SUSTAIN

Sustainable tailored integrated care
for older people in Europe

"I want **to be taken care of as a person first** rather than as a generic patient. It's important not just to take care of my physical health but also of my wellbeing. I need care to support my social, cultural and emotional needs and expectations."

"I wish I had spent my partner's last years of life **closer to home** and our community where our story began and which was so important to us. I honestly think that would have given him a lot more peace and even a few more years of happiness."

"Where [integrated care] does work, we see not only the older person, and their relatives happy but **also staff**. The counties and municipalities responsible for cost are even happier because there is no duplication in care."

"As a family caregiver, I feel that the **current system is a labyrinth**, in which it is easy to lose continuity of care and potentiate adverse events. With my mother, I experienced this situation, where, going to different consultations led to a failure of information and duplication of medication."

1. THE SUSTAIN PROJECT

From 2015 to 2019, the SUSTAIN project worked with local stakeholders from thirteen initiatives (sites) in seven countries aiming to improve integrated care. The SUSTAIN-project was carried out by thirteen partners in: Austria, Belgium, Estonia, Germany, Norway, Spain, the Netherlands, and the United Kingdom.

SUSTAIN's objectives were twofold:

1 **to support and monitor improvements** to established integrated care initiatives for older people living at home with multiple health and social care needs, and in so doing move towards more person-centred, prevention-oriented, safe and efficient care; and

2 **to contribute to the adoption and application** of these improvements to other health and social care systems, and regions in Europe.

Integrated care initiatives, which were already operating within their local health and social care systems, were invited to participate in the SUSTAIN-project. Criteria for including these initiatives, were defined by SUSTAIN research partners and drawn from the principles of the Chronic Care Model and related models [1-3].

Accordingly, initiatives were identified if:

- They were 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;
- They were **focused on people aged 65 years** and

older, who live in their own homes and who have multiple health and social care needs;

- They **support** people to stay in their own homes (or local environments) for as long as possible;
- They **address older people's multiple needs**, and were not single disease oriented;
- They **involve professionals** from multiple health and social care disciplines working in multidisciplinary teams (e.g. nurses, social workers, pharmacists, dieticians, general practitioners);
- They were already **established** and preferably operational for at least two years;
- They cover one **geographical area** or local site;
- They are **mandated by one organisation** that represents the initiative and that facilitates collaboration with SUSTAIN research partners.

The thirteen SUSTAIN sites selected according to these criteria showed great diversity in the type of care services provided [4,5]. Their focus ranged from proactive primary care for frail older people and care for older people being discharged from hospital, to nursing care for frail older people, care for people with dementia, and palliative care.

In the SUSTAIN-project, we adopted an implementation science approach in which local stakeholders and research partners co-designed and implemented improvement plans. Each site agreed to implement their plans over an 18-month period from autumn 2016 to spring 2018. At each site, implementation progress and outcomes were monitored by SUSTAIN partners [6]. SUSTAIN partners used both qualitative and quantitative data collection tools. The sites were supported by several research institutes and European-wide organisations including the AGE Platform Europe (located in Belgium), the European Health Management Association (located in Ireland) and the International Foundation for Integrated Care (located in The Netherlands).

THE ROADMAP

Improvement in home care support is particularly necessary due to existing fragmentation that knows no geographical boundaries. Whether you are living in Osana, Catalonia or in SUSTAIN's northern frontier in Estonia or Norway, people are experiencing fragmented care.

The document you have in hand has a **range of resources** in the form of guides for implementation, improvement, design and engagement of stakeholders in system-wide transformation. All these resources aim to support health and social care professionals, managers, decision-makers, -policy-makers and even users or their families to respond to the urgent need to support care in the home environment to better meet the needs of older people.

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ROADMAP

2. ABOUT THE ROADMAP

SUSTAIN partners worked in close collaboration with health and social care staff in 13 sites across 7 countries in Europe.

This has involved working closely in a multilevel participatory process with local authorities, managers, professional, but also users and their carers to improve integrated care for older people. Initiatives involved five different areas of care: home nursing services, transitional care, dementia care, primary care, and rehabilitative care.

These experiences have been captured in the roadmap which aims to bridge the gaps between research, practice and health systems policy that impedes far too often the scaling up of innovations across Europe and transfer to other settings.

While the Roadmap is designed principally as an improvement aid to support improving integrated care for older persons living at home, it also helps readers who may not know where their site or service is in terms of the important elements of an effective integrated

care service'. The roadmap suggests that integrated care teams assess their progress to date again by focusing on improving those areas (or initiating those areas) that would appear to be furthest away from best practice.

The roadmap is set up as five books.

BOOK 1 Designing Integrated Care Services: is a guide for planning services and outlines the key design features required for integrated care so that these can be understood and assessed in terms of the capabilities required.

BOOK 2 Setting up Integrated Care: is a "how to" guide to managing change that supports key decision makers in the process of implementation of integrated care including monitoring, evaluation and quality improvement.

