carer had a high level of education. Three carers lived with the users and five in close proximity to the user. Six informal carers had a paid job, and two were of retirement age. The average number of hours spent on caregiving activities was 24 per week, ranging from a minimum of 5 and a maximum of 80.

The sample at Medendi includes 24 users, two-thirds of whom were female, and approximately one-third of users were over the age of 85, and almost half of the users were 75-84 years old. Two-third of users attained a high level of educations, and 25% of users achieved a middle level of education. 33% of users were married, 29% of users were widowed, and 21% were divorced.

The users are either living alone at their homes (38%) or with a spouse/partner (29%) or at least one other family member (25%) (one living with a daughter, one living with a grandchild, and one temporarily living with daughter and granddaughter, and two living temporarily in a home for the elderly).

Users reported having between 3 to 10 different chronic conditions, with an average of 7 per user. The most frequent conditions were problems with vision (63%), diabetes (46%), dizziness with falling and hearing problem (37%) stroke (33%), incontinence (33%), broken bones (33%). Whereas anxiety, asthma, hip fractures (17%), depression, osteoporosis, dementia (13%) were less frequent.

Table 3 - *Summary of data collected for Medendi.*

Surveys	N = Total
P3CEQ (Person-centred Coordinated Care Experience Questionnaire)	24
PCHC (Perceived Control of Health Care)	24
TCI (Team Climate Inventory)	18
User Demographics	24
Carer Demographics	8
Manager Demographics	1
Professional Demographics	13
Care Plan Data	24
Interviews	
Dyad interviews (user + carer)	6
Professional/manager interviews	1
Steering group notes and reflective notes	
Meetings (steering group, intervention meetings)	6

6.2 What seems to work?

Coordination
Managers outlined that steering group meetings involved a great deal of inter- and intra-organisational collaboration. For example, a home nurse would call a GP or social worker. There was a lot of information sharing, identification of problems, thinking through improvements, etc.

The local authority's contribution to the improvement process in Medendi was considerable. The head of Viimsi municipality's Social Department and the key social worker were involved in the development process. The social worker worked with Medendi to pilot a new care plan for the clients and made alterations. The head of the Social Department decided that social workers would take responsibility for fulfilling the new joint care plan. The involvement of a local GP and a leader of municipal social issues encouraged all parties to understand the broader picture of the need for the involvement of different parties (primary health, home nursing and municipal social services)

  "*The service provided by Medendi's nurses was highly valued among service users. Their flexibility and availability were appreciated. "You can call the nurse even on weekends and in the evenings," the families engaged in the project point out*" (User 1, User 2).

During the project, the new admission procedure and the new care plan in the form of a goal-based diary were developed and implemented. The paper-based care plan was designed and adopted by all staff members, and service users started to follow it on a daily basis.

Nevertheless, based on management interview data as well as on TCI, which indicates obstacles in people keeping one another informed (4.2 and 4.0, both scores below the TCI average), there was a lack of a formal mechanism for sharing the content of the care plan among professionals and organisations related to a person's integrated care. For example, in one case the home nurse shared information orally or by sending e-mails to the doctor. This may lead to a more fragmented care.

There is evidence that carers are relatively isolated in dealing with care issues. Only three of 24 respondents had had care from further informal carers, such as acquaintances or neighbours. Thus, most of the care responsibilities fell on the immediate family.

The CEO and owner of Medendi is well-placed to achieve a highly coordinated service. Having had a leading role in the association and its home nursing special interest group for 15 years, she believes that:

  "*Nurses are the only trained health care workers who can practise across the spectrum of people's needs, and in such diverse settings hospitals, assisted living centres, home care or at a family doctor's office or during surgery. They often assume multiple roles simultaneously, encompassing carer, coordinator, communicator, teacher, coach, manager, team member, motivator and delegator. They are in the unique position of knowing how well or otherwise the health policy or framework underpinning existing integrated care delivery is working*".

Medendi's home nurses are therefore often the primary care providers for users receiving its services. They provide both medical and non-medical services to support people in living their lives to the fullest and remaining in their homes for as long as possible.

Person-centredness

According to PCHC data, the most significant supporters of service users are family members (7.9). Half of all older people had joint control of their care with family members (50%), while one-third (38%) felt independent in their decisions related to care (38%). Family support is most keenly expected when it comes to information, while the second most critical issue is financing. At the same time, family members are not prepared for such duties, as these obligations are often of a professional nature.

