SUSTAIN
Sustainable tailored integrated care for older people in Europe

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

Lessons learned from improving integrated care in Europe

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Executive summary with key points

Integrated care programmes are increasingly being put in place to provide care to older people who live at home with multiple health and social care needs. Improvements to the current way of working in existing initiatives are considered necessary, to make them more person-centred, prevention-oriented, safe, efficient and coordinated. Knowledge of how to further develop integrated care and how to transfer successful initiatives to other contexts is still limited. To take a step forward in the development of integrated care, the cross-European research project 'SUSTAIN' was initiated with a twofold objective: 1 to support and monitor improvements to established integrated care initiatives for older people living at home, and in so doing move towards more person-centred, prevention-oriented, safe, efficient, and coordinated care; 2. to contribute to the adoption and application of these improvements to other health and social care systems, and regions in Europe.

In the project, thirteen established integrated care initiatives from seven European countries designed and implemented projects to further improve existing practice, together with SUSTAIN researchers. The initiatives experienced quite similar challenges in their current ways of working, despite differences in their characteristics and contexts within which they operated. Upon these challenges, improvement projects to tackle these challenges were developed. Two types of improvement projects were identified: 1. projects that primarily focused on improving or expanding collaboration, communication, and coordination between different health and social care organisations, and 2. projects that primarily focused on improving the actual care delivery process.

Integrated care sites undertook different types of integrated care activities in order to deliver and improve person-centred, prevention-oriented, safe, efficient, and/or coordinated care. As part of the SUSTAIN-project, sites either implemented additional activities to improve these aspects or revised existing ones.

The key lessons learned are that improving integrated care is an incremental process that takes time, for which an enabling environment needs to be created, and which is dependent on several factors at different levels of countries' health and social care systems. Factors influencing (un)successful implementation of integrated care activities were quite generic among the different integrated care sites, despite differences in integrated care initiatives and health and social care systems across countries. Commitment of professionals and managers, leadership and ownership, and policy and legislation influenced to a great extent the successful or unsuccessful implementation of integrated care activities.

Based on the lessons learned, sets of recommendations to policy-makers, service providers, and the research community to (further) improve integrated care delivery across the EU have been formulated. Sharing lessons learned can inspire and influence other initiatives and countries undertaking similar efforts, and as such contribute to improving care for older people living at home.

CONTENTS

1. INTRODUCTION

1.1 What is the status of integrated care in the EU?

An increasing number of older people with multiple health and social care needs live in their homes and communities until old age. Their complex care needs require multidisciplinary collaboration and coordination. Integrated health and social care is regarded as a promising approach for organising continuous and person-centred care for older people with complex needs living at home (Boult et al., 2009; De Bruin et al., 2012; Gress et al., 2009; Hopman et al., 2016; Mattke et al., 2007; Wagner et al., 2005; World Health Organization, 2016). We define integrated care as those initiatives that proactively seek to structure and coordinate care and support around older people's needs, in their home environments (Barr et al., 2003; Boult et al., 2009; De Bruin et al., 2012; Epping-Jordan et al., 2004; Raleigh et al., 2014; Wagner et al., 2005). Integration of care and support can be achieved at different levels, i.e. at the system (system integration), institutional (organisational integration), professional (professional integration), and service (clinical integration) levels (Valentijn et al., 2013).

Numerous integrated care initiatives have been introduced, in a wide range of settings and contexts, in and outside Europe, as new models for person-centred, safe, efficient, and prevention-oriented care to an increasing number of older people (European Innovation Partnership on Active and Healthy Ageing, 2018; Hébert et al., 2003; Hopman et al., 2016; Kodner and Kyriacou, 2000; Noordman et al., 2015; Van der Heide et al., 2015). Evaluations have established potential benefits of greater levels of service integration, but they have also highlighted limitations of integrated care initiatives. For instance, evidence for the effectiveness of integrated care for older people living at home remains inconsistent (De Bruin et al., 2012; Hoogendijk, 2016). Also, knowledge of how to successfully implement and improve integrated care is still limited, as is knowledge of how to transfer these experiences to other contexts (Leichsenring et al., 2013). Furthermore, improvements to the current way of working in existing initiatives are considered necessary, to make them more person-centred, prevention-oriented, safe and efficient (Banerjee; Blom et al., 2016; Hoogendijk, 2016; Noordman et al., 2015; Onder et al., 2015). In addition, more insight into how to measure and evaluate (improvements in) integrated care programmes is needed to be able to capture outcomes and processes adequately and consistently across different programmes and evaluation studies. This experience suggests that there is a lack of understanding about how best to lead, manage and improve integrated care innovations in practice. Or, to the extent that such understandings do exist, that there may be insufficient commitment, expertise or other resources to ensure their effective application (Goodwin, 2016).

Over the last couple of years, different EU-funded (research) initiatives have been initiated, including SUSTAIN (http://www.sustain-eu.org/), SELFIE (https://www.selfie2020.eu/), ACT@Scale (https://www.act-at-scale.eu/), JA-CHRODIS (http://chrodis.eu/), SCIROCCO (https://www.scirocco-project.eu/), the B3 Action Group on Integrated Care of the European Innovation Partnership on Active and Healthy Ageing (https://ec.europa.eu/eip/ageing/actiongroup/index/b3_en), and INTEGRATE (http://www.projectintegrate.eu.com/). These initiatives either aim to take innovative approaches to measure the outcomes of integrated care practices and/or to provide guidance to a broader implementation and scaling up of good practices in integrated care across European regions (Rutten-van Mölken, 2017). Although each project has its own unique approach, perspective and/or target group, together they will result in a more comprehensive evidence base or greater consensus on how to evaluate and implement integrated care. The current report features the SUSTAIN-project.

Table 1 - *Definitions of SUSTAIN's key domains.*

Person-centredness	Involve older people and their informal carers in decision-making and planning their care process in order to tailor the delivery of care and support as much as possible to individual needs, preferences and capabilities, taking into account socio-demographic factors, cultural backgrounds and gender (Coulter et al., 2013; Lloyd and Wait, 2006).
Prevention- orientation	Preserve and promote health and wellbeing of older people with multiple needs by preventing deterioration in existing conditions, and providing active support to help them to maintain and regain as much autonomy, independence and resilience as possible, and to make optimal use of individual resources (Claassens et al., 2016).
Safety	Prevent adverse outcomes of care (e.g. drug related problems, unnecessary hospitalisations and admissions in long-term care institutions), decrease preventable decline in health status (e.g. falls) and address treatment adherence (Lau et al., 2007).
Efficiency	Affordability of interventions and effective use of infrastructure, resources for sustainability (e.g. hours of service and labour allocated to recipients) and equipment and technology (e.g. IT), and the extent to which interventions may be able to shift activity from acute services to primary care services, improve alignment between the care professionals involved and reduce waste in healthcare spending (e.g. unnecessary readmissions within 30 days) (Shaw et al., 2011; Suter et al., 2009).
Coordination	Bringing together a range of services from the health and social care sectors and getting them to function seamlessly together. When done effectively, care coordination is a person-centred, assessment-based, interdisciplinary approach to integrating health and social care in a cost-effective manner around the specific needs and preferences of individuals and their informal caregivers. The care process typically involves a designated lead care coordinator (Goodwin et al., 2013; National Coalition on Care Coordination, 2011).[1]

1.2 Why SUSTAIN?

To take a step forward in the development of integrated care, the cross-European research project called 'SUSTAIN' was initiated, which stands for 'Sustainable Tailored Integrated Care for Older People in Europe' (www.sustain-eu.org). The project was funded under Horizon 2020 – the Framework Programme for Research and Innovation (2014-2020) from the European Commission (EC). 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, efficient, and coordinated care (please see Table 1 for an explanation of concepts); and
2. To contribute to the adoption and application of these improvements to other health and social care systems, and regions in Europe.

1.3 What is the SUSTAIN-project about?

The SUSTAIN-project was 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[2], 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 European Commission'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; and
- Be mandated by one organisation that represents the initiative and that facilitates collaboration with SUSTAIN research partners.

[1] Person-centredness, prevention-orientation, safety, and efficiency were key domains from the start of the project. Coordination was added in a later stage since it appeared to be a prominent theme in our data. [2] No integrated care initiatives were invited in Belgium. This was because SUSTAIN partners from Belgium focused on knowledge brokering and transfer, in contrast to partners from the other seven countries who focused on research.

In SUSTAIN, all integrated care sites were stimulated to improve their current ways of working by implementing improvement projects. More details about the SUSTAIN-project, the sites and their improvement projects can be found in Chapters 2 and 3 of this report. Annex 1 describes in more detail the methods used in the SUSTAIN project. Here the design of the project, the frameworks underpinning SUSTAIN, procedures and measures and the data analysis approach are presented.

1.4 What will you find in this report?

The overall objective of this report is to present the lessons learned from the SUSTAIN-project. To fulfil this aim, we did an overarching analysis (Annex 1) of findings from the SUSTAIN sites, to work towards the following specific objectives:

1. To provide insight into the characteristics of integrated care initiatives for older people across Europe, and the challenges they were facing;
2. To describe the integrated care activities that were undertaken by integrated care initiatives to improve their services;
3. To describe what works and what doesn't work when improving integrated care, and what kinds of factors should be taken into account when improving integrated care;
4. To do recommendations for improving integrated care across Europe.

Chapter 2 is dedicated to the characteristics of integrated care initiatives for older people across Europe, participating in the SUSTAIN-project, and the challenges they were facing. The chapter describes the settings in which the initiatives were operating, and the characteristics of the users, informal carers, professionals, and managers that were involved. The chapter further explains the challenges integrated care sites across Europe were experiencing in their current ways of working. Chapter 3 presents the integrated care activities that were undertaken by the integrated care initiatives to improve their services, and more specifically, how the SUSTAIN core domains (i.e. person-centredness, prevention-orientation, safety, efficiency, and coordination) were addressed. Chapter 4 is dedicated to the main lessons learned from the different integrated care sites by explaining what seemed to work and what did not seem to work when making improvements to integrated care. In this chapter, also factors for (not) succeeding in improving integrated care are addressed. Chapter 5 features recommendations for policy-makers, service providers, and the research community, based on the experiences we obtained in the SUSTAIN-project. The overall conclusions are given in Chapter 6.

2. INTEGRATED CARE IN EUROPE: THE SUSTAIN SITES

2.1 What will you find in this chapter?

In this chapter, you can learn about the characteristics of integrated care initiatives for older people across Europe, participating in the SUSTAIN-project. We describe their characteristics in terms of settings in which they operate, the managers and professionals that are involved in the sites, and the older people and their informal carers receiving care and support from these sites. In addition, we briefly highlight the challenges that were perceived in the ways of integrated care working of the sites that were identified by stakeholders. More details about the SUSTAIN sites can be found in seven country reports that were published in August 2018 (Ambugo et al., 2018; Billings et al., 2018; De Bruin et al., 2018b; Häusler and Ruppe, 2018; Hoffmann et al., 2018; Reynolds et al., 2018; Rull et al., 2018).