BOOK 3 Improving integrated care: aims to support those sites, which have already initiated the process of implementation and want to improve integration. This booklet captures the experiences of SUSTAIN in the steps and tools that were of greatest use and what the lessons learned were including various tools to analyse and capitalize on motivations for change.

BOOK 4 Context of Integrated Care: examines how to develop an enabling environment. This means how to develop a coalition towards integrated care, building the support for change, and developing collaborative capacity.
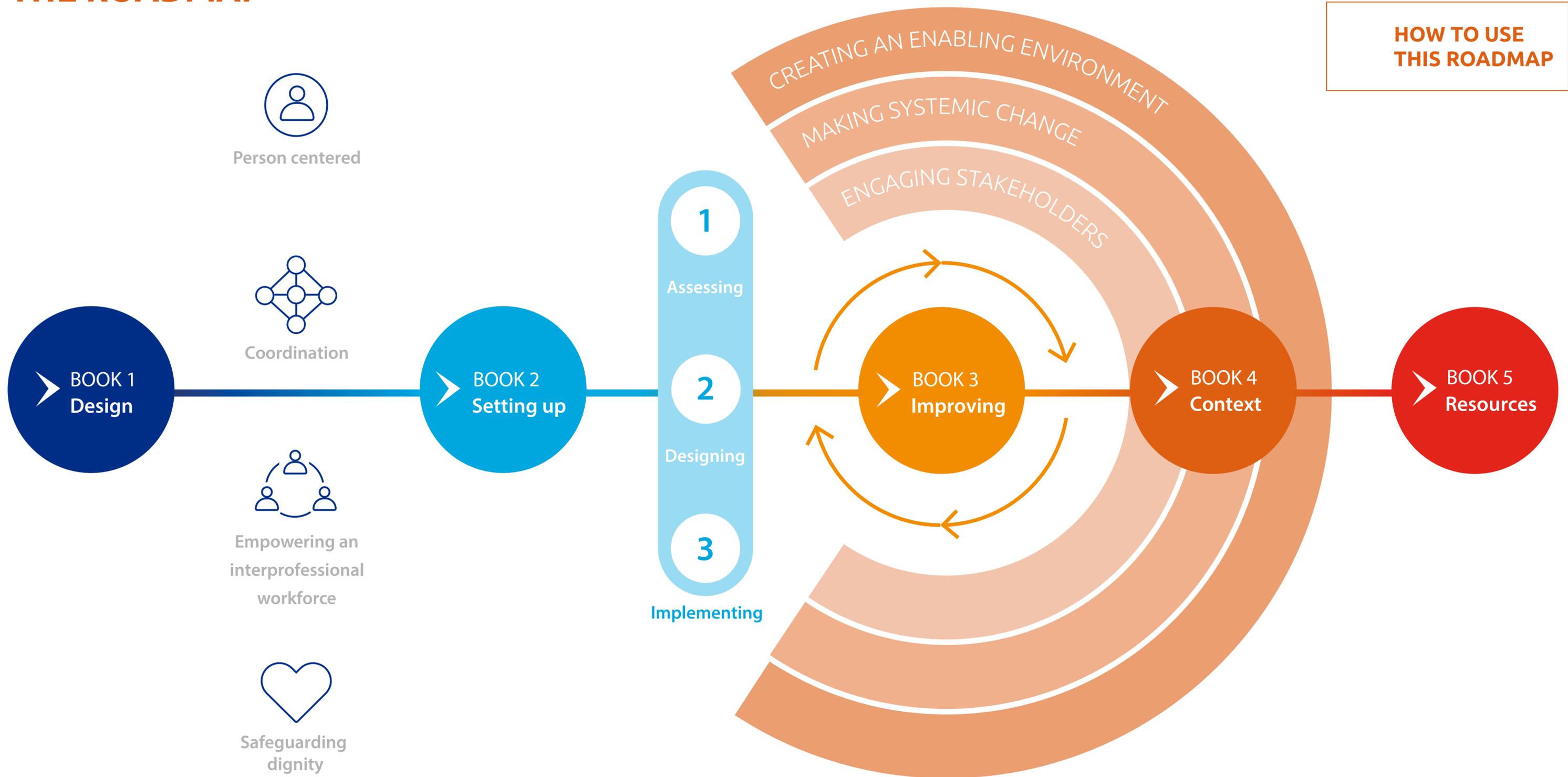
BOOK 5 Resources: contains all the references of each books, advocacy, assessment tool book 1, casestories and factsheets of the casestories.
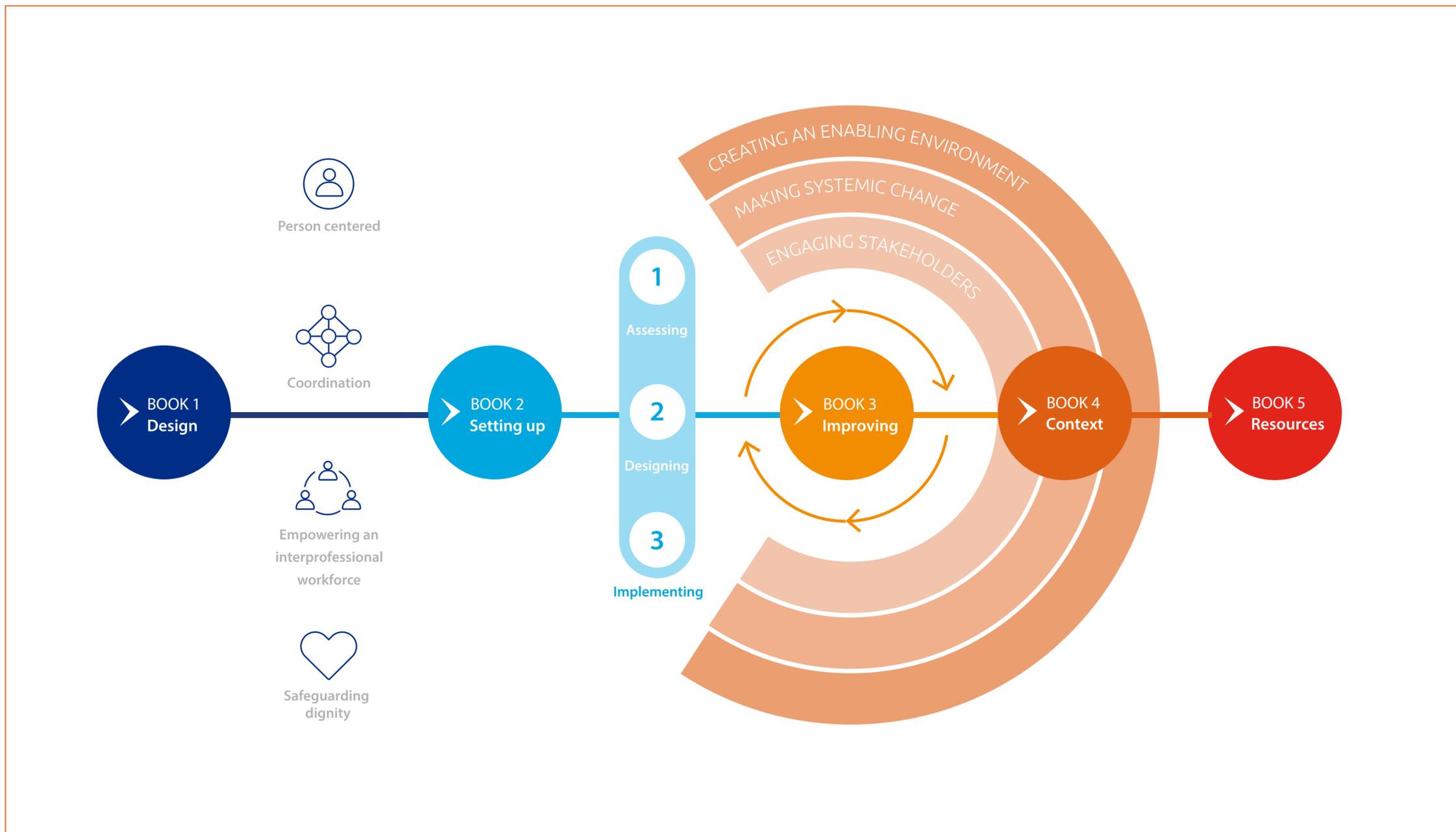
Enjoy!