"I do the injecting, yes. Once a month, on the 15th. I wasn't instructed how to do it — I just started doing it myself. It's not rocket science. I've even been over to give my neighbour an injection". (Carer 9)

"I've not had any practical training. First, I was looking after my grandmother — she was bed-ridden before my mother-in-law was. And secondly my mother is a medic. So, I'm in an advantageous position". (Carer 7)

The service users agreed that the home care nurse respects the users, and this engenders cooperation and trust. Users and informal carers perceive strong support from the home care nurses.

Efficiency

The steering group members felt that throughout the improvement process, the partners (see above) found reasons for greater collaboration – to understand efficiency and serve the same manager. This improves the likelihood of better outcomes for everybody: the service user, their family member(s), the service manager, the home nurse, the municipality and the GP are better able to achieve a more holistic care.

Overall, the care plan is seen as a tool for professionals rather than users. According to P3CEQ, the paper-based care plan helped 14 professionals to better coordinate their service.

Prevention orientation

Several older people expressed the expectation of professional advice from their home nurse related to their potential demands for extra equipment or medical services.

"Nobody says anything. Basically you just have to know it yourself — nobody tells you anything. Not in the Social Department, no one tells you what you'll need. I know I need a wheelchair, but if I needed something else as well and I was able to get it, there's no one I can ask, or at least no one tells me, and then I don't know either". (User 4)

Analysis of care plan data indicated that mental health services were included in the care plan for only one user, while 30% of clients reported suffering from depression.

Also, older people in hospital would like to have a doctor being assigned to them personally. For proper treatment an older person needs to interact with their doctor and nurse, and this is impossible if the doctor only "communicates" via the results of diagnostics or the patient has no assigned nurse or doctor.

With regard to safety instructions, service users had received recommendations from the service provider when they asked for them. Home visits by nurses on a regular basis are perceived by informal carers as something that creates a feeling that everything related to safety is under control.

"Well, I guess it's support of a sort that Liina [the home nurse] comes and sees me. That way I'm sure there'll be someone to ask if I have questions". (User 11)

"My home nurse knows that I need that reassurance that everything's just the way I think it should be". (User 17)

"Well, they could give me the once-over from time to time to check what I'm doing and whether I'm doing it right. At the moment there's no initiative coming from outside – you have to give them a sign yourself". (User 4)

As such, for many families the permanent GP and nurse form part of their security plan. In terms of real security measures, serious consideration should be given to the fact that clients and their family members do not take the need for the provision of security seriously. One detailed conversation revealed that a mobile phone is considered the main tool for security, even if it is useless in reality.

"Readiness plan? I call the ambulance, and that's my plan. Yes, I still have a mobile phone in my pocket. But, of course, now, yes, it's unfortunate that my eyesight has almost gone. I can't see the numbers on the buttons, so there's no plan." (User 7)

Several misconceptions were revealed: security should only be provided by a relative, and there is no need to think about a security plan if you know people with more severe limitations. Control visits conducted by the team of integrated care or volunteers would help to stimulate readiness for possible emergency situations. The family needs help from outside to prepare a security plan because otherwise the focus on acute health problems obscures the broader view.

In Medendi it was also recognised that there is a need for better staff training in the field of maintaining people's physical fitness and psychological health. Team members need to be able to provide detailed and personalised preventive instructions instead of general advice like "you need to do more exercise". For example, in the case of service users' bedsores, professionals need to know and recommend activities that are available to the person to maintain their physical fitness. Information about extra equipment or medical services for future needs, as well as the accessibility of local public places and possibilities for personal development and fulfilment, need to be shared by the service provider by visiting the person.

Several older people expressed their expectation of professional advice from their home nurse related to their potential demands for extra equipment or medical services.

"Nobody says anything. Basically you just have to know it yourself – nobody tells you anything. Not in the Social Department, no one tells you what you'll need. I know I need a wheelchair, but if I needed something else as well and I was able to get it, there's no one I can ask, or at least no one tells me, and then I don't know either". (User 8)

Analysis of care plan data indicated that mental health services were included in the care plan for only one user, while 30% of clients reported suffering from depression.