Key messages

- **Different shapes and forms:** Integrated care for older people with complex needs comes in many shapes and forms across Europe. Different types of care and support services were provided by the integrated care initiatives participating in SUSTAIN including: proactive primary care for frail older people, home nursing and rehabilitative care, transitional care, dementia care, and palliative care for people at the end of their lives.
- **Variation in composition of teams:** the composition of integrated care teams varied naturally across initiatives since they had different aims and objectives as defined by their specific nature and focus. Professionals from health care organisations, in comparison with professionals from social care organisations, were in the majority in the initiatives that participated in SUSTAIN. Volunteers and representatives from the voluntary services were underrepresented, and integrated care organisations[3] were not yet widespread.
- **Service users with complex needs:** the majority of service users from the SUSTAIN sites were people older than 75 years with multiple medical conditions. This seems to imply that integrated care initiatives participating in SUSTAIN realized their aims to provide care and support to service users with complex care needs, and as such indeed focused on the target group that the SUSTAIN project was seeking to assess.
- **Willingness and commitment to improve services:** the different integrated care initiatives participating in SUSTAIN were established initiatives, and several integrated care activities were already taking place. Nevertheless, they were willing and committed to improving their current practices by working towards more person-centred, prevention-oriented, safe, efficient, and coordinated care. This is why these initiatives were selected for participation in the SUSTAIN-project.
- **Different contexts, similar challenges:** SUSTAIN shows that integrated care initiatives across Europe experienced quite similar challenges in their ways of working, despite differences in their characteristics (e.g. settings, care and support services, types of service users) and contexts within which they operated (e.g. national legislation and funding, maturity level). Challenges were related to: 1. coordination and collaboration; 2. competences, motivation, and workload of professionals; 3. communication and information; 4. person-centred working, and 5. resources and support. However, the nature, importance, and priority attached to these challenges across the sites were dependent on individual contexts.

[3] Integrated care organisations were in this project defined as care organisations specifically developed to provide integrated health and social care services.

Table 2 - *Characteristics of integrated care initiatives that participated in SUSTAIN.*

Country	Region	Integrated care initiative	Type of care services	Abbreviation used in the report
Austria	Vienna	Gerontopsychiatric Centre	Dementia care	AT1
	Styria*	Coordinated Palliative Care	Palliative care	AT2
Estonia	Ida-Viru	Alutaguse Care Centre	Home nursing and rehabilitative care	EST1
	Tallinn	Medendi	Home nursing	EST2
Germany	Uckermark	KV RegioMed Zentrum Templin	Rehabilitative care	GER1
	Berlin Marzahn-Hellersdorf	Pflegewerk Berlin	Home nursing and rehabilitative care	GER2
Norway	Surnadal	Surnadal Holistic Patient Care at Home	Home nursing and rehabilitative care	NO1
	Søndre Nordstrand in Oslo	Søndre Nordstrand Everyday Mastery Team	Rehabilitative care and mastery of activities of daily living	NO2
Spain	Osona	Severe Chronic Patients/ Advanced chronic disease/ Geriatrics Osona	Proactive primary and intermediate care	SP1
	Sabadell	Social and health care integration Sabadell	Proactive primary care	SP2
The Netherlands	West-Friesland	Geriatric Care Model	Proactive primary care	NL1
	Walcheren*	Walcheren Integrated Care Model	Proactive primary care	NL2
	Arnhem	Good in one Go	Transitional care	NL3
United Kingdom	Kent	Over 75 Service	Proactive primary care	UK1
	Kent	Swale Home First	Transitional care	UK2

* These initiatives decided to withdraw from the SUSTAIN project before the design of improvement plan was completed.

2.2 What does integrated care in Europe look like?

The integrated care sites participating in SUSTAIN were mostly established initiatives. As outlined in more detail in Chapter 3, several integrated care activities were already taking place in the different sites. In several initiatives, for instance, local or regional networks of stakeholders from multiple disciplines (e.g. GPs, practice nurses, home care organisations, hospitals, municipalities, social care organisations, volunteers, representatives from the voluntary services) had been set up and agreements had been made on how to give shape to integrated care delivery. Some initiatives consisted of (allied) health care professionals exclusively, whereas in other initiatives, more or less equal numbers of health and social care professionals were involved. A small number of sites additionally involved volunteers and representatives from the voluntary services.

A wide range of care and support services were provided by the integrated care initiatives participating in the SUSTAIN-project (Table 2). Five sites provided proactive primary care for frail older people, six sites provided home nursing and rehabilitative care, two sites provided transitional care[4], one site provided dementia care, and one site provided palliative care for people at the end of their lives. Services were delivered by different professionals in a range of settings.

A total of 35 managers and 201 professionals participated in the study (Annex 2 contains more detailed information about the managers and professionals).

- On average, about 31% of the managers were working in a health care organisation, 33% were working in a social care organisation or for a local government, 19% were working in an integrated care organisation, and 17% were working in another type of organisation.
- On average, 61% of the professionals were working in a health care organisation, 18% were working in an

[4] Transitional care means care between one care setting to another setting, e.g. between hospitals, rehabilitation centres, short-term care facilities, or home care settings.

integrated care organisation, 13% were working in a social care organisation and 7% were working in another type of organisation (e.g. voluntary organisation).
- In seven sites, the majority of professionals were from health care organisations, whereas in one site all professionals were working in an integrated care organisation. One site had a relatively high proportion of professionals from a social care organisation (57%).

The integrated care initiatives provided services to older people with complex needs and their informal carers (Annex 2 contains more detailed information about the users and their informal carers). In total, 244 service users participated in the study.

- On average, 23% of the users were aged between 65 and 74 years, 42% were aged between 75 and 84 years, and 35% were 85 years or older.
- On average, 67% of the users were female.
- The users had 5.2 medical conditions on average.
- The average proportion of users living alone was 51%. There was wide variation across sites in this proportion, ranging from 20% to 90%.

In total, 80 informal carers participated in the study.

- On average, 15% of the informal carers were aged between 18 and 44 years, 39% were aged between 45 and 64 years, and 46% were 65 years or older.
- The average proportion of female informal carers was 69%. The average proportion of spousal carers was 46%.
- Five sites had relatively low proportions of spousal carers (lower than 33%).
- Overall, informal carers not being spouses were mostly children, other family members or hired carers (paid by themselves, family, or by the state/insurance). Six sites had relatively high proportions of spousal carers (higher than 67%).

In SUSTAIN, we started with fourteen sites; two sites per country. However, two sites (one in the Netherlands, and one in Austria) decided to withdraw from the SUSTAIN project before the design of their improvement projects was completed. Reasons mentioned were limited personnel resources, restricted time, insufficient support of stakeholders involved, and lack of ownership of managers and/or professionals. The site that dropped out in the Netherlands was replaced by a new site. The site that dropped out in Austria was not replaced. This report is therefore dedicated to thirteen SUSTAIN sites.

The different integrated care initiatives that participated in SUSTAIN were mostly highly mobilised towards integrated care. They had high motivation and commitment to improving their current practices by working towards more person-centred, prevention-oriented, safe, efficient, and coordinated care. Because of this synergy with the aims of SUSTAIN, they were selected for participation in the project. Integrated care improvements are the main focus of the further report.

2.3 What types of challenges do integrated care initiatives face?

During the first phase and start of the second phase of the SUSTAIN-project (please see Annex 1 for more details), it became clear that the integrated care initiatives were experiencing a wide range of challenges in their ways of working (Arrue et al., 2016). Upon these challenges, improvement projects to tackle these challenges (Chapter 3) were developed. Although there were several differences between the SUSTAIN sites in terms of for instance the settings they operated within, care and support services that they provided, and the characteristics of their target populations, perceived challenges were very similar across sites. As Table 3 shows, five clusters of challenges were identified, being challenges related to:

1. **Coordination and collaboration**, e.g. lack of coordination and lack of sustainable agreements between different health and social care providers and agencies, and unclarity of roles and responsibilities of different health and social care providers involved;
2. **Competences, motivation, and workload of professionals**, e.g. lack of training and education opportunities and heavy workloads of staff;
3. **Communication and information**, e.g. lack of information sharing within and between organisations and providers, and incompatible IT systems of organisations that hamper information sharing;
4. **Person-centred working**; e.g. insufficient involvement of users and informal carers in the care process, and lack of tailoring of services to the needs and preferences of older people;
5. **Resources and support**, e.g. lack of (sustainable) financial resources, constrained staffing levels, and unsupportive legal frameworks.

Common threads across the five areas include collaboration issues, technical issues, resource issues (i.e. funding, workforce, time), and care delivery issues (i.e. delivering care that is tailored to what is important to older people and their informal carers). The importance of the challenges for the initiatives and the priority level to tackle these were highly context-dependent, which will be further described in Chapter 3.

Table 3 - *Perceived challenges in the ways of working within the integrated care initiatives that participated in SUSTAIN.*

Coordination and collaboration
• Lack of coordination and integration of services between different health and social care providers
• Weak collaboration with regional health insurers and local governments
• Lack of formal and sustainable agreements of collaboration with different health and social care providers
• Inability to hire or involve specialists from outside the integrated care initiative (e.g. physical therapist)
• Fragmentation of services and competition between different health and social care professionals
• Lack of continuity of services across different sectors
• Poorly attended periodic multidisciplinary meetings
• Lack of clearly defined and allocated roles and responsibilities of health and social care professionals involved
• Lack of knowledge of and trust in one another's expertise
• Potential for duplication of services
• Unfamiliarity with one another's care and support services
• Lack of leadership
• Insufficient alignment between staff and management
Competences, motivation, and workload of professionals
• Lack of training and education opportunities for staff (e.g. shared-decision-making; user empowerment)
• Weak learning culture among staff
• Weak staff motivation
• Heavy workload of staff
• Lack of acknowledgment of staff
Communication and information
• Lack of communication /bad information flow between professionals within one organisation
• Lack of communication and information sharing across care providers involved
• Lack of shared/incompatible IT system between health and social care organisations
• Lack of follow-up information on service user after discharge from service
• Weak telecommunications network
• Lack of information about initiative's performance due to lack of systematic assessment and monitoring
Person-centred working
• Insufficient involvement of users and informal carers in the care process (e.g. lack of shared decision-making)
• Limited time to communicate with service users
• Lack of coordinated, systematic and person-centred needs assessment and joint care planning
• Difficulties in tailoring services to the needs and wishes of the older person
• Inadequate information provision about available services towards older people and their informal carers
• Lack of informal carer support
• Lack of mobility and transportation opportunities, resulting in poor access to health and social care services
Resources and support
• Lack of (sustainable) financial resources
• Lack of funding of improvements to IT infrastructure
• Constrained staffing levels
• High staff turn-over
• Lack of time of staff, resulting in lack of time for training, communication with service users etc.
• Fragmentation of budgets resulting in weak collaboration with other health and social care providers
• Unsupportive regional legal framework, hindering cross-sector joint efforts (between local social services and health institutions)
• Unclear national policies regarding municipal health services
• Non-supportive national policy

3. HOW TO IMPROVE INTEGRATED CARE?

3.1 What will you find in this chapter?

In this chapter, you will find information about how to improve integrated care. In order to address the challenges the integrated care initiatives faced (as described in Chapter 2), SUSTAIN researchers, in collaboration with stakeholders from the sites, organised several meetings to brainstorm ideas and create concrete plans (De Bruin et al., 2018a). These meetings were attended by a wide range of local stakeholders (e.g. managers, health and social care professionals, representatives from the voluntary sectors, representatives of older people and informal carers, local policy officers). These stakeholders jointly worked towards improvement projects outlining integrated care activities that reflected their local priorities. The improvement projects and the integrated care activities that were undertaken are central in this chapter.