THE ROADMAP

Person centered

Coordination

Empowering an interprofessional workforce

Safeguarding dignity

BOOK 1
Design

BOOK 2
Setting up

1 Assessing

2 Designing

3 Implementing

CREATING AN ENABLING ENVIRONMENT

MAKING SYSTEMIC CHANGE

ENGAGING STAKEHOLDERS

BOOK 3
Improving

BOOK 4
Context

BOOK 5
Resources

HOW TO USE THIS ROADMAP

BOOK 1
Design

Person centered

Coordination

Empowering an
interprofessional
workforce

Safeguarding
dignity

BOOK 2
Setting up

1
Assessing

2
Designing

3

Implementing

CREATING AN ENABLING ENVIRONMENT

MAKING SYSTEMIC CHANGE

ENGAGING STAKEHOLDERS

BOOK 3
Improving

BOOK 4
Context

BOOK 5
Resources

This is a visual of the
complete roadmap. See
here all the different
books with the most
important content.

Click on one of the round
buttons to go directly to
a specific book.

Each book has its own
specific color.

X

CLICK FOR KEY MESSAGES

BOOK 1

Design of Integrated Care

The goals of SUSTAIN were to move sites towards improvement in terms of person centredness, prevention orientation, efficiency and safety. As sites pursued these four goals and developed their improvement plans, the SUSTAIN project found that sites focused on four areas or "design features" as particularly relevant in achieving these goals.