In Medendi it was also recognised that there is a need for better staff training in the field of maintaining people's physical fitness and psychological health. Team members need to be able to provide detailed and personalised preventive instructions instead of general advice like "you need to do more exercise". For example, in the case of service users' bedsores, professionals need to know and recommend activities that are available to the person to maintain their physical fitness. Information about extra equipment or medical services for future needs, as well as the accessibility of local public places and possibilities for personal development and fulfilment, need to be shared by the service provider by visiting the person.

Safety

While the service manager reported that the care plan make it more likely for the home nurses to pay attention to a wide spectrum of needs, our data currently offers no indication whether this is or is not the case. It may be that the implementation of the care plan is a first step and its outcomes become evident later.

6.3 What are the explanations for succeeding and improving integrated care initiatives?

Strong organisational acceptance of visionary leadership culture has helped the improvement process. The leader of Medendi has the positivity to lead a new initiative in a way that all staff feel secure sharing their thoughts and raising objections.

Ongoing leadership at a strategic level ensured that the improvement project pressed on with implementation by insisting on a start date and regular updates on progress. Having the right people in the group (including both operational and management staff) and flexibility of membership so that new people could come in meant that the steering group could understand the issues and challenges and ensure a good fit in the wider context.

Medendi is professional in the way it provides services. It does what it does well – better than most service providers

in the sector. The leader appears to be charismatic and has strong values regarding meeting service users' needs. She is highly focused on providing quality, rather than quantity.

The discussions in the steering group and the staff focus group suggested that the team at Medendi was well-placed to implement the SUSTAIN project and interested in making the transition to an integrated e-health system. The organisation promotes the use of e-records to manage service user information responsibly and professionally. Staff have been trained to include all relevant information, despite the system not yet being set up for this. They receive support for investing time and resources in improving relationships between health and social providers. High motivation among employees to make changes and not let extra work cause them to be stressed has also been constructive.

Although Medendi is promoting the use of e-records to manage service users' information, only paper-based care plans were used in the SUSTAIN project. Still, every older person had a paper plan and that could be considered a success factor in the project since it may have helped to coordinate the service better to address service user's needs. Service users indicated a high level of satisfaction with the home nurse service. In addition, they recognise the enormous workload of their service providers and acknowledge the lack of professionals in the health and care sector in general. Therefore, they take every request made by their home nurse as a personal request for help. Therefore they were very much ready to fill in the integrated care diary. However, many still felt there was little point in doing so or were otherwise unable to maintain the diary.

Generally, informal carers have experienced the medical services becoming friendlier for patients (e.g. getting prescriptions) because the attending doctor has quick access to the patient's complete health information (via the health information system).

6.4 What are the explanations for not succeeding and improving integrated care initiatives?

The phenomenon of integrated care can be defined as a coordinated mix of services (primary care, nursing, social work, etc.). But there are also other ways of increasing the level of integration within a care service. The interviews showed that the service of a home nurse is somewhat limited to what is prescribed by a doctor leaving the full set of knowledge, skills and potential of an experienced nurse unused. For example, addressing the issues of declining wellbeing.

"Home nurses aren't allowed to give advice or deal with problems not related to the task the GP has assigned them." (User 9)

Some patients have been fighting for the right to be involved in discussions. However, the ability to stand up for yourself depends on the condition of the patient. A distressed person (either patient or caregiver) will not fight for themselves. Self-assertion is also hindered by the perception that treatment may no longer be valid. Patients do not want to waste a doctor's or nurse's time, and there is the perception that doctors should deal with treatment, not negotiations.

Professionals underestimate the ability of the elderly to represent themselves and often cut them out of conversations. The elderly feel invisible when doctors and their family members make decisions regarding them. Official communication is directed at the caregiver/accompanying person. Thinking along and engaging in discussion have also been made impossible because of the professional terms used by medical professionals. This is one of the reasons the question about the importance of personal wishes was perceived as nonsense ("a stupid question"). Demands regarding quality of service are relatively low.

Since the structure of the integrated care plan has not received any recommendations or critical feedback from professional users, it can be considered a good example of collecting diverse, person-centred information that is useful for professionals. At the same time, there is room for development. Interview data revealed, for example, a range of signs of ageism experienced by clients and their informal carers, e.g. by ambulance crews or emergency department staff. Taking into account the paralysing effect of ageist behaviour on a person's ability to assert themselves, we recommend recording the implications of ageism in a care diary and integrating these data into the service. In addition, several service users (11 of 23 respondents) highlighted the fact that professionals often discuss things with their families rather than with them personally. So…what does this mean in term of person-centredness?