Key messages

- **Local priorities:** SUSTAIN researchers, together with local stakeholders from the integrated care initiatives, regularly met to design improvement projects including integrated care activities that reflected their local priorities.
- **Two types of improvement projects:** two types of improvement projects were identified: 1. projects that primarily focused on improving or expanding collaboration, communication, and coordination between different health and social care organisations, and 2. projects that primarily focused on improving the actual care delivery process. Differences in the maturity levels of the integrated care initiatives may have influenced local priorities for improvement, and thus the challenges local stakeholders sought to address in their improvement projects.
- **Five clusters of integrated care activities:** stakeholders from the integrated care initiatives undertook a wide range of integrated care activities to improve their services. Five clusters of activities could be distinguished across the sites: 1. design of health and social care delivery process; 2. development of tools and instruments; 3. communication and information exchange with users and informal carers; 4. organisation of training of professionals, service users, and informal carers; 5. facilitation of user and informal carer involvement.
- **Implementing one activity, tackling several challenges:** some integrated care activities (e.g. tools and procedures for care plans, changing the location and timing of health and social care delivery, training on inter-professional communication and collaboration) addressed several aspects of health and social care delivery (i.e. person-centredness, prevention-orientation, safety, efficiency, coordination) simultaneously. Hence, these activities might tackle several challenges at the same time.

Table 4 - *Improvement objectives of the different integrated care initiatives that participated in SUSTAIN.*

Integrated care initiative	Objective improvement project
AT1	To improve detection of dementia and improving case- and discharge management of hospitalised people identified with a cognitive disorder.
EST1	To develop a person-centred way of working by engaging users, informal carers and multidisciplinary team in process of defining goal-directed nursing plan.
EST2	To increase the engagement of the older person, informal carer and different professionals into development of joint care plan, and to support information exchange on older person's situation, needs and objectives between older person, informal carers and professionals.
GER1	To enable people with care needs (including people who completed the complex therapy programme) to receive the right services by providing information and advice on available care and support services.
GER2	To improve inter-professional case management and multidisciplinary collaboration between GPs and healthcare therapists/nurses by transferring prescription-competence from GPs to healthcare therapists and nurses; and to establish formalised interactions and communication space among involved (formal and informal) carers.
NO1	To expand and improve healthcare services delivered at home.
NO2	To increase sense of mastery, reduce reliance on traditional care services and maintain and encourage good functional ability and social participation among users post Everyday Mastery Training (EMT) service provision.
SP1	To improve person-centredness of care by conducting a standard, multidimensional joint assessment and elaborating a shared individualised care plan among involved health care and social care professionals and the user and informal caregivers: PIIC plus.
SP2	To establish a systematic, multidimensional assessment and care plan tailored to multiple health and social care needs of each user and to establish care plans that people feel knowledgeable and active about, targeted at those unknown to social services.
NL1	To improve collaboration between professionals involved in the Geriatric Care Model (GP and practice nurse) and case manager and community social care team to adequately address older people's health and social care needs, to improve professionals' person-centred way of working and to make further collaboration agreements between staff.
NL3	To clarify and align the various scenarios of a sudden need for more intensive care of a person living at home in a crisis situation (such as dementia or brain injury).
UK1	To keep older people with long-term conditions and complex care needs at home independently for as long as possible and to improve care coordination across existing services around these people.
UK2	To ensure medically optimised hospitalised people are able to be discharged straight home with the right support and to make the person's discharge smoother, quicker and safer by moving to a single assessment.

3.2 What kinds of improvement projects were undertaken?

Roughly, two types of improvement projects (Table 4) can be distinguished:

(i) in six initiatives (AT1, EST2, GER2, NL1, NL3 and UK1), the improvement projects focused on improving or expanding collaboration, communication and coordination between different health and social care organisations, while also enhancing knowledge and understanding of each other's roles and responsibilities;
(ii) in seven initiatives (EST1, GER1, NO1, NO2, SP1, SP2, UK2), the improvement projects primarily focused on improving the actual care delivery process. Activities or actions for realizing this included for instance the use of a common multidimensional assessment tool or the provision of rehabilitation services at home instead of in an institution.

Differences in the maturity levels of the integrated care initiatives may have influenced local improvement priorities, and as such the challenges local stakeholders sought to address in their improvement projects. In practice, the SUSTAIN evidence shows that, generally speaking, initiatives in an early developmental phase tended to focus on the first type of improvement project while more developed initiatives focussed on the second type.

Although some improvement plans had a similar focus, they all included a unique combination of actions and integrated care activities. Table 5 outlines the integrated care activities that were undertaken by the sites in relation to the SUSTAIN core domains. We distinguish five different clusters of activities which will be discussed in more detail in Chapter 4:

1. **Design of health and social care delivery process**, e.g. building a multidisciplinary team and changing the timing and location of health and social care delivery;

2. **Development of tools and instruments**, e.g. tools for needs assessment and care planning;
3. **Communication and information exchange with users and informal carers**, e.g. implementing a single point of access for users and informal carers;
4. **Organisation of training of professionals, service users, and informal carers**, e.g. training on providing information to users and informal carers and training on inter-professional communication and collaboration;
5. **Facilitation of user and informal carer involvement**, e.g. empowering users and involving informal carers in the care process.

Some integrated care activities (e.g. changing the location and timing of health and social care delivery, developing tools and procedures for care plans, training on inter-professional communication and collaboration) addressed several aspects of health and social care delivery (i.e. person-centredness, prevention-orientation, safety, efficiency, coordination) simultaneously. Hence, these activities might tackle several challenges at the same time. More details about the activities can be found in seven country reports that were published in August 2018 (Ambugo et al., 2018; Billings et al., 2018; De Bruin et al., 2018b; Häusler and Ruppe, 2018; Hoffmann et al., 2018; Reynolds et al., 2018; Rull et al., 2018).

Table 5 - *Integrated care activities undertaken by the sites in relation to the SUSTAIN core domains.*

Integrated care activities	Design of health and social care delivery process	Development of tools and instruments	Communication and information exchange with users and informal carers	Organisation of training of professionals, service users, and informal carers	Facilitation of user and informal carer involvement
Person-centredness	• Building a multi-disciplinary team (AT1, EST, GER1, GER2, SP1, SP2, NO1, NO2, NL3, UK1) • Changing the location of health and social care delivery (GER1, NO1, SP1, SP2, UK1, UK2)	• Developing tools and procedures for needs assessment (AT1, GER2, NO1, SP1, SP2, NL1, NL3, UK1) • Developing tools and procedures for care plans (EST1, GER1, GER2, SP1, SP2)	• Implementing a low threshold single point of contact for users and informal carers (GER1, GER2, NL1, UK1) • Offering various options to communicate with health and social care professionals (GER1, GER2, NO2, NL3, UK1)	• Training of professionals on early detection of dementia (AT1); • Training of professionals on shared-decision making and per-son-centredness of care (SP1, SP2). • Training on inter-professional communication and collaboration (NL1) • Training on shared decision-making and self-management for service users (SP2)	• Empowering users (UK2) • Shared decision-making with users and/or informal carers (GER1, GER2, NO1, NO2, SP1, SP2, NL3) • Involving informal carers in the care process (GER2, SP1, SP2, NL3, UK1)
Prevention-orientation	• Changing the location and timing of health and social care delivery (AT1, SP1, SP2, UK1, NO1) • Adding care and support services to existing ones to address prevention (AT1, GER1, NO1, NO2, SP1, SP2, NL1, NL3, UK1) • Addressing the service users' home environment in the care delivery process (EST2, SP1, SP2, UK1, UK2)	• Developing tools and procedures for care plans (EST1, GER1, GER2, SP1, SP2)	• No activities mentioned in this cluster.	• Training and providing information to service users and informal carers (EST2, NO2, SP1, SP2, NL1, NL3)	• No activities mentioned in this cluster.

Integrated care activities	Design of health and social care delivery process	Development of tools and instruments	Communication and information exchange with users and informal carers	Organisation of training of professionals, service users, and informal carers	Facilitation of user and informal carer involvement
Safety	• Doing home safety assessments (SP1, SP2, UK1, UK2,) • Carrying out medication reviews (AT1, NO1, NO2, SP1, SP2, UK1) • Implementing equipment, adaptations or services for (home) safety and maintaining independence in users' homes (AT1, EST1, GER1, NO1, NO2, SP1, SP2, NL1, NL3, UK1)	• Developing tools and procedures for care plans (SP1, SP2)	• Informing or referring users to safe(r) places (EST1, NO1)	• No activities mentioned in this cluster.	• Providing safety information and advice to users and informal carers (EST1, GER1, NO1, SP1, SP2, NL1, NL3, UK1)
Efficiency	• Improving coordination, collaboration and communication within the care delivery process (SP1, SP2, NL1) • Changing the location and timing of health and social care delivery (GER2, NO1, SP1, SP2, UK1, UK2) • Bringing health and social care services together under one roof (GER1)	• No activities mentioned in this cluster.	• No activities mentioned in this cluster.	• Training on inter-professional communication and collaboration (NL1)	• No activities mentioned in this cluster.
Coordination	• Enabling multi-disciplinary working (AT1, EST1, EST2, GER1, GER2, NO1, NO2, NL3, SP1, SP2, UK1, UK2 • Improving inter-professional information sharing (EST1, EST2, SP1, SP2) • Bringing health and social care services together under one roof (GER1)	• Developing tools and procedures for needs assessment (AT1, GER2, NO1, SP1, SP2, NL1, NL3, UK1, UK2) • Developing a format for case conferencing (SP1, SP2) • Developing procedures for care planning (EST1, EST2, SP1, SP2)	• Establishing a single point of contact/ key contact (UK1)	• No activities mentioned in this cluster.	• No activities mentioned in this cluster.

4. WHAT WORKS WHEN IMPROVING INTEGRATED CARE?

4.1 What will you find in this chapter?

In the previous chapter, we provided an overview of what kinds of integrated care activities were undertaken by the sites to improve person-centredness, prevention-orientation, safety, efficiency, and coordination of health and social care delivery. In this chapter, you will find information about what worked and did not work in moving towards more person-centred, prevention-oriented, safe, efficient, and coordinated care (section 4.2). This chapter further features the explanations for (not) succeeding in realizing improvements (section 4.3).

Key messages

- **Revising existing integrated care activities and implementing new ones:** SUSTAIN shows that integrated care sites undertook different types of integrated care activities in order to deliver and improve person-centred, prevention-oriented, safe, efficient, and/or coordinated care. As part of the SUSTAIN-project, sites either implemented additional activities to improve these aspects or revised existing ones.
- **Person-centredness most frequently addressed:** Among the SUSTAIN core domains, the majority of activities focused on improving person-centredness while the other domains received rather less emphasis.
- **Improved person-centredness of service delivery:** Evidence from managers, professionals, users, and informal carers indicated that a number of integrated care activities have the potential to (further) improve person-centredness. Examples of these activities are: developing tools and procedures for needs assessment, developing tools and procedures for care plans, implementing a low threshold single point of contact for users and informal carers, and providing training to professionals and users to promote shared-decision-making and empowerment.
- **Different views on person-centredness:** There is a discrepancy between managers' and professionals' views on person-centred approaches vis-à-vis those of users and informal carers. Experiences of managers and professionals with the implemented integrated care activities were mostly more positive than those of users and informal carers. This implies that there is a tension between what managers and professionals think are person-centred approaches and how users and informal carers understand and evaluate them.
- **More confidence as a result of activities targeting prevention-orientation:** Integrated care activities have the potential to improve prevention-orientation in the sense that users and informal carers feel more confident to live independently at home. Activities include: adding care and support services to existing ones to reduce risks to independent living or changing the location and timing of health and social care delivery. There was evidence that some of these activities, such as those related to early detection and management of risks and one's own health and wellbeing, might be less appropriate for those with complex care needs.
- **Addressing safety in integrated care not common yet:** SUSTAIN shows that there is room for improvement in integrated care when it comes to safety in service users' home environments. Addressing safety in integrated care is not common practice in all countries yet. Those integrated care sites that did work on safety issues, merely focused on routine health-focused safety aspects such as reducing falls and reviewing medication, and to a lesser extent on other more social-focused safety aspects in users' home environments such as personal security (e.g. doorstep sales, telephone fraud, house security).