They were:

FEATURE 1 Person centered care
FEATURE 2 Coordination
FEATURE 3 Empowering an interprofessional workforce
FEATURE 4 Safeguarding the dignity

Person centered

Coordination

Empowering an interprofessional workforce

Safeguarding dignity

START

Click for the key messages up on the right. Here you can read the most important content of the book.

Start each book by clicking on the start button.

BACK   NEXT

INTRODUCTION
Summary

BOOK 1
Design

> **FEATURE 1**
> **FEATURE 2**
> **FEATURE 3**
> **FEATURE 4**

BOOK 2
Setting up

BOOK 3
Improving

BOOK 4
Context

BOOK 5
Resources

Navigate through the book by clicking on the links in the menu on the left side.

To go back and forward through the pages simply click on the BACK and the NEXT button. To go back to the overall roadmap visual, click on ROADMAP.

BACK   ROADMAP   NEXT

BACK   NEXT

BOOK 1

Design of Integrated Care

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FEATURE 1 Person centered care
FEATURE 2 Coordination
FEATURE 3 Empowering an interprofessional workforce
FEATURE 4 Safeguarding the dignity

Person centered

Coordination

Empowering an interprofessional workforce

Safeguarding dignity

START

In order to improve **person centredness**, **prevention orientation**, **safety** and **efficiency** in integrated care, four design features have become apparent and relevant: improving user-involvement; improving coordination; empowering the workforce and safeguarding the dignity of older people at a community level.

Each of these design features can be reinforced by a range of activities that SUSTAIN projects have found useful.

Most common to all design features is **taking the time to listen** and learn from users what is important to them.

The motivation and satisfaction of both users and providers is **reciprocally related**. Where users are happy so are professionals. And vice versa.

INTRODUCTION

PERSON CENTRED CARE

This means orienting care around people's individual needs, preferences, culture, capabilities and strengths, rather than their illness(es) or limitation(s). For older people living at home, person-centredness implies involving users and their **informal carers** in decision-making and the planning of their care in a way that is inclusive and meaningful for them.

COORDINATION

This means focusing on integration of health and social care needs to ensure continuity and the simultaneous delivery of multiple interventions, including both care-related and care-facilitating (e.g. shared IT systems) processes. When done effectively, coordinated care is a **person-centred**, assessment-based, **interdisciplinary** approach to integrating **health care** and **social support** in a manner that is cost-effective and specific to the needs of users and their informal carers.

EMPOWERING AN INTER-PROFESSIONAL WORKFORCE

This means focusing on the professionals from various disciplines **within health and social care**, as vital to the success of integrated care and devoting efforts to ensure that professionals but also the various non-professionals (voluntary sector, administrative staff, etc..) are supported to deliver the best possible integrated care.

SAFEGUARDING THE DIGNITY

This means users and their families are respected as active participants in society and tensions do not arise from mis-led assumptions about what can and cannot be done in one's older years. Greater efforts need to be made to ensure that care – regardless of setting - does not undermine, but rather **supports and promotes an older person's self-respect, self-determination, privacy and social inclusion**.

FEATURE 1 Person-centered care

1.1 WHAT DO WE MEAN BY IMPROVING PERSON-CENTRED CARE?

Improving person-centred care means increasing the **focus on orienting care around people's individual needs**, preferences, culture, capabilities and strengths, rather than their illness(es) or limitation(s). For older people living at home, more can be done to **involve users and their informal carers** in decision-making and the planning of their care in a way that is inclusive and meaningful for them. This means promoting more autonomy of the user, while still ensuring their safety.

Efforts to promote users' **autonomy and engagement in their decision-making** must necessarily be adjusted according to the user's knowledge, skills and confidence to take on this active role. In circumstances where a user is unable to express their own needs and/or wishes (due to cognitive difficulties, for example), person-centredness can still be achieved through engaging with family and/or carers about the user's capabilities, experiences and preferences.

1.2 WHY IS THIS IMPORTANT?

As the prevalence of **frailty**, (multi) **morbidity**, dependency and disability increases with age [1, 2], the care needs of older people become more complex [3, 4], requiring multiple health and social care solutions [5]. As these needs increase and solutions become more complex, **medical errors** and the risk of incompatible or **redundant interventions** rise [6, 7].

By improving person-centred care in ways that are more **comprehensive** and seek to meet users' needs in and/or near their homes, **integrated care initiatives in SUSTAIN** have been able to reduce risks and complexities by working with other factors that influence the users' wellbeing, i.e. loneliness, social isolation etc.

In some cases, users' health outcomes may have been improved as care becomes more accessible, appropriate and acceptable for them to participate in. This not only helps providers to be more responsive to users' needs but also helps **users** and **informal carers** have a better understanding of how to improve prevention and safety measures in their care.