"The eye doctor spoke to my son-in-law more than he spoke to me. He thought I was a silly old fool. While he was checking my eyes I was visible, but the rest of the time I was invisible! [Laughs] It did make me laugh". (User 10)

If the primary source of information is not the person themselves, it is impossible to introduce the service as a personalised one because only a secondary source of information is used.

A better fit with personal circumstances needs to be achieved by professionals of integrated care in preventive and rehabilitation work. Service users have perceived a lack of detailed and personalised preventive instructions related to their physical fitness.

"They said I should exercise more and lose weight. I don't get it, though – if my legs don't work and my spine is knackered, how am I supposed to do more exercise, lose weight? But that's the only advice I get – exercise and lose weight. They never say how I'm supposed to achieve either of those things. So how do I go about it?" (User 11)

The team of integrated care needs to be able to recommend activities that are available to a person in order to maintain their physical fitness.

In their interviews, some of the service users expressed the opinion that filling in the diary felt like an obligation instead of a personalised tool for personal purposes.

"The nurse wants me to fill in some booklet, but I can't remember where I put it". (User 12).

Furthermore, according to P3CEQ, of the 23 respondents, as many as 14 considered the care plan rather useless for them personally (0.78) and the other nine respondents gave no answer to the question.

The older people also expressed confidence in the professionals and therefore were simply not interested in becoming involved in their work.

"I take the medicine, and that's enough". (User 13)

As long as the care plan seems to be related to medical issues, it is somewhat challenging for them to oppose it.

The lack of a flexible transport service seems to be of greatest contributor to the passivity and low quality of life among frail people in homes.

"And of course the biggest problem for everyone is transport – how to get to the hospital and how to get back again. Both my son and daughter have cars, but they both work and they're both teachers, so they can't come and chauffeur me around in the middle of the day. How can they make that work and take turns? Everyone knows teaching's a profession where you can't just ask for two hours off". (User 14)

Flexible transportation for disabled people should be available for necessary trips (like visits to a doctor) as well for activities that satisfy people's emotional, social and intellectual needs, because older individuals should be considered as a whole.

Generally, informal carers have experienced that medical services are becoming more friendly for patients (e.g. getting prescriptions) because the attending doctor has quick access to the patient's health information (via the health information system).

This result is in line with the desire expressed by respondents who miss communication with professionals with no strict time limits.

"I don't know how to improve my health. Sometimes I would like to be with someone who at least listens to me". (User 15)

The quote indicates the lack of psychological support for clients. Moreover, the PCHC indicators showed that it is somewhat difficult for people to adapt to setbacks (3.0 on a 5-point scale) and assert themselves (3.1).

At least for current older generations, e-platforms are

acknowledged as being inaccessible to many older people, and the personal engagement, person-centredness and goal of empowerment are not achieved by using e-platforms alone.

One of the reasons for a lack of procedure for sharing care plans stems from the fact that the integrated care plan is not electronic as was initially planned in the project. At the same time, it is unreasonable to assume that frail clients will fill in a diary using a smartphone, tablet or computer. As such, there are two main actors whose needs are contradictory to some degree – professionals from different organisations; and service users with limited ability to use electronic devices. Any future solution should meet the needs of both parties. The process of sharing the content of the care plan among professionals, organisations, service users and informal carers needs to be described in a way that considers the real abilities of the main target group.

Preventive activities targeted at informal carers tended to be inadequate. One main actor in integrated care is the informal carer of the service user.

The scope of the home nurse service has mainly been focused on specific medical procedures prescribed by a doctor. On the one hand, the authority and rights of a home nurse are relatively limited. On the other hand, the price of the service is calculated on the basis of a visit, not taking into account the time spent by the nurse conducting the visit. Therefore, the structural limits on the provision of integrated care need to be recognised.