Key messages

- **Impact of activities addressing safety still uncertain:** Some integrated care activities, such as home safety assessments, have the potential to enable people to live safely in their own homes. However, in several sites, it was difficult to establish whether the improvement projects had actually enhanced perceived safety. This was because evidence was limited or the time frame of the project too short to notice any changes yet. Moreover, managers and professionals appeared to have different views on the impact of the activities related to safety compared with users and informal carers. Where managers and professionals thought that their activities had sufficiently addressed safety issues, users and informal carers often still felt concerned, insecure, or insufficiently informed about how to live safely in their homes. Also they felt that they had to wait a long time for home adaptations to eliminate physical barriers and risks.
- **Efficiency addressed to a limited extent:** Relatively few activities were undertaken with the explicit aim of improving efficiency. Moreover, the outcomes of such activities were not always apparent since the activities were still under development at some sites, and there was not sufficient data to assess efficiency at other sites. However, it was anticipated that some activities (e.g. improving coordination, collaboration, and communication; changing location and timing of health and social care delivery; bringing health and social care services together under one roof) would be efficient in the longer term.
- **Several activities seem to improve coordination:** SUSTAIN's findings, based on the experiences of professionals and managers, suggest that there are several integrated care activities that improve collaboration and communication among professionals, and thereby coordination of care. Examples of such activities are: multidisciplinary working and using shared tools for needs assessment, care planning, and case conferencing. However, despite these activities, in some sites the extent and level of collaboration was (still) perceived to be insufficient. Moreover, while professionals identified some of these activities (e.g. care planning) as important, users and informal carers were not fully aware of these care planning processes and their documentation or were not finding them important in meeting their needs effectively.
- **Information sharing still challenging:** SUSTAIN underlines findings from earlier studies that, though inter-professional information sharing will probably improve care coordination, it is difficult to achieve in practice. Often mentioned reasons are the lack of a (IT) platform to share information across organisations and professionals, but also the lack of a legal framework enabling data exchange and ensuring data protection.
- **Factors influencing (un)successful implementation of integrated care activities on different levels of the health and social care system:** Factors influencing (un)successful implementation of integrated care activities were quite generic among the different integrated care sites. They were related to different levels (micro, meso, macro levels) of the health and social care systems. Commitment of professionals and managers, leadership and ownership, and policy and legislation influenced to a great extent the successful or unsuccessful implementation of integrated care activities. In addition, we identified several site-specific factors which were mostly related to cultural and historical developments (e.g. stigma of social care, war, ageism).

4.2 What integrated care activities maintained or enhanced person-centredness, prevention-orientation, safety, efficiency and coordination in health and social care delivery?

A wide variety of activities was undertaken to improve person-centredness, prevention-orientation, safety, efficiency, and/or coordination in health and social care delivery of the integrated care sites (Table 5, previous chapter). Most sites had already implemented several integrated care activities to enhance these aspects of care delivery within their existing ways of working. To improve their current ways of working, according to the SUSTAIN core domains, they either implemented additional activities or revised existing ones. The different clusters of integrated care activities, and the extent to which they worked, are described in more detail below.

4.2.1 Person-centredness

Design of health and social care delivery process

A first cluster of activities was related to the design of the health and social care delivery process. An activity implemented by several sites included **building a multidisciplinary team** around the users by involving more and different types of health and social care professionals. For some sites, managers, professionals or users indicated that this contributed to a comprehensive approach towards health and social care needs of users, consistency and continuity in the team of professionals, collaboration between different health and social care professionals, sharing of information between different health and social care professionals, and the delivery of joint up care. Another activity was **changing the location of health and social care delivery**. In several sites, delivery of health and social care services was shifted to service users' home settings, which was mostly appreciated by users. For instance, needs assessments, care plan discussions, or enablement or rehabilitation services took place in service users' homes instead of in for instance rehabilitation centres or hospitals. A rationale for providing services in service users' home settings was that this would be

comforting for older people, and was therefore considered by professionals as a more person-centred way of working. Moreover, professionals stated that home visits helped them to understand the situation of their service users' home situations better (e.g. how they live and organise their daily living, how they organise and keep medicines) which made advice and support more personalised as it was based on the user's home environment. In contrast, some users that were discharged from hospital experienced difficulties with receiving services in their homes. They felt rushed out of the hospital before they were fully prepared or they experienced a lack of (timely) support at home.

Development of tools and instruments

The second cluster of activities to improve person-centredness included the development of tools and instruments to support the health and social care delivery processes. Most integrated care sites incorporated multidimensional needs assessments in their existing ways of working, and therefore **developed tools and procedures for doing needs assessments**. Also, as part of the SUSTAIN project, tools were refined or new procedures around needs assessments were developed. For instance, social needs of users or health and social care needs of family carers were added to existing tools, different types of health and social care professionals were involved in the needs assessment process or the assessment was done in an earlier stage of the care process. Overall, professionals and managers in the sites that worked on their needs assessments felt that this helped improve person-centredness since they were better able to identify the broad range of their service users' and informal carers' care needs. The experiences of users and informal carers were, however, more diverse. Some of them were satisfied and felt that all their needs were assessed and they were at the centre of attention rather than their disease, whereas others indicated that their needs were not or insufficiently assessed.

Another activity in this cluster was the **development of tools and procedures for care plans**. In some sites, a clear care planning process was not yet established. These sites therefore developed tools and procedures as part of the SUSTAIN project. As with the needs assessment, also, in several sites care plans were already in place. Existing tools and procedures for care plans were refined, as part of the SUSTAIN project. For instance, care plans were discussed and shared with all health and social care professionals involved in the care process, were made available for or discussed and evaluated with users and informal carers, or were extended with users' and informal carers' goals. With these revisions, care plans were expected to become more individually tailored to one's needs and preferences and more goal-oriented, and thereby resulting in more person-centred care. Professionals and managers from those sites that worked on their care plans, felt that more person-centred care was actually achieved by their improvement projects. As with the tools and procedures for needs assessments, also here users and informal carers had mixed views. For instance, some users and informal carers expressed that they felt involved in decisions about their care and support, while other users felt that decisions were made for them, or that information was discussed with their informal carers rather than with themselves. They also differed in how important they found access to their care plans, in whether or not they had access to their care plans at all, or in their awareness of the existence of care plans.

Communication and information exchange with users and informal carers

The third cluster of activities to improve person-centredness was related to communication and information exchange. In the context of person-centredness, this merely entailed communication and information exchange between health and social care professionals with service users and informal carers. A first activity that took place to improve person-centredness in some of the sites was the implementation of a **low threshold single point of contact for users and informal carers**, e.g. a case manager or a practice nurse. Such a single point of contact was appreciated by users. It also helped to improve the information flow about for instance services available to users and informal carers. Information was for instance unlocked in the sites by installing a central information point (e.g. service centre), informed professionals (e.g. professionals knowledgeable about local services through a resource map) or ad hoc personal triads formed by a GP, nurse, and social worker facilitating access to the (unknown) social services available. As such, they were better able to better address users' needs and ultimately enhance person-centredness of their services. A second activity was **offering various options to communicate with professionals** to ensure quick and easy access to them, such as home visits, phone calls, e-mail contact, or face-to-face meetings. These options were appreciated by users and their informal carers. Personal relationships between professionals and users were appreciated by users. Also spending time, paying attention, listening well, and being respectful, kind and empathetic were highly valued characteristics of professionals by users and informal carers, and were often observed in professionals working with them.

Organisation of training of professionals, service users, and informal carers

A fourth cluster of activities addressed the organisation of training of professionals and service users. Several sites organised different types of training to facilitate a more person-centred way of working. The topics of the training sessions differed between the sites. One site organised **training for professionals on early detection of dementia**. This was done to raise awareness of hospital staff of dementia, to enable them to recognise dementia of their patients in an earlier stage, and to act upon it. This training was perceived as successful by staff and the organisations involved, since they became more aware of signs of dementia, even when people were in earlier stages of the dementia process. According to them, this led to more person-centred care. Other sites provided a **training for professionals on shared decision-making and person-centred care**. However, professionals considered the extent and content of this training did not meet their needs. They instead felt the need for more in-depth training, particularly on how to communicate with users to foster for instance shared decision-making. Further,

one of the sites organised **training on inter-professional communication and collaboration**. This was for instance done through inter-professional intervision meetings between professionals from different disciplines. These are meetings in which peer supervision and discussions help participants to reflect on their personal and professional development (e.g. to help professionals reflect on their ways of working in relation to their clients). Overall, the professionals appreciated the training and felt that they were able to work in a more person-centred way afterwards. One site offered **training on shared decision-making and self-management for service users**. This included for example a workshop on aspects related to growing older and enabling reflections on their situation and preferences with peers. Topics of the sessions were active and healthy ageing, social and personal development and engagement in self-management of health. Participants and professionals were satisfied with the content and especially with the workshop facilitator, who was a local expert in gerontology.

Facilitation of user and informal carer involvement

A fifth cluster of activities was the facilitation of user and informal carer involvement. A first activity that took place with the intention to improve person-centredness was **empowering users**. In one of the sites, a service stimulated enablement and self-care at home for people returning from hospital. Although such a service can be empowering, users indicated this can be difficult, particularly when they have just returned from a stay in hospital and may be feeling anxious, exhausted and in need of being looked after a little. Users indicated that there sometimes appeared to be a lack of compassion amongst staff working to 'enable' self-care, and users were sometimes missing the 'softer' aspects of a care visit. Another activity implemented by multiple sites to improve person-centredness was **shared decision-making with users and/or informal carers**. In these sites, professionals gave users and informal carers for instance the opportunity to explain needs and wishes, to discuss possibilities for care and support and to set goals. Professionals indicated user or informal carer involvement enhanced person-centredness. Among users, however, there were mixed views on the extent to which they had been involved in decisions on care options. Most felt involved, but some felt decisions were made without them or felt care options were only discussed with their close ones rather than with them. Moreover, managers and professionals observed that part of the users did not necessarily feel competent or were capable of contributing to shared decision-making. This could be explained by cognitive capabilities and cultural factors. A third activity, undertaken by some sites, was the intention to **involve informal carers in the care delivery process**, for instance in the definition of care plans. This was done to validate the extent to which planned actions met their needs and preferences. However, this was not always successful since the involvement of informal carers by professionals was sometimes less than expected.