A range of measures that aim to promote person-centredness have been proven to have a positive impact on, amongst other things, patient satisfaction [8], costs of care

FEATURE 1 Person-centered care

[9] , length of hospital stay [10], functional performance [11] and quality of care [12, 13]. The impact of person-centred care is sometimes documented in terms of clinical outcome measures (such as length of stay, planned and unplanned hospital admissions, emergency room visits). However, far more often, the **positive impact** of person-centred care is appreciated by users, professionals and managers in terms of non-clinical measures (such as user engagement and user satisfaction)[8, 10].

1.3 WHAT ARE THE ACTIVITIES THAT ENABLE IMPROVEMENTS IN PERSON-CENTRED CARE?

1. Communication and active listening.
2. Shared decision making and co-production of a care plan
3. Relational continuity for the user with health and social care providers over time
4. Supported self-care

ESSENTIAL ACTIVITIES

> **Communication and active listening**

> **Supported decision making and co-production**

> **Relational continuity over time for the users**

> **Supported self-care**

COMMUNICATION AND ACTIVE LISTENING

WHAT DO WE MEAN BY COMMUNICATION AND ACTIVE LISTENING?

Communication and active listening are key for building trust with users and supporting the engagement of users and their informal carers in care planning. Active listening requires the listener to **fully concentrate**, understand, respond and then remember what **the user** and his/her carers have said. It involves not just listening with one's ears, but also with one's heart and mind to carefully **try to understand the user's needs** or worries. In order to design and deliver care that is truly person-centred, attention must be paid not only to what users and their informal carers say but also what they do, as well as observing their home environment and the circumstances in which they live. **Communication should be appropriate** in terms of minimising medical or profession-specific jargon and decreasing the **asymmetry** in knowledge between the user and the professional. Effective communication opens up discussion with the user and his/her informal carer as opposed to taking on a patronising and pedantic tone. **Body language** of the professional or non-professional is also important in demonstrating to the user and his/her informal carer that their stated needs, wishes and emotions have been heard.

WHY ARE COMMUNICATION AND ACTIVE LISTENING IMPORTANT?

By devoting efforts to understanding what people are saying, professionals gain better insight into the user's health, social, emotional and relational situation. For example, i**n Surnadal, Norway**, by prompting healthcare staff to adopt the language of '**what is important to you**', rather than '**this is what I can do/should be done**' as a starting point, users have felt more encouraged to discuss their needs. The same was observed in Austria, when nurses adjusted their language to users, which were suspected of suffering from dementia. Instead of speaking of "dementia disease" they used terms like "forgetfulness" or "reviewing your memory" when they screened the user for the possibility of dementia. This helped the older person **to feel safe** and **prevent unnecessary anxiety**. Furthermore, the Austrian hospital staff received further training to raise the staffs awareness of early signs of dementia. Early signs are not obvious and became apparent during staff-user communication and by observing the user's behaviour e.g. nutritional behaviour, orientation etc. Consequently, active listening was key when it came to an early detection of dementia.

This approach can be expected **to empower users** to consider medical and professional knowledge and at the same time actively involve themselves in conversations and decisions related to their care.

COMMUNICATION AND ACTIVE LISTENING

In the 'Over 75 Service' at Sandgate Road Surgery in Kent, UK, personal independence coordinators, who are part of the voluntary sector workforce, approach assessment in terms of the goals the older person wants to achieve, rather than applying their own assessment framework. In this way, the needs of the user are put first. On the flip side, this has been **particularly challenging in Estonia**, where a shortage of health and social care professionals has resulted in staff facing enormous workloads and struggling to **find the time to engage in in-depth conversations** and provide relevant information for users and their families. As a result, users and their families feel less comfortable communicating their needs and wishes to nurses and other care providers.

Improving communication and active listening among professionals towards users is also vital for understanding and managing both users' and professionals' expectations. This is particularly important in **enablement activities** that strive to promote independence. In the **Swale Home First service in the UK**, for example, some users were not clear why they were (or were not) receiving certain support at home. Their expectations around enablement support, as opposed to directly provided care, were not always managed well.

Active listening to both the users' health and social care needs (e.g. values, fears, life events) can have a **major impact on both the process and outcomes of care** [1-4]. Active listening is therefore key for professionals to be able to deliver safe care and provide support that is **tailored to the individual's needs**, preferences and capacities, while not overlapping or providing unnecessary or unexpected care. It is important that professionals do not arrive at their own conclusions about the users' needs and/or wishes or with incomplete information, as this can also result in increased costs and inefficient use of resources.

SUPPORTED DECISION MAKING AND CO-PRODUCTION

WHAT DO WE MEAN BY SHARED DECISION-MAKING AND CO-PRODUCTION?

This means that decisions involving the users' care are made in a comprehensive and anticipatory manner while involving users, their close family and their carers. The process of shared decision-making results in the **co-production of care plans** and care pathways. These care plans seek to address the older person's full range of needs by taking into account their health, personal, social, economic, educational, mental health, ethnic and cultural background and circumstances. For example, during the shared decision-making process, users arriving in Templin, Germany work with a range of professionals (doctors, nurses, physiotherapists, lawyers and social workers) in the KV RegioMed Zentrum as well as in its connected service-center, to set goals based on the user's needs and the available resources.