The engagement of service users was perhaps too superficial during the project. The phase of motivating participants and clarifying the benefits of the integrated care plan need to be planned and explicitly highlighted. A non-medical side to care needs to be introduced and emphasised among service users. It is also important to recognise that the ability of older people to stand up for themselves depends on their current condition. A distressed person, either a service user or a caregiver, tends not to fight for themselves and therefore attention should be paid to the emotional state of the client. The assessment of needs should provide services proactively, e.g. by calling on a doctor to visit simply for precautionary reasons.

The service provided by Medendi's nurses is highly valued among service users. Their flexibility and availability is very much appreciated. The owner of Medendi selects her staff carefully and makes an effort to maintain high standards of service as described in the project case.

7.   MAIN LESSONS LEARNED FROM MEDENDI

7.1 Introduction

Considering the unique position of a home nurse — who works in close contact with service users and informal carers on a regular basis — the mandate of a **nursing** institution should have a **wider scope** and its financing needs to be in line with the actual workload. The phenomenon of integrated care can be defined as a mix of services (GP, nurse, social worker, paramedic, etc.). But there are also other ways of increasing the level of integration in care service, e.g. by broadening the range of functions of a home nurse.

A service provider like Medendi should carefully maintain and develop staff not only for service standard reasons but also for supporting a sense of security among clients. Switching home nurses or GPs has damaging consequences for older service users and reduces the sense of security and stability.

Informal carers need to be treated as equal partners in the model of integrated care, while GPs should observe the condition of caregivers preventively and treat them simultaneously as both colleagues and patients. GPs and nurses do not pay attention to the informal caregiver as a vulnerable person.

Information about possible extra health services and tools is insufficient. The patient only receives information on such services upon asking the right questions. There is an acute need for smooth and consistent consultation — the nurse should note a potential need for equipment or extra medical services and share information about alternatives. Nurses complete relatively small tasks, and they are not allowed to give advice or address problems not related to the function the GP has assigned to them. The nurse's mandate, in general and for the duration of the phone consultation service, ought to be more extensive.

Since ageism has a paralysing effect on a person's ability to assert themselves, **we need to reduce practices that de-personalise the person in need** (e.g., only asking the

(informal) carer to answer questions). There could also be a section for adverse events, such as experiences of ageist behaviour as perceived by patients or their family members recoded in the integrated care plan.

Underestimating the emotional condition of older people is an overwhelming phenomenon and needs public discussion and further attention. Their lack of motivation to become involved and take a more active role in cultivating their care experience should be addressed by everyone involved in order to maintain a sense of purpose and future in their lives.

Paper-based tools should not automatically be considered old-fashioned or less promising than entirely electronic systems. Considering the frail target group, both, electronic data as well as audio-recorded and written data needs to be utilised. The printed version was poorly designed, not taking into account the fact that users might not be able to read small text. This is a major issue of universal design, one which must take into account the needs and restrictions of all care plan users. Doing so will guarantee the continuous inclusion of clients and their input into integrated care.

A relatively simple service that is easy to implement in the 21st century is flexible transport for clients with varied physical, mental, intellectual, social and emotional needs. This should be integrated into the medical and social care service as well.

7.2 Working towards integrated care improvements that could have an impact

Any future electronic solution for integrated care should meet the needs of all parties involved. In the context of the frail target group, the developments need to support

the mixing and sharing of any data, be it electronic or handwritten, video, image or audio.

The list of integrated care services needs to be broadened by adding services, including a transport-on-demand service enabling, among other things, clients' emotional, social and intellectual needs to be met. Also, preventive rescue work which can be prepared and provided on a voluntary basis should be included in integrated care.

The basis of price calculation for the integrated service needs to be reviewed. The current price only takes into account the event of a visit, but the time spent on conducting the visit by the nurse needs to be considered as well.

The structure of the integrated care plan needs to be developed further and a section for more social measures (like signs of ageist behaviour and other reasons for changes in emotional states) needs to be integrated into the current structure.

Further research is needed to develop and test models of integrated care in which informal carers are included as partners equal to professionals.

7.3 Working towards integrated care improvements that could be transferable across the EU

The nursing care plan which has been developed is transferable to other similar organisations as well as to anyone at home. The care plan was designed in such a way that the focus is on the older people who need a simple tool wherein they or their family members can write down and follow their care needs. The person-centred nursing care plan is comprehensive and universal. It encompasses the user's diseases, needs, goals, contact details, etc. The ageing of the population has a number of consequences, which to a greater or lesser extent are to do with health and decreased functional ability. Awareness on issues requiring further attention and professional support might prevent deterioration. This simple but comprehensive paper-based nursing care plan makes it easier for professionals to share relevant information and help provide the right services in a timely manner. It makes it possible to overcome challenges that the information system exposes, like data protection regulations, and also helps to break down two-system segregation.