4.2.2 Prevention-orientation

Design of health and social care delivery process

In this cluster, several integrated care activities were undertaken with the aim to improve prevention-orientation of health and social care delivery. As was done to improve person-centredness, some sites also decided to **change the location or timing of health and social care delivery** in order to improve prevention-orientation. Some sites shifted health and social care delivery to service users' home settings. One of the sites for instance organised the rehabilitation at home service, which had an emphasis on prevention. Developing sense of mastery and independence underlay the rehabilitation training that users received. By promoting users' competence in activities of daily living, the service aimed to enable users to continue living safely and independently at home. Other sites implemented activities focused on reducing risks or addressing needs in an early stage to reduce or delay the need for acute care. These activities allowed for early detection and management of risks, problems and needs that contributed to prevention of deterioration or preservation of abilities, and as such had a clear focus on prevention-orientation. Activities included preventative interventions (e.g. pressure area care), systematic medication reviews, checking users' and informal carers' capacity of self-administrating medication, anticipation of required future care, and detection of dementia.

Most sites, as part of SUSTAIN, further **added care and support services to existing ones to address prevention**. These services aimed at enabling independence in service users' home situations and preventing negative outcomes like hospitalisations. Examples of these services were: low threshold voluntary services like social activities, (instrumental) activities of daily living support by home care or adjustments to the house, early detection and management of risks and one's own health and wellbeing, and adult day services for users to relieve informal carers, and support users in social activities, building confidence, or setting goals. Users and informal carers felt the care and support they currently received would help them to remain in their homes for as long as possible. Informal carers indicated that support at home for instrumental activities of daily living and adult day care helped them to take care of their spouse longer as it gave them some respite. Activities related to early detection and management of risks and managing own health and wellbeing may not be appropriate for the most frail group older people. Both professionals and users themselves indicated that users may not always be able to following advice on healthy habits or safety, may not feel confident or capable of being involved in managing their health and wellbeing, or feel that their situation could not be improved because of their complex health situation.

Another activity, in this cluster, undertaken by some sites, included **addressing the service users' home environment in the care delivery process**. Through home visits, for instance, professionals identified barriers for users' daily routines such as presence of stairs or absence of raised toilet seats. These were addressed accordingly by for instance providing the necessary adjustments in users' homes.

Development of tools and instruments

Tools and procedures for care plans were not only developed to improve person-centredness but also to improve prevention-orientation. In several sites, care plans included actions to increase (instrumental) activities of daily living support at home or to promote self-management of health and healthy habits. Also identification of risks was included in some of the care plans, like medication adherence, fall tendencies, financial problems, caregiver burden, and hazards at home (e.g. stairs or bath).

Organisation of training of professionals, service users, and informal carers

Sites offered **training and information to service users and carers** with the aim to enhance prevention-orientation. Topics included self-management of health, medication adherence, building competences in activities of daily living, prevention of falls, applying for aids and services at home, stimulating independence and empowerment, healthy lifestyle, and social participation. These advice and training activities were initiated to help users to live independently in their homes. A sign of greater user empowerment and user's capability of self-managing health was observed in one of the sites.

4.2.3 Safety

Design of health and social care delivery process

Some sites did **home safety assessments** to identify potential hazards (e.g. fall risks) to enhance safe and independent living at home. According to professionals, reviewing safety risks in the service users' home settings, helped them to understand problems with safety in daily living and thereby allowed them to organise tailored care and support at home. In some sites however, users did not feel they had received sufficient information or support on safety issues, which made them feel vulnerable or scared (e.g. support was limited or they found their home settings not suitable for safe recuperation). Medication safety was considered important by professionals, users and informal carers. **Medication reviews** (including advice on medication adherence, side effects and polypharmacy) were conducted in some sites. However, in other sites, users and informal carers were concerned about the medication prescribed and indicated that they did not receive a medication review. It became apparent that in some sites medication reviews were not always recorded in the care plans. Another activity in this cluster included **implementing equipment, adaptations or services for (home) safety and maintaining independence in users' homes**, such as medication management services and the use of medication distribution rolls (dispensers), which were considered helpful by informal carers. Other services included the application of assistive equipment and home adaptations (e.g. safety alarms, mobility aids, beds, raised toilet seats). In some sites, attention was paid to reducing fall risks, such as fall prevention programmes. Some sites routinely recorded the number of falls per individual in their care plans, whereas other sites didn't.

Development of tools and instruments

Tools and procedures for care plans also contributed to safety. In some sites, care plans included actions to reduce safety risks at home through providing advice to users and informal carers. This will be further explained in the next paragraphs.

Communication and information exchange with users and informal carers

Integrated care activities related to communication with users and informal carers to enhance safety, include **informing or referring users to safe(r) places**. In some sites, adult day services centres or nursing homes provided a safe environment for users. Informal carers considered adult day services centres as a safe daytime alternative to the homes of their relatives, and therefore these centres gave them some respite. In other sites, professionals assisted users and informal carers with their application for sheltered housing (such as a nursing home), as such a facility made them feel more safe than living independently at home any longer.

Facilitation of user and informal carer involvement

Multiple sites provided **safety information and advice to users and informal carers**, for instance about how to deal with (potential) risks and deteriorations, and as such how to live independently and safely. Topics were home adjustments to live safely at home, availability of support services, and information about medication. In some sites, informal carers indicated that attention to them was insufficient (including lack of carer needs assessment). Informal carers stated that they did not receive information or advice on how to care for and support their relatives, which may have contributed towards reduced feelings of safety.

4.2.4 Efficiency

Design of health and social care delivery process

Most sites implemented activities that aimed to **improve coordination, collaboration and communication within the care delivery process** to enhance efficiency. These activities consisted for example of defining clear roles and responsibilities of different health and social care professionals, better alignment of care activities of different professionals, bringing all professionals together under one roof, and better information exchange. Professionals and managers thought that with the improved coordination, collaboration and communication the efficiency would improve as well. However, at the same time, staff remarked that any efficiency improvements in relation to better coordination and communication were not yet evident at the time of the evaluation.
Another integrated care activity that was implemented to improve efficiency was **changing the location and timing of health and social care delivery**. In some sites, this entailed better discharge management by reducing delayed transfers of care and as such reducing hospital length of stay. In other sites, one started with delivering services in users' home settings to reduce risk of institutionalisation but also to avoid (too many) transfers in care and/or admission to a rehabilitation centre. It was expected that, as such, costs on transfer could be saved and stays in an institution that would have otherwise been incurred. Although it was thought that being at home

would be beneficial for users, at the same time some users felt they were discharged too early. Another activity that took place that entailed a change of timing of health and social care delivery, was early detection of health and social care needs which facilitated the opportunity for preventive measures and advanced care planning. More efficiency was expected to be realised by anticipating, through early detection, on future needs.
A third integrated care activity to improve efficiency was **bringing health and social care services together under one roof**. In one site, health and social care services, and their unique competencies, were brought together in one service centre. According to managers and professionals, as a result, there was better alignment of activities of different professionals and better inter-professional communication. Further, more clarified roles andresponsibilities of different professionals could be attained. This was anticipated to raise efficiency.

Organisation of training of professionals, service users, and informal carers

In relation to organisation of training, one site implemented an activity to improve efficiency; **training on inter-professional communication and collaboration**. As also mentioned under 'person-centredness', one site organised inter-professional intervision meetings between professionals from different disciplines and stimulated work place visits. Professionals mentioned that, after these meetings and visits, they felt more able to arrange the appropriate care and support more quickly because they were more aware of the services their colleagues could provide and felt more comfortable asking them for help. However, they also indicated that it did not become apparent whether this was improved as a result of the improvement project. Further, these meetings and visits created awareness of similarities in client information collection methods and experienced issues with regard to information sharing. These insights created starting-points for more efficient health and social care delivery.

4.2.5 Coordination

Design of health and social care delivery process

Multiple sites attempted to improve coordination of care by **enabling multidisciplinary working**. Several integrated care activities were undertaken to enable multidisciplinary working, such as the organisation of case conferencing meetings or multidisciplinary meetings (planned and structured interdisciplinary meetings involving relevant professionals for each particular user with complex social and health needs). These meetings were held in order to provide integrated and coordinated care through the different care providers. During these meetings, the users' needs, preferences, and objectives were discussed taking into account the perspectives of the different professionals involved, leading to the formulation of coordinated actions to be included in users' care plans. According to some managers and professionals, multidisciplinary working led to better communication and collaboration between organisations involved. Although this was confirmed by some users and informal carers, others (still) felt lack of coordination between organisations, miscommunication, a lack of information sharing, and unnecessary transfers between facilities. Some informal carers additionally indicated that it was difficult for them to contact professionals directly and they felt that they had to take the lead in the coordination of care rather than a professional.

Another integrated care activity that was undertaken to improve coordination of care was **improving inter-professional information sharing**. For instance, care plans were being shared between different professionals and organisations. Users and informal carers confirmed that professionals shared information with each other and were knowledgeable of users' care needs. Electronic health records facilitated information exchange between professionals and organisations, but also a paper-based plan at users' homes were in place in some sites. However, issues around information exchange occurred, including problems with obtaining one another's care plans, professionals not filling in (their parts of) the care plans in the shared electronic health records, professionals only sharing information orally, or the lack of a platform to share care plans across organisations and professionals.

A third integrated care activity included **bringing health and social care services together under one roof**. As also mentioned under 'efficiency' this did not only improve alignment of one another's activities and communication, but also improved coordination of activities and services.

Development of tools and instruments

In several sites, tools and instruments were developed to support multidisciplinary working, and as such to support coordination of care. Examples were the **development of tools and procedures for needs assessment** (more details can be found under 'person-centredness: development of tools and instruments'), **development of a format for case conferencing** (more details can be found under 'coordination: design of health and social care delivery process'), and the **development of procedures for care planning**. This included a care plan format in which staff could indicate which professionals were involved in the care planning process and who would be in charge of each action to be undertaken. According to professionals, this helped them to align their activities and thereby facilitated coordination between all different professionals involved. In some sites, most users' care plans did not include any information about the role of informal carers in the care processes of the service users.

Communication and information exchange with users and informal carers

Some sites aimed to improve coordination of care through communication and information exchange with users and informal carers. An example of an integrated care activity to achieve this was **establishing a single point of contact** for both users and professionals. These key contacts usually had more knowledge of users' situations and had quicker access to services. These professionals fulfilled a coordinating role in the multidisciplinary team and helped professionals to communicate and collaborate.

4.3 What are explanations for (not) succeeding in improving integrated care initiatives?

In section 4.2, we described whether or not integrated care activities worked or did not work. In other words: whether or not these activities were able to enhance person-centredness, prevention-orientation, safety, efficiency, and coordination. This section outlines the explanations for (not) succeeding in enhancing these aspects of integrated care. Some of the explanations are related to the characteristics of the integrated care activity itself, as is also described in section 4.2. Other explanations are related to the context (i.e. the micro, meso, and macro levels of the health and social care systems) in which the integrated care activities were implemented. Tables 6a and 6b below outline the factors explaining successful or unsuccessful improvement of integrated care initiatives. Table 6a outlines the overall factors, and 6b those factors relating to specific sites.

Overall (Table 6a), the factors mentioned were generic and experienced by several sites. Factors mentioned resembled several of the perceived challenges in the ways of working of the integrated care sites before participating in SUSTAIN (Table 3). Also during the implementation of improvements, the following challenges were regularly mentioned: insufficient resources (e.g. workforce, time), lack of information exchange between professionals, and organisations, lack of funding, and unsupportive policy and legislation. Other factors explaining successful or unsuccessful improvement of integrated care initiatives which were regularly mentioned were commitment of professionals and managers to the improvement project, leadership and ownership of the improvement project, organisations' cultures and visions, and governance arrangements.