In the case of Osana (Catalonia), a meeting was organised with the care team, users and their carers to present, **discuss and validate** draft care plans that had been produced from the multidisciplinary case conference. This ensured that users were able to participate in their care planning but also accept the actions outlined in the care plan. At the other Catalonian site, Sabadell, **'Growing Older' workshops** were run for service users, with the aim of giving older people the tools to recognise and explore their needs and emotions. In doing so, the workshops enabled users to be more active participants in decisions regarding their care plan.

In Estonia, professionals often underestimate the ability of older people to represent themselves when deciding on a care plan, often cutting them out of the conversation. Added to this, **user interviews** in Estonia revealed that older people's lack of sense of the future may be a crucial feature in being a relatively passive agent in their care. Low self-esteem and stereotypes of inadequacy among older people and their informal carers reduce **overall readiness** to be active partners in an integrated care service. The Alutaguse improvement project sought to address this by implementing new procedures for involving older people in identifying their needs, planning and evaluating the services provided to them. Through the improvement project professionals learned that, although **engaging users and their carers** in the co-production of care plans is more time consuming, ultimately the user's needs were better met and satisfaction with care increased.

The main purpose of care plans is to provide the case manager, or care coordinator, with a structure that sets out older people's needs and goals in a way that is **integrated and aligned**. Care plans also need continual review as the care needs of the older person changes over time [5].

SUPPORTED DECISION MAKING AND CO-PRODUCTION

WHY ARE SHARED DECISION-MAKING AND CO-PRODUCTION IMPORTANT?

Shared decision-making can help users and the care team decide—together—**which options are the right ones for each user** whilst paying attention to each user's unique needs. The co-production of a care plan lies at the heart of good case management and acts as the basis for decision-making, enabling a case manager or team to: make referrals to appropriate services; coordinate all the different services around a user's needs; ensure that care is enacted in a timely, safe and efficient way; and help to monitor whether the older person has made any progress over time against the care outcomes that were agreed.

Living with complex conditions is **an emotional journey** and can leave **users feeling very vulnerable.** As the user faces new challenges or further complications, ongoing adjustments to care plans should be made. If users are more involved in developing their care plans, they may be better prepared and more resilient to these changes. Shared decision-making and co-production that takes place with older people and their informal carers allows for **reflection, reorientation and recording of user's values and wishes** before an older person's health deteriorates or before a health crisis occurs. Working closely with the care team, including the user and his/her carer/s, lets the team explore all the available options for the user, and can help ensure that the care chosen is the most suitable for the user.

Shared decision-making and co-production have been shown to be **associated with fewer hospital admissions, fewer days in hospital and lower costs** [6]. Systematic reviews also suggest that shared decision-making and co-production leads to improvements in certain indicators of physical and psychological health statues, and people's capability to self-manage their condition when compared to usual care [7].

RELATIONAL CONTINUITY OVER TIME FOR USERS

WHAT DO WE MEAN BY RELATIONAL CONTINUITY OVER TIME?

Relational continuity over time means professionals securing an ongoing **therapeutic relationship** with the user over time and across different health and life events [8]. This often is secured by identifying one main contact provider, who is usually the primary care provider [9]. Increasingly, continuity has also been shown to involve teams of providers [7]. Whether relational continuity is established through an individual or a group, a primary care provider or some other provider, it is important that users and their informal carers experience continuity in their care; and that this is not compromised (even with staff turnover) in a way that threatens users' wellbeing or disregards their wishes and priorities. For example, both Catalonian improvement projects involved **greater visibility of an integrated care team** (GP, primary care nurse, social worker) rather than one single person who was knowledgeable of their case and with whom they could talk and discuss their care. This enhanced **relational continuity**, as once the user and carer had become familiar with a team, the relationship depended less on one single professional.

WHY IS RELATIONAL CONTINUITY OVER TIME IMPORTANT?

Relational continuity has been shown to result in **trusting relationships**, which promote empathic, collaborative consultations in which users understand their conditions and treatment thereof [10]. Relational continuity therefore also enhances empowerment, enablement and adherence to treatment. A targeted literature review by the World Health Organisation looking at **relational continuity** found that it improved the experience of care not only for **users** but for the **professionals and non-professionals** taking care of the user. Relational continuity also improves the quality of care, contributes to better health outcomes and improved health system performance [10]. Continuity and care coordination are closely related. Continuity enables care coordination by creating the conditions and relationships that can support seamless interactions among multiple providers within interdisciplinary teams or across care settings/sectors. An international health policy survey has shown that an ongoing therapeutic relationship between a user and a professional is associated with **positive outcomes** regarding the process of care [11]. This includes outcomes such as greater uptake of preventive and health-promoting strategies [12-15], reduced diagnostic testing [16], reduced use of the emergency department [17] and reduced emergency hospital admissions [18]. Given that a very large proportion of user complaints are associated with missed or delayed diagnoses, relational continuity can also contribute efficiencies in healthcare costs/spending [19].