7.4 Methodological reflections

The aim of the improvement process was to identify patients who needed many different services, but such patients were not found in great numbers. The reason for this was not so much the lack of cooperation between the two (the social worker from the municipality and the home

nurse from Medendi), but the fact that the patient often received services from only two service providers (usually a home nurse and a social worker). Also, most Medendi patients are already in poor condition and need end-of-life care, so they are unable to use the plan.

7.5 Reflections and keypoints

The paper-based tool, which was developed and implemented during the project, helped take the next step towards integrated care in Estonia by making care services more person-centred. Based on this experience, Medendi is currently helping the Estonian state to implement a relevant section in its national electronic patient record (e-health).

The process of data collection from different parties, including the client themselves, was implemented but the process of systematic data sharing is still obscure. There is also a further need for procedure and motivation measures to achieve the better engagement of patients and their family members.

It was also recognised that the general shift in attitudes towards old age and quality of care form prerequisites for the implementation of the integrated care plan. Tools alone, be they paper-based or electronic, cannot guarantee the quality of a goal-based integrated care system.

PART 3

8. OVERALL (NATIONAL) REFLECTIONS

8.1 Introduction

In the previous chapters we described the experiences that we acquired in the context of improving integrated care in Alutaguse Care Centre and Medendi. At both sites the aims were to improve communication, collaboration and coordination of care, while considering the views and needs of frail older people and their families. The primary need for improvement at Alutaguse is in information sharing and communication within the organisation as well as the within the whole field.

While the plan implemented at Alutaguse focused on frail older people living mainly in a care home, the Medendi initiative focused on frail older people who needed more medical care but were living in their own homes. This chapter highlights some of the lessons learned from both sites (section 8.2). Based on these lessons, we aimed to formulate policy recommendations and recommendations for service providers, which are outlined in sections 8.3 and 8.4, respectively. The end of the chapter contains general conclusions (section 8.5).

8.2 Implications of SUSTAIN for integrated care in Estonia

The project focused on the service users' perspective on integrated care allowing for an understanding of clients' ability to be engaged and their intention to be committed to improving the service. To date mainly service providers, financing institutions and administrative institutions have been included in research and monitoring.

SUSTAIN is one of the few studies in which the frailest part of the society formed the main group of participants. We

suggest there is a need for further research to develop methods of researching frail people over a longer time span.

Service user participation is not an inherent part of the services and this needs to be carefully cultivated. To avoid a tokenistic approach, the staff as well as the service leaders need to be trained. In addition, procedures for such information flow need to be put in place and the feedback needs to be considered for service improvement in a transparent fashion. It is essential that the interest to learn more about service users' and their families' perspectives is genuine and seen as a unique insight that helps to improve the service.

We found some evidence for **gaps in the services** offered to our participants. Particularly when it came to mental health needs. The service users only expected their very basic survival needs (nutrition, hygiene, pain management) to be met and thus did not consider emotional needs worth discussing with the staff. At the same time, a sense of hopelessness and learned helplessness surfaced in the interviews suggesting the services could do more to improve wellbeing.

A related issue is the fragmentation of services which leads to **poor exchange of information** between the services that in turn translates to unmet needs for service users. For example, home nurses need to follow a strict protocol regarding physical health procedures and thus are less likely to notice additional needs, including those of mental health. Still, home nurses may be best placed to notice any additional problems the service user might have.

Additionally, such segregation means that when going to a specialist, the service user may have to recount their whole anamnesis. This carries the risk of some relevant

information will not be communicated. Additionally, it may erode service users' confidence in the services. Indeed, when conducting this study, the research team found it difficult to establish the variety of services our participants were receiving or had received. This project and its results illustrate the need for social care and welfare services to be integrated to the existing e-health system (or similar) allowing for seamless information sharing.

We found that both, Alutaguse and Medendi, are already trying to bridge the gap between services with the means available for them. A wider policy framework would help (see below).