Factors were often two sides of the same coin. For instance, several sites felt that strong leadership promoted the implementation of integrated care activities, whereas the lack of it hindered their implementation. In this table, we therefore present the factors that affected the implementation of integrated care activities by theme. In Table 6b, we also identified site-specific factors. These factors were mostly related to cultural and historical (i.e. past events that still influenced the present) factors. Detailed explanations of the different factors can be found in Annex 3.

Table 6a - *Overall factors explaining successful or unsuccessful implementation of integrated care activities.*

Level	Factor
Micro	Attitude of professionals towards (culture) change
	Commitment, motivation, and willingness of professionals
	Engagement of users and informal carers in the improvement project and/or care delivery process in general
Meso	Available time of professionals
	Available resources and capacity
	Commitment and support at managerial level
	Communication
	Composition of improvement team
	Governance arrangements
	Information exchange (by IT) between professionals/ organisations
	Leadership and ownership
	Organisational cultures
	Organisational structures
	Organisations' visions
	Project management and planning
	Prior experiences with improvement initiatives
Macro	Connection with existing local and regional initiatives and networks
	Engagement of local community
	Funding and payment schemes/systems
	Local, regional, and national policy and legislation
	Privacy regulations and data protection legislation
	Valuation of health care, social care, and voluntary sectors

Table 6b - *Site-specific factors explaining successful or unsuccessful implementation of integrated care activities.*

Level	Factor
Micro	Attitude of professionals towards older people
	Attitude of users and informal carers towards themselves
	Awareness of professionals, users and informal carers of new services
	Expertise of professionals
Meso	Physical space
Macro	Attitude towards social services
	Historical context
	Geography and location
	Knowledge of social services
	Policy on long-term care
	Seasonal pressures

5. RECOMMENDATIONS TO IMPROVE INTEGRATED CARE DELIVERY ACROSS THE EU

5.1 What will you find in this chapter?

This chapter brings together lessons learned from the SUSTAIN-project, looking at different aspects of improving integrated care; what seems to work, what does not seem to work, how to implement and maintain improvements, and what kinds of improvements can be transferred to other regions and countries. Based on these lessons learned, we aim to make recommendations for policy-makers, service providers, and the research community to (further) improve integrated care delivery across the EU.

5.2 Policy recommendations

The following recommendations for policy-makers emerged from SUSTAIN's experiences of implementing improvements to health and social care services to promote integrated care:

- **Promote integrated care training and education:** SUSTAIN suggests that health and social care professionals may lack the skills and knowledge to work in an integrated way due to a lack of training and education on what integrated care actually means. At a national level, revisions of the undergraduate and graduate curricula for health and social care are therefore needed. Education and training should be centred around (older) persons' needs so that professionals better understand how they can contribute to meeting them. In addition, other important aspects of integrated care should be included in education and training such as inter-professional collaboration, collaboration between professionals and volunteers, communication skills, and information sharing. This might help to create trust, to identify shared interests and to learn to understand each other's (professional) language early on. As was also suggested by Rijken et al. (2017), at EU level, policy-makers could emphasise the importance of professional development to improve care for older EU citizens as part of the European Commission's policy to promote continuous professional development of the workforce.

- **Ensure dedicated funding for integrated working:** The experience of several SUSTAIN sites was that funding levels had been insufficient, unstable, and not sustainable enough to deliver integrated care or to continue new integrated care activities. Further, financial barriers between the health and social care sectors were perceived as major obstacles for working in an integrated way or for implementing integrated care improvements. Policy-makers at national, regional, and local levels should define a clear vision on integrated working and commit to removing or at least minimising perceived barriers. This can be realised both by ensuring dedicated funding for integrated working and by supporting stakeholders in creating integrated care networks designed to support older people to live in their own homes for as long as possible. This is also expected to facilitate expansion of integrated care, meaning integration of services that go beyond the health and social care systems, such as public health services and different types of community services. Such initiatives, often labelled as population (health) management, are emerging internationally and are seen as the 'next step'. They are characterised by collaborations of stakeholders including health and social care providers, health insurers, municipalities, representatives of community services, and representatives of citizens or patients who are working jointly to achieve better population outcomes and better quality of care, while slowing down cost growth (Struijs et al., 2015a; Struijs et al., 2015b).

- **Support good practice sharing:** Over the last couple of years, different EU-funded (research) initiatives have been initiated. In addition to SUSTAIN, these initiatives include SELFIE2020, ACT@Scale, JA-CHRODIS, SCIROCCO, the B3 Action Group on Integrated Care of the European Innovation Partnership on Active and Healthy Ageing, and INTEGRATE. These initiatives provide guidance for broader implementation and scaling up of good practices in integrated care across European regions (Rutten-van Mölken, 2017). It should be acknowledged that improvements of integrated care are highly context-dependent and that there is rarely a one-size-fits-all approach. It is for this reason that policy-makers at national, regional, and local levels are strongly recommended to creatively support good practice sharing and to facilitate knowledge exchange, both within and between regions and countries. This could be by promoting the dissemination and take-up of more site-specific and applicable components that will optimise successful implementation, as identified through SUSTAIN. In this way, regions and countries can learn from one another (e.g. how to overcome financial barriers, how to build relationships, how to organise person-centred coordinated care and support, how to implement and improve integrated care) while also developing understandings about how to apply lessons learned in their own contexts. Moreover, this will support scaling-up and spread of integrated care initiatives and activities.

- **Create a robust legal framework that enables data sharing and protection:** SUSTAIN was not exempt from the enduring problem of inadequate governance procedures surrounding digital information exchange. Privacy and data protection regulations hindered communication and information sharing between professionals from different organisations in most countries. This was particularly so for data sharing between health care professionals and other staff (social care, voluntary sector, municipality). In general, across Europe, data is scattered across systems that do not interoperate and, alongside privacy concerns, are characterised by technical challenges that block effective data recording and transfer at local, national and European levels (Ling et al., 2012; Politico, 2017; Sorensen et al., 2018). If care is to be improved at all levels, these challenges urgently need addressing. We therefore recommend that policy-makers improve technological infrastructures that enable seamless data sharing together with robust data protection and can be operated through inter-operable national digital systems to support well-coordinated integrated care systems.

5.3 Recommendations for service providers

The following recommendations for service providers emerged from SUSTAIN's experiences of implementing improvements to health and social care services to promote integrated care:

- **Starting-point of improving care is users' and informal carers' needs:** Several improvement projects demonstrated that users and informal carers found it very important to be taken seriously, respected, and understood. They should therefore be seen as important actors in integrated care, not only in their own care processes (e.g. goal setting, care planning), but also in the larger process of service development and improvement. Informing and educating users and informal carers, and empowering them to become actors in integrated care will therefore be important. This is to ensure that their needs and preferences are met in the care and support that are provided. This is important since users and informal carers may have very different views on what is needed and what is person-centred care compared with what managers and professionals think. A shift is needed from 'what is the matter with you' to 'what matters to you'. The result may be that a different operationalisation of 'person-centredness' in integrated care is needed. Do older people really want a care plan? What do they think of shared decision-making? What is really important to them when it comes to integrated care? (De Bruin et al., 2018b; Van der Heide et al., 2017).

- **It is all about health AND social care needs:** In order to comprehensively address the needs of the users and informal carers, it is important to pay equal attention to both their health and social care needs. From the different improvement projects, we have learned that several integrated care activities can potentially facilitate a more comprehensive approach to users' and informal carers' situations, and can be applied in and transferred to different contexts. Strategies that can be put in place include the involvement of a broad range of professionals (both from the health and social care sectors) and volunteers in the care process. This enables cross-sector ownership of the approach, and a comprehensive understanding of users' and informal carers' health and wellbeing. This can for instance be achieved by organising multi-disciplinary or so-called case conferencing meetings since these meetings bring different professionals and non-professionals together and enable the necessary exchange of information related to one user between the different professionals, levels, and sectors involved. Another strategy, which can be transferred to other contexts, is the use of a single shared multidimensional assessment form that can be used by staff from any service to assess health care needs, social care needs, and other needs, and the use of shared care plans. A third strategy is conducting care planning processes through home visits, since such visits will give professionals a better understanding of users' and informal carers' situations and preferences as well as support to design plans for achieving such goals. According to stakeholders involved in the improvement projects, the strategies mentioned here are essential for delivering comprehensive, continuous and high-quality care.

- **Start with a small-scale improvement first:** To improve integrated care successfully, it is important to design and implement a small-scale project with integrated care activities that build upon what is already there on site (e.g. that connects with preferences and goals of staff and users, and are consistent with local or regional policy objectives). This will help to leverage internal and external commitment to project goals, thereby supporting its feasibility and sustainability. Also when faced with limited resources (e.g. funds, manpower, time), it may help to focus on a small improvement initiative that capitalises on existing resources and staff competencies. Such an improvement initiative may or may not be especially innovative; it may or may not have immediate or visible impact, but it is more likely that it will be implemented successfully.

- **Find common ground:** Sites have learned that the definition of a shared vision of different organisations involved at the start of an improvement project is important for its success, but also for its sustainability. Also the formulation of clear shared project goals, that are consistent with both local organisations' priorities and local/regional policy are important. Given that health and social care operates within a system of frequent and often rapid change, clear aims and objectives and a shared vision are essential so that these can also be adopted by new members of staff joining the service. A facilitator external to the organisation can be beneficial in seeking common ground and taking this process forward.

- **Build trust and understanding:** Another lesson learned in SUSTAIN is that for organisations and professionals to collaborate, the relational elements of trust and understanding should be built both on professional and management levels. This can be achieved by creating a structure that facilitates collaboration and information exchange, such as by activities like multidisciplinary meetings to discuss cases and sharing information from needs assessments or sharing care plans. It is deemed important that professionals get to know each other, get familiar with one another's work content, and learn to speak or understand one another's language. To assure the sustainability of the implemented integrated care activities sustainable collaborations need to be built between different professionals and between health and social care. Historically, existing inter-professional and inter-organisational distances need to be closed, especially between health and social care.

- **Good leadership is important:** In order to support successful implementation, but also to enhance sustainability of integrated care improvements, it is considered vital by sites to appoint people who can be effective in enabling and managing the implementation of integrated care activities. This can be either an (external) project leader who guides the process and holds stakeholders accountable, or a local, impartial, champion that is broadly trusted and has the leadership ability to build commitment and motivate people in multiple organisational layers. These people should be able to create enthusiasm and further commitment among professionals and managers, since both will be needed to successfully implement and sustain the integrated care activities. Several SUSTAIN projects appeared to depend on a single person or a small group of people. This may put the sustainability of the project at risk if key stakeholders withdraw. Shared leadership among different stakeholders involved and commitment within all layers of an organisation is needed for sustainable implementation of improvements.

- **Create an enabling environment:** It is important to ensure the organisational structures are configured for the operationalisation of integrated care and to create an enabling environment for change. This includes creating a safe environment and building trust, as mentioned before, but also with respect to management support and allocation of the resources needed, particularly in view of sustainability. This also includes investments by health and social care organisations in the development of their professionals' knowledge and competences to provide integrated care (Rijken et al., 2017). It is important to have a dedicated well-managed and truly person-centred integrated care workforce with a ringfenced budget to strengthen the workforce and combat the problems with workforce fragmentation. This is deemed necessary, since SUSTAIN for instance suggests that there still is a tension between what managers and professionals think are person-centred approaches and how users and informal carers perceive these. In addition, managers and professionals appeared to have different views on best ways to address safety in integrated care than users and informal carers, and in how care plans are used. It is therefore recommended that health and social care organisations allocate resources for training of professionals. Important themes to be addressed in training are: how to assess and address service users' needs, preferences, and goals (e.g. motivational interviewing techniques), how to do a comprehensive needs assessment including needs on different domains of life, how to collaborate in multidisciplinary teams, how to work with informal carers etc. Another aspect of an enabling environment is a proper digital infrastructure, compliant to data protection regulations, that enables an easy access to relevant personal data to all agents, with the necessary training, involved in integrated care.