RELATIONAL CONTINUITY OVER TIME FOR USERS

As providers interact with a user, they should be aware of the user's primary care provider and **who the user is most comfortable with**. Often this is the person a user sees/trusts the most, in which case, other providers should be willing/prepared to act as receptors and communicators of user's queries/information—transmitting pertinent information to/from other care professionals as needed. Relational continuity appears to be particularly important for more vulnerable users, e.g. those who are older, sicker, or require long-term and complex care [20]. A good example of establishing relational continuity was seen in the **'Over 75 Service'** at Sandgate Road Surgery in Kent, UK, which uses Practice Matrons to conduct an in-depth assessment of the needs of frail users. The Practice Matrons play a central role in developing a care plan, managing referrals, coordinating the users' care and act as the key single point of contact for both users and carers. The Practice Matrons are easily accessible, with users and carers given a direct telephone number to contact them on.

At the Medendi site (Estonia) **home visits** are performed **by nurses** on a regular basis. These are highly valued by users and their informal carers – giving them a sense of safety. The leader of the Medendi service continuously maintains and develops staff and this service, understanding that switching home nurses has damaging consequences for older service users and diminishes their sense of security and stability.

SUPPORTED SELF CARE

WHAT DO WE MEAN BY SUPPORTED SELF-CARE?

Supported self-care involves supporting individuals, carers and families to take **responsibility in managing their own health and wellbeing**. This is done by emphasising the user's essential role in managing their own health, wellbeing and health and social care; and by using effective interventions that reinforce self-care initiatives. Part of supported self-care is improving health literacy. Health-literacy refers to all activities undertaken to increase the user's capacities to identify their own needs, and areas of their care where they might need more or less assistance so that health and social care providers can act on these needs [21]. Supported self-care also **includes understanding user's health, health risks, and medical interventions** and technologies so as to optimise user's capacity to contribute to discussions and decisions about their health.

In the SUSTAIN sites, support for users and their informal carers in self-management has helped users become actively involved in **defining outcomes** that are important to them and how to achieve them. Where users have demonstrated an improvement in managing their own health and wellbeing on an ongoing basis in SUSTAIN sites, users have felt more confident about their ability to get access to support within the health service and also beyond, in the community. An important part of the Swale 'Home First' service in the UK was to conduct **care needs assessments in the home setting**, rather than in hospital. In this way, presumptive decisions about longer-term care needs were avoided, and more tailored assistance could be arranged to support the person (and their informal carer(s), where relevant) in their own home. At the KV RegioMed Zentrum in Templin, an important goal of the three-week therapy programme is to enable users to manage their own health and wellbeing. This is done by providing an individual therapy plan that is tailored to the user's specific situation.

WHY IS SUPPORTED SELF-CARE IMPORTANT?

Older people's ability to manage their own care is essential for improved: adherence to treatment, use of services, and maintenance of health and wellness [22, 23]. Supported **self-care** gives older people the tools to lead a happier and healthy life; to meet their social, emotional and psychological needs; to care for their **long-term conditions**; and to prevent (further) illness or accidents. Low engagement in self-care and low health literacy have been linked to poor health outcomes, including increased rates of hospitalisation and decreased use of preventive services. **Self-management** support is therefore important for the following reasons [24]:

1. Older people with long-term health conditions, and their carers, can enjoy a better quality of life, self-confidence and achieve the goals that are important to them;
2. Older people with long-term health conditions experience better clinical outcomes;
3. Professionals can have more meaningful conversations with older people and their carers, which improves professionals' job satisfaction; and
4. Services are likely to be delivered in a more coordinated and cost-effective way.

SUPPORTED SELF CARE

Without ongoing support, users' knowledge, skills and confidence to self-manage can decline over time. Lack of **supported self-care** is associated with **increased** emergency service use and **higher preventable hospitalisations** [25]; a lower likelihood of using preventative services such as vaccinations, cancer screening and cardiovascular stress tests [26]; and sicker admissions with increased likelihood of developing complications.

Supported self-care can take many forms, including: the provision of general education and advice specific to a person's needs; providing access to programmes that help build users' competencies in self-management (for example, such as pain management); and coaching users about the most appropriate services to contact when needs arise or during a crisis. Coaching techniques include **motivational interviewing, goal-setting, action-planning and problem solving**. In Templin, the newly created service-center helps users and their relatives by giving them practical advice and orientation for the whole care-process (how to make requests for care, how to find care-services, how to get along with legal matters etc.)