An **untapped resource** we identified **is that of the family**, other service users and the community. We found that the families were open to be considered as partners in care provision and be trained to care for their member of the family. More informally, one participant said that encouragement from their roommate in the care home helped them to be more physically active.

8.3 Policy recommendations

- **Improve information sharing** between services providing care for older people. Therefore, GPs and care providers as well as hospitals, Emergency Medical Care Departments and community and family representatives need to be included. This must take place via an information sharing system in Estonia, for example the e-health system, which enables secure and timely connectivity. Such connectivity would facilitate information sharing and can support staff in making informed decisions in real time.
- **Improve care-coordination** between health and social care. This is critical in ensuring the effective provision of long-term care. Currently, in Estonia, long-term care is fragmented across care episodes, providers, settings and services with little coordination and information sharing. This also includes improved referral procedures.
- Include **systemic thinking** about services as well as service users into the curricula of professionals' training.
- Mandate **a stronger emphasis on mental health needs** in the care for older people. This could include changes in the curricula for nurses and doctors as well as changes in the procedures for care.
- Establish a platform that facilitates **relationships between different organisations** and staff. When we hosted the launch event for SUSTAIN for different stakeholders, the guests found it empowering and consoling to learn about others with similar issues.

8.4 Recommendations for service providers

- Institutions providing full-time nursing care, a GP service or home visits should **widen their scope**. Firstly, informal care providers need to be partners as well as a target group for preventive activities. Secondly, medical and care institutions should take more responsibility for educating possible target groups and sharing preventive knowledge and skills. Clients expect GPs to take the initiative.
- **To enhance capacity**, institutions like Alutaguse could **engage family members** on a voluntary basis in a more targeted way by training and giving them specific roles within the service. This would require coordination of such volunteers. A similar approach is employed in palliative care in Diakooniahaigla.
- The project results revealed that the patients tend to be rather passive in having a say in their care plan. Service user participation should include procedures by which the care plan, the objectives and outcomes are regularly reviewed with the service user and changes implemented where the need is identified. We found evidence that while the service users may have been included in developing their care plan at admission, they were not asked to give feedback or to express their opinions later during their stay.
- **All staff** should be **trained to notice signs of mental health problems** and how to help service users access help.
- **Ensure promotion of good mental health, prevention of mental health problems and early identification of mental health problems in care settings**. This could take the form of a designated mental health worker, teaching users' strategies to take care of their mental health and/or access to a mental health professional to identify problems early. Underestimating the emotional condition of older people is an overwhelming phenomenon and needs broader discussion. In our experience, service users only dare to discuss material things and physical suffering with staff; emotional concerns are not considered worth raising.
- Improve physical activity in service users. For example, Alutaguse employs a physiotherapist and an occupational therapist. Physical activity is related to both, an ability for an independent living and is a premise for good mental health.

8.5 Conclusion

The results of the SUSTAIN project in Estonia helped to generate discussion about the ways in which to engage clients in the planning and implementation of their integrated care service. All of the activities comprising the project helped to enhance professionals' mindset of **person-centredness, prevention orientation** and **safety**. The improvement plan has improved the quality of the integrated service because all professionals observe and follow the complete list of indicators essential to a patient's well-being, and there are fewer possibilities to forget certain aspects.

The project raised several questions for further research and highlighted certain issues in the methodology. Findings and recommendations for service providers will certainly help to implement a goal-based integrated care tool of this sort in other similar organisations.