- **Ensure continuity:** Some SUSTAIN sites experienced constant and large-scale change of organisations or professionals involved which was disruptive to progress, relationships, and sustainability of the improvement project. Different factors as mentioned above (e.g. clear shared vision and project goals, a champion that creates ongoing commitment on different organisational layers, steering from outside to provide resources) are of importance to ensure continuity. It is recommended to health and social care organisations that they have an allocated budget to combat these problems with sustainability, motivation, and initiative cessation.

- **Improving care takes time:** Some managers and professionals from the SUSTAIN sites felt that their improvement projects could have had a greater and wider

impact. Others, however, realised that improving care is an incremental process that takes time, and is dependent on several factors, as mentioned above. Measurable impact, particularly on the level of service users and their informal carers, may therefore not be realistic in the short-term.

5.4 Recommendations for the research community

The following recommendations for the research community emerged from SUSTAIN's experiences of evaluating improvements to health and social care services to promote integrated care:

- **Consider alternative study designs:** In SUSTAIN, we used a multiple embedded case study design (Yin, 2013). Inextricably bound up with studies adopting such a design is the use of several data sources that span qualitative and quantitative approaches (i.e. surveys, interviews, care plans/clinical notes, field notes, notes of meetings, data from data registries). Such an approach also enhances data credibility (Creswell, 2009). As such, in SUSTAIN we made an effort in taking innovative approaches to evaluating progress and outcomes of integrated care. Though some aspects of this design appeared to be challenging, at the same time this design proved to be valuable since the collected data gave us insight into processes and experiences with improving integrated care from different viewpoints and evidence sources. Based on our experiences, we therefore recommend researchers to step beyond the more common research designs (e.g. RCTs). Other approaches, such as case studies and realist evaluations are increasingly being recognised as approaches 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). Applying mixed methods approaches are also key to any design.

- **Develop appropriate tools and approaches to engage and capture experiences of users and their informal carers:** It appeared to be challenging to find an appropriate measure to capture the experiences of service users and their informal carers. Although several patient reported experience measures (PREMs) are being developed nowadays (Klazinga and Fujisaw, 2017), many of these seem not be appropriate to assess the quality of integrated care for older people. They either focus on care provided by a single discipline, on medical interventions for a specific or single condition, or only address medical and health-related aspects of care. Quality of life indicators for frail older people are equally unsuitable, as they do not account for the rapid variations in health status at given points in time. Therefore, we focused on an examination of improvement to care and the personal impact of care delivery. This included degrees of person-centredness, experiences of coordination, and perceived control and independence. These were obtained through the P3CEQ and the PCHC (see Annex 1) both validated for our population group, alongside interviews with older people and their informal carers. We did experience, however, some repetition between these two questionnaires, and in conjunction with the interviews, this did create fatigue in the more frail participants and low recruitment numbers. There is a clear need to employ more innovative data collection techniques that step aside from traditional survey and interview approaches, towards methods that are interactive, engaging and experiential and take account of ageing. Talking Mats, a tested and validated vehicle to support older people to communicate about things that matter to them, is gathering momentum as a research tool and increases participation and sample sizes (Murphy and Oliver, 2013) and may be a way forward. We recommend that further research is conducted to explore these options.

- **Fund research on integrated care economic evaluation:** Efficiency data that provides a picture of cost and resource implications in any integrated care initiative is vital to 'bargain' for dwindling health and social care finance, and plan for service continuation and sustainability. However, these data were difficult to measure and collect from sites within SUSTAIN, and is underreported in this report. This challenge reflects the wider debates within the literature. For example, lack of standardised outcomes and continuous changes in care delivery render the employment of traditional economic models unusable (Evers and Paulus, 2015) and this is still not fully appreciated. Further research is therefore needed to better understand and measure the relationship between resource and cost changes in integrated care. In keeping with growing opinion, the focus must move away from traditional health economic models towards a more realistic and pragmatic perspective of what can be measured. Recasting cost objectives towards investigating a 'better use of resources' within the integrated care environment may be a start. Therefore, we recommend that further research should be funded in order to develop more appropriate European measurement and indicators.

6. CONCLUSIONS

In the EU, initiatives in the area of integrated care are widespread, though the maturity of these initiatives varies significantly. Often, one is still looking for better ways to set up new initiatives and to improve existing ones, with the ultimate goals of improving people's experiences of care delivery, enhancing care outcomes, limiting health and social care costs, and improving the working life of health and social care professionals. By evaluating progress and outcomes within improvement initiatives in different countries, SUSTAIN has obtained new insights into what has worked, and what has not worked, when implementing improvements to integrated care initiatives. The key lesson learned is that improving integrated care is an incremental process which takes time, and is influenced by factors at different levels of countries' health and social care systems. Several of these factors were, despite differences in integrated care initiatives and health and social care systems across countries, universal. Based on the lessons learned from SUSTAIN, we were able to formulate sets of recommendations to policy-makers, service providers, and the research community to (further) improve integrated care delivery across the EU. By sharing these lessons, we hope to inspire and influence other initiatives and countries undertaking similar efforts, and help to minimise the wastefulness of 'reinventing the wheel'.

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8. ANNEX 1: THE SUSTAIN PROJECT AND METHODS USED

8.1 Design

In the SUSTAIN-project, we used a multiple embedded case study design (Van der Eerden et al., 2014; Yin, 2013). Data were collected from fourteen established integrated care initiatives for older people across Europe. Each initiative, also referred to as 'site', was treated as one case study in the research. The initiatives were located in seven European countries: Austria, Estonia, Germany, Norway, Spain, the Netherlands and the United Kingdom. In each country, two initiatives were selected.

In the SUSTAIN-project, we adopted an implementation science approach using the Evidence Integrated Triangle (EIT) (Glasgow et al., 2012), which fostered a rapid, staged evaluation approach and where local stakeholders and research partners co-designed and implemented 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 (Arrue et al., 2016) 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 evaluated by SUSTAIN partners using a multiple embedded case study design, in which each initiative was treated as one case study (Yin, 2013). Within the EIT approach, the evaluation took place in two stages in order to facilitate timely feedback of evidence to enable the assessment of successes and how problems could be resolved going forward.

De Bruin et al. (2018a) describes in more detail the design of the SUSTAIN-project.

8.2 Procedures and measures

A hallmark of case study design is the use of several data sources, a strategy which also enhances data credibility (Creswell, 2009). In all countries, country-specific research teams consisting of SUSTAIN partners therefore used a set of qualitative and quantitative data collection tools (see Table 7).

This allowed us to collect data from different data sources, being: surveys to users, surveys to professionals, interviews with users and informal 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 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.

Table 7 - *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 Co-ordinated Care Experience Questionnaire (P3CEQ) (Lloyd et al., 2018; Sugavanam et al., 2018) 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
OUTCOMES		
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

8.3 Data analysis approach

We took a two-step data analysis approach: 1. Site-specific overarching analysis in each site and 2. SUSTAIN-wide overarching analysis of all sites.

Site-specific overarching analysis

The site-specific overarching analysis was 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 (quantitative 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. Data were analysed against the propositions and analytical questions presented in Table 8. Outcomes of the different site specific analyses are reported in seven country-specific research reports (Ambugo et al., 2018; Billings et al., 2018; Häusler and Ruppe, 2018; Hoffmann et al., 2018; Reynolds et al., 2018; Rull et al., 2018).

SUSTAIN-wide overarching analysis

After conducting site-specific overarching analysis in each site, a SUSTAIN-wide overarching analysis was performed, the outcomes of which are presented in this report. As was the case with the site-specific overarching analysis, also in the SUSTAIN-wide analysis, the principles of the case study design were followed. In the overarching analysis, the individual case studies were compared (i.e. differences and similarities) and integrated to identify recurring patterns in the implementation of the integrated care improvements. By comparing outcomes, barriers, facilitators, and experiences, as well as taking into account the characteristics of the study participants and initiatives, we aimed to get an understanding of generic and contextual factors affecting outcomes and progress of implementing integrated care improvements. This way, we aimed to generate knowledge about what works and with what outcomes when making improvements to integrated care. The starting-point of the overarching qualitative analysis were the country-specific reports mentioned above. Wherever we experienced gaps in knowledge or uncertainties based on the country-specific reports, the content of the original analysis frameworks used during the site-specific overarching analyses were consulted.

Table 8 - *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 coordination 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 your analysis that could be seen as having an impact on integrated care improvements?
Analytical question 5	What factors can you identify in your site analysis that could apply to integrated care improvements across the EU, and be transferable?

9. ANNEX 2: CHARACTERISTICS SUSTAIN SITES

9.1 Characteristics of professionals and managers from the sites

A total of 35 managers and 205 professionals participated in the study. The average proportions of managers aged between 35 and 54 years or 55 years or older were 60% and 29% respectively. The large majority were female and employed fulltime (80% and 91% on average, respectively). On average, about 31% of the managers were working in a health care organisation, 31% were working in a social care organisation or for a local government and 20% were working in an integrated care organisation.

The numbers of professionals that provided demographic data varied widely across sites. Their numbers varied from 6 (AT1) to 59 (SP1). As with the managers, the professionals were also mostly aged between 35 and 54 years (59% on average). Exceptions were GER2 and AT2,that respectively had high proportions of staff aged between 18 and 34 years (93%) or of staff aged 55 years or older (100%). The average proportion of staff members with a high educational level was 67%. Exceptions were NO1 (65%), NO2 (50%) and GER2 (50%) with relatively high proportions of staff members with a middle level of education. In four sites (GER2, NO1, NO2), proportions of staff members with low educational levels were relatively high (between 28% and 35%). The large majority of staff members were female (87% on average). On average, 61% of the professionals were working in a healthcare organisation, 18% were working in an integrated care organisation, 13% were working in a social care organisation and 7% were working in another type of organisation (e.g. voluntary organisation). In six sites (AT1, EST2, GER2, SP2, NL1, UK2), the large majority of professionals were from a healthcare organisation, whereas in one site (EST1) 100% of the professionals were working in an integrated care organisation. One site (GER1) had a relatively high proportion of professionals from a social care organisation (57%).

9.2 Characteristics of users and informal carers from the sites

In total, 244 users participated in the study. On average, 23% of the users were aged between 65 and 74 years, 42% were aged between 75 and 84 years, and 35% were 85 years or older. Particularly NO2 and NL3 had high proportions of users aged between 65 and 74 years (64% and 60%, respectively), whereas NL1 and UK2 had high proportions of users aged between 75 and 84 years (62% and 67%). NO2, NL3, and UK2 had relatively low proportions of users aged 85 years or older (lower than 20%). On average, 67% of the users were female. In AT1, the proportion of male users was higher (57%), whereas in NL1 and UK2 the proportions of male and female users were similar. The users had 5.2 medical conditions on average. In NL3 and UK2, the average numbers of medical conditions were relatively low (3.2 and 3.6, respectively), whereas this number was relatively high in SP1 and SP2 (6.5 and 6.6, respectively). The average proportion of users living alone was 51%. There was wide variation across sites in this proportion, ranging from 20% in NL3 to 90% in GER2.