A key aspect of supported self-care includes the enabling older people to connect with ongoing support network. As part of the SUSTAIN project in Sabadell (Catalonia), "**Growing Older Workshops**" were organised for users aged 65+ to enhance empowerment and self-management. The topics of the sessions were active and healthy ageing, empowerment to participate in decision-making social and personal development, and engagement in self-management of health. **The workshops enabled users to better express their wishes and preferences**.

Figure 1, below, demonstrates a continuum of tools and strategies that may be employed to support self-management. The evidence suggests that tools/strategies that focus on both self-efficacy and behaviour change are more likely to have the most lasting positive impacts.

Figure 1: continuum strategies to support self management
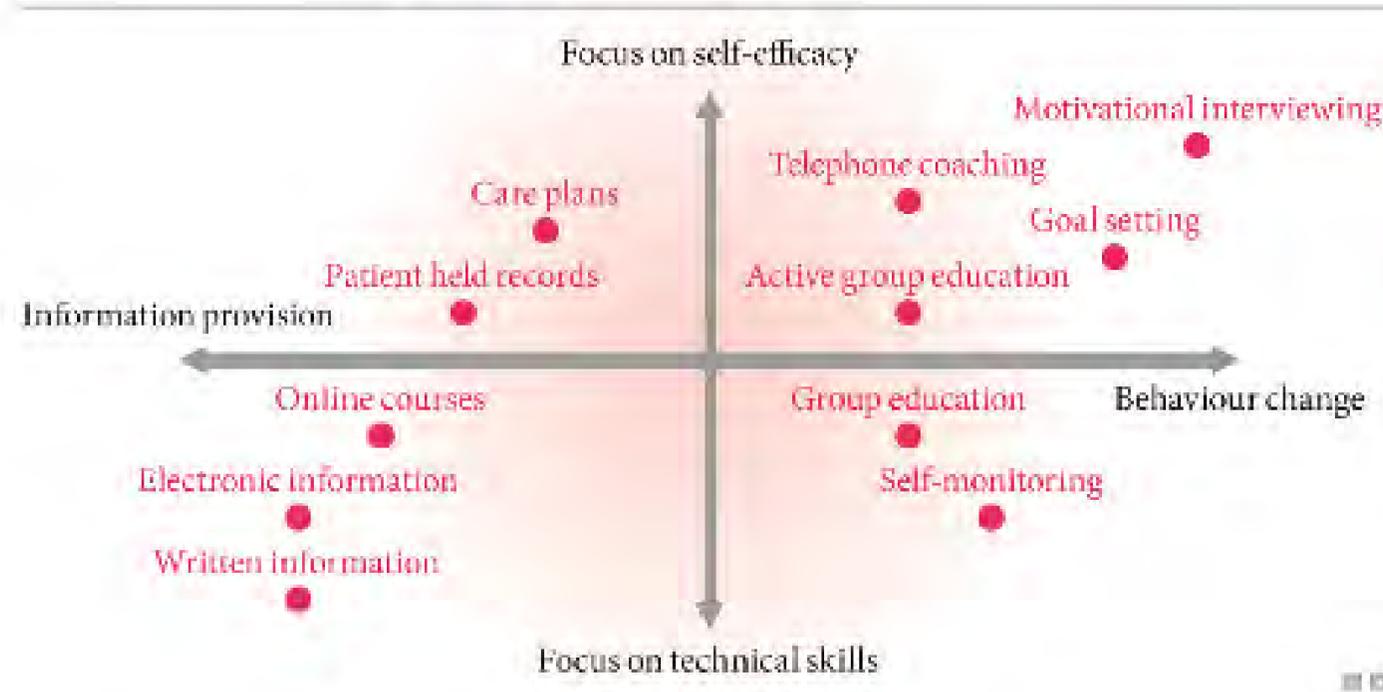
Source Health Foundation

FEATURE 2 Coordination

2.1 WHAT DO WE MEAN BY IMPROVING CARE COORDINATION?

Coordinated care means bringing together a range of services from the health and social care sectors and enabling them to function seamlessly together. When done effectively, coordinated care is a **person-centred, assessment-based, interdisciplinary** approach to integrating **health care** and **social support** in a manner that is efficient, cost-effective and specific to the needs of users and their informal carers [16]. The approach ensures that the **comprehensive** needs and preferences of people are assessed, a comprehensive care plan is developed with the user, and that services are managed and monitored through an evidence-informed process. This typically involves a designated care **coordinator** who is supported by an interdisciplinary team of professionals.

2.2 WHY IS THIS IMPORTANT?

Coordinated care strategies have become well established across Europe and they are often targeted at 'at risk' individuals in the community. However, whilst it is known that **vulnerable populations**, such as older people, are the most in need of more coordinated care , they are often the least likely to receive it [17]. Without effective coordination of services, all aspects of health and social care performance can suffer. For instance, older people in need of care may get lost in the system, needed services may be delayed (or not delivered at all), **user** satisfaction can decline, outcomes could worsen, and the potential for cost-efficiencies can diminish [18].

Greater coordination of care has been shown to be associated with a range of benefits including: reduced hospital