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10. ANNEXES

10.1 Practical measures for monitoring outcomes and progress of the implementation of the improvement plans.

Item	Data collection tool	Short description
DEMOGRAPHIC INFORMATION		
Socio-demographics of older people (users)	Demographic data sheet – older people, administered to older people	Survey developed by SUSTAIN researchers requesting information on age, gender, education, marital status, living situation and self-reported medical conditions
Socio-demographics of informal carers	Demographic data sheet – carers, administered to informal carers	Survey developed by SUSTAIN researchers requesting information on age, gender, education, marital status, relationship and distance to older person (user), paid work and caregiving activities
Socio-demographics of professionals	Demographic data sheet – professionals, administered to professionals	Survey developed by SUSTAIN researchers requesting information on age, gender, nationality and occupation
Socio-demographics of managers	Demographic data sheet – managers, administered to managers	Survey developed by SUSTAIN researchers requesting information on age, gender, nationality and occupation
OUTCOMES		
Person-centredness		
Patient perceptions of quality and coordination of care and support	The Person Centred Coordinated Care Experience Questionnaire (P3CEQ) (Sugavanam et al., under review), administered to older people	Survey measuring older people's experience and understanding of the care and support they have received from health and social care services
Proportion of older people with a needs assessment	Care plan template (in case sites do not work with care plans, information will be retrieved from clinical notes or other documentation)	Template developed by SUSTAIN researchers for predetermined content analysis of care plans of older people
Proportion of care plans actioned (i.e. defined activities in care plan actually implemented)		
Proportion of care plans shared across different professionals and/ or organisations		
Proportion of informal carers with a needs assessment and/or care plan		
Perception and experiences of older people, informal carers, professionals and managers with person-centredness	Semi-structured interviews and focus group interviews with older people, informal carers, professionals and managers	Interview and focus group schedules developed by SUSTAIN researchers including interview items on perception and experiences with receiving person-centred care

Item	Data collection tool	Short description
PREVENTION ORIENTATION		
Perceived control in care and support of older people	Perceived Control in Health Care (PCHC) (Claassens et al., 2016), administered to older people	Survey addressing older people's perceived own abilities to organise professional care and to take care of themselves in their own homes, and perceived support from the social network
Proportion of older people receiving a medication review	Care plan template (in case sites do not work with care plans, information will be retrieved from clinical notes or other documentation)	Template developed by SUSTAIN researchers for predetermined content analysis of care plans of older people
Proportion of older people receiving advice on medication adherence		
Proportion of older people receiving advice on self-management and maintaining independence		
Perception and experiences of older people, informal carers, professionals and managers with prevention	Semi-structured interviews and focus group interviews with older people, informal carers, professionals and managers	Interview and focus group schedules developed by SUSTAIN researchers including interview items on perception and experiences with receiving prevention-oriented care
SAFETY		
Proportion of older people receiving safety advice	Care plan template (in case sites do not work with care plans, information will be retrieved from clinical notes or other documentation)	Template developed by SUSTAIN researchers for predetermined content analysis of care plans of older people
Proportion of older people with falls recorded in the care plan		
Perception of older people, informal carers, professionals and managers with safety	Semi-structured interviews and focus group interviews with older people, informal carers, professionals and managers	Interview and focus group schedules developed by SUSTAIN researchers including interview items on perception and experiences with receiving safe care, and safety consciousness
EFFICIENCY		
Number of emergency hospital admissions of older people	Care plan template (in case sites do not work with care plans, information will be retrieved from clinical notes or other documentation); template to register staff hours and costs	Template developed by SUSTAIN researchers for predetermined content analysis of care plans of older people; template developed by SUSTAIN researchers to collect data on costs and the number of staff hours from local services, organisations or registries
Length of stay per emergency admission of older people		
Number of hospital readmissions of older people		
Number of staff hours dedicated to initiative		
Costs related to equipment and technology or initiative		
Perception of older people, informal carers, professionals and managers with efficiency	Semi-structured interviews and focus group interviews with older people, informal carers, professionals and managers	Interview and focus group schedules developed by SUSTAIN researchers including interview items on perception and experiences with receiving efficient care, and finances

Item	Data collection tool	Short description
IMPLEMENTATION PROGRESS		
Team coherence of improvement team (professionals)	Team Climate Inventory – short version (TCI-14) (Anderson and West, 1994; Kivimaki and Elovainio, 1999), administered to professionals	Survey measuring vision, participative safety, task orientation and experienced support for innovation of the improvement team
Perception and experiences of professionals	Focus group interviews with professionals and minutes from steering group meetings	Focus group schedule developed by SUSTAIN researchers including interview items on experienced factors facilitating and impeding outcomes and implementation progress Minutes cover progress, issues and contextual issues impacting on outcomes and implementation progress
Perception and experiences of managers	Semi-structured interviews with managers and minutes from steering group meetings	Interview schedule developed by SUSTAIN researchers including interview items on experienced factors facilitating and impeding outcomes and implementation progress Minutes cover progress, issues and contextual issues impacting on outcomes and implementation progress

SUSTAIN

Sustainable tailored integrated
care for older people in Europe

Tallinn, 2018