In total, 80 informal carers participated in the study. On average, 15% of the informal carers were aged between 18 and 44 years, 39% were aged between 45 and 64 years, and 46% were 65 years or older. Particularly GER2 had a relatively high proportion of informal carers between 18 and 44 years (57%), whereas AT1, NO1, NO2, NL1, UK1, and UK2 had relatively high proportions of informal carers aged 65 years or older (more than 65%). The average proportion of female informal carers was 69%. This proportion, however, widely varied across sites, ranging from 40% in UK1 to 100% in AT1 and GER1. The average proportion of spousal carers was 46%. Five sites (AT1, EST1, GER1, GER2, SP1) had relatively low proportions of spousal carers (lower than 33%). Overall, informal carers not being spouses were mostly children, other family members or hired carers (paid by themselves, family, or by the state/insurance). Six sites (NO1, NO2, NL1, NL3, UK1, UK2) had relatively high proportions of spousal carers (higher than 67%).

10. ANNEX 3: FACTORS EXPLAINING SUCCESSFUL OR UNSUCCESFUL IMPLEMENTATION OF INTEGRATED CARE ACTIVITIES

This annex outlines the factors explaining successful or unsuccessful improvement of integrated care initiatives, clustered according to the micro, meso, and macro levels of the health and social care systems. Table 9a outlines the overall factors, and Table 9b outlines those factors relating to specific sites.

Table 9a - *Overall factors explaining successful or unsuccessful implementation of integrated care activities.*

Level	Factor	Explanation
Micro	Attitude of professionals towards (culture) change	Some professionals and organisations perceived change in existing ways of working as beneficial which facilitated the implementation of improvement processes, whereas others were more hesitant towards news ways of working which hampered such processes (e.g. collaboration with professionals from other sectors, changing user-provider relationships).
	Commitment, motivation, and willingness of professionals	Realisation of the aims of the improvement project depended on the motivation, commitment and willingness of professionals. In some sites, improvement project objectives were insufficiently aligned with preferences of professionals which affected the motivation to actively participate in the improvement project. Recognition of the importance of the improvement project and a belief in its benefits positively affected implementation of the project.
	Engagement of users and informal carers in the improvement project and/or care delivery process in general	Engagement of users and informal carers, and their positive experiences with the implemented integrated care activities, could boost the efforts of professionals.

Level	Factor	Explanation
Meso	Available time of professionals	Professionals usually had high caseloads/ workloads making it challenging for them to dedicate time to the improvement project. Mostly, no additional staff were hired or exclusively appointed to the new integrated care activities, meaning that the fulfilment of objectives depended on the willingness and commitment of professionals.
	Available resources and capacity	Available human resources (staff allocated to the improvement project) facilitated the project implementation. Some sites had to deal with limited human resources on top of their workload due to flu vaccination season, maternity leave etc. which hampered the implementation of the improvement project.
	Commitment and support at managerial level	Commitment and support at the managerial level enabled professionals to invest resources, time, and effort in improvement project.
	Communication	Clear and continuous communication with and convincing of internal and external stakeholders were seen as crucial factors when making improvements to integrated care.
	Composition of improvement team	A broad composition (i.e. health care professionals, social care professionals, policy-makers, representative of older people, both operational and management staff) of the teams designing the improvement project and actually carrying out the improvements appeared to be beneficial for success of the improvement project. Consistency of composition was found important. Changes in composition often led to changes in group dynamics, resulting in less constructive meetings due to repetition, distrust, uncertainty, lack of understanding of the topics discussed, and key decisions that could not be taken. Also a lack of sufficiently senior level staff in the improvement team was seen as a barrier since seniority was deemed necessary to push for change or commitment.
	Governance arrangements	Effective governance arrangements through the development of terms of reference, transparent/flat project structure, clear accountability, and risk management arrangements facilitated success in carrying out the improvement project.
	Information exchange (by IT) between professionals/ organisations	Insufficient exchange of user and informal carer information between professionals and organisations resulted in a slowly executed improvement project. In several sites, information exchange appeared to be a challenge. This was due to non-communicating IT systems, used by the different organisations involved or due to the lack of a device to remotely access user data. In one site, however, the lack of a shared IT system, somewhat paradoxically, may have promoted direct communication between individuals either face-to face or over the telephone, and the development of trusted relationships which enabled faster response times in meeting users' needs.
	Leadership and ownership	(Impartial) leadership at different layers within organisations collaborating in the integrated care network are important when improving integrated care. However, in several sites a number of challenges were observed including withdrawal of leadership, lack of proper leadership, leadership from SUSTAIN instead of from local stakeholders, or changing leadership by people having different interests. In some sites, none of the organisations involved took ownership of the improvement project resulting in the SUSTAIN project team members taking the leading role. Lack of ownership and unstable and inconsistent leadership challenged roll-out of the improvement project and put sustainability of implemented integrated care activities at risk.
	Organisational cultures	Differences in organisational cultures leading to different interests, priorities, interpretations, and lack of connection between organisations made it difficult to align the different organisations' ways of working.
	Organisational structures	Involvement of different types of organisations revealed differences between and within (health and social care) systems. This included different payment systems and legislation, different reporting tools, different administrative procedures, and incompatible IT systems which eventually hampered close collaboration.
	Organisations' visions	A shared sense of urgency and vision among stakeholders from different organisations about what would be important when taking care of older people were good starting-points for setting up an improvement project.
	Project management and planning	Implementation of improvement projects was facilitated by following a clear timeline and planning of what to do and when, and by clearly defining roles and responsibilities. Having a project manager responsible for planning regular meetings, setting deadlines and priorities, and challenging to come to tangible agreements supported achieving the set objectives.
	Prior experiences with improvement initiatives	Managers of one site had negative experiences with earlier projects that aimed to improve collaboration between different service providers (e.g. lack of tangible results, unsuccessful efforts to improve collaboration). Such experiences hampered their motivation and enthusiasm. However, other sites indicated that prior experiences facilitated the project implementation, as they were for instance already used to communicating and collaborating with professionals from other disciplines or had obtained knowledge relevant for this improvement project.

Level	Factor	Explanation
Macro	Connection with existing local and regional initiatives and networks	Connection and alignment of improvement projects with existing local and regional collaborative initiatives and networks were facilitating.
	Engagement of local community	Engagement of the local community (i.e. municipality, local social care organisations, representatives of older people) facilitated the implementation of an improvement project. Also it helped to place the improvement project in a 'broader context'. This may result in more possible points of reference in the future and therefore a broader implementation of processes.
	Funding and payment schemes/systems	Tensions over ongoing funding for the integrated care sites, as for the implemented integrated care activities (as part of SUSTAIN), hampered the improvement projects. In some sites, reforms in funding schemes actually facilitated the implementation of the improvement project.
	Local, regional, and national policy and legislation	Good alignment with local, regional or national policy (e.g. political agenda on care for older people; wider transformation processes) facilitated the implementation of the improvement project, and positively affected stakeholders' commitment. Some improvement projects, however, touched legal prohibitions/legal grey areas – such as cooperation prohibition between doctors and therapists. This could potentially hinder the improvement process.
	Privacy regulations and data protection legislation	Privacy and data protection regulations hindered communication and information sharing between professionals from different organisations. This was particularly so for data sharing between health care and non-medical professionals (social care, voluntary sector, municipality).
	Valuation of health care, social care, and voluntary sectors	Sectors were not equally valued among professionals, users and informal carers which hampered possibilities and efforts of services. Stigma of social services hindered users and informal carers' acceptance of the role of the social worker, and home care services were less valued than other services, which may have had implications in the area of budget allocations.

Table 9b - *Site-specific factors explaining successful or unsuccessful implementation of integrated care activities.*

Level	Factor	Explanation
Micro	Attitude of professionals towards older people	Professionals were often (personally) dedicated to provide adequate care and support to older people. However, apparent ageism and dehumanising behaviour by medical staff was still prevalent in one of the countries where SUSTAIN took place. This attitude towards older people appeared to undermine attempts to improve care (e.g. empowerment of older people, shared decision-making).
	Attitude of users and informal carers towards themselves	Low self-esteem and self-stereotypes of inadequacy among older people and their informal carers reduced overall readiness to be active partners in an integrated care service in one of the countries where SUSTAIN took place
	Awareness of professionals, users and informal carers of new services	In one site, despite different information and public relations efforts, a lack of awareness among professionals, users, and informal carers of the implementation of a new service centre negatively affected the success of the improvement project.
	Expertise of professionals	Expertise of professionals supported the implementation of the improvement project. In one site, professionals had insufficient e-skills, which was one of the reasons why an improvement project could not be implemented as intended. In another site, professionals found they needed more training in order to improve their communication and shared-decision making skills with the target users, as communication issues were identified as a key barrier hindering the improvement project.
Meso	Physical space	In one site, there was an attempt to increase capacity of an adult day services centre, as part of their improvement project. However, they only partly succeeded since a larger physical space was needed if more users were to be served.

Level	Factor	Explanation
Macro	Attitude towards social services	In one country, users of social services tend to be stigmatised since, traditionally, social services focused on people at risk of social exclusion or in conflictive situations (e.g. extreme poverty, substance abuse, family violence etc.). Only in the last decade, social services have also provided a charter of services for 65+ population, together with becoming responsible for assessing degrees of dependence.
	Cultural factors and historical context	Shared decision-making in one of the countries that participated in SUSTAIN may not always work in the current 65+ population, for several reasons. This is seen to be due to perceived stigma, as well as other cultural and age-related factors. For instance, the medicalisation of health care could have created a barrier to participation in health care, and hence shared decision-making. Also the country's historical context played a role. In this particular country, people grew up in the frame of a dictatorship and were not used to expressing preferences or participating in decisions. This can hamper the implementation of certain integrated care activities. In one of the other countries, however, the historical context was rather a facilitator than a barrier for the improvement project. Also in this country, individualised solutions and offers as well as personal needs were not part of their day-to-day life and reality. Getting individualised care and processes were a relatively new experience for them that they did not have in their past. The excitement and pleasure of the users about the fact that their personal needs (for the first time) were in focus therefore was an explanation for succeeding and improving integrated care initiatives.
	Geography and location	In one site, key organisations involved in the improvement project did not share geographical boundaries with each other, and service provision was highly fragmented. This was a barrier for improving integrated care.
	Knowledge of social services	In one country, users and informal carers generally lacked knowledge of the local social services roles and resources that might be available to 65+ persons. The connotations behind being visited by a social worker (also see 'attitude towards social services') hindered users' and informal carers' acceptance of the role of the social worker.
	Policy on long-term care	Institutional care settings in one of the countries were SUSTAIN was carried out tend not to encourage older people to make a real effort to manage their life at home independently. Often it is taken for granted that the nursing home is the final destination. This hampered implementation of (part of) the improvement project
	Seasonal pressures	Two sites experienced so-called 'winter pressures', being extreme pressure on services over winter periods. As a result, professionals were required to cancel anything not deemed to be urgent, which was disruptive to the new improvement initiatives.

SUSTAIN
Sustainable tailored integrated care for older people in Europe

Bilthoven/Amsterdam/Canterbury, December 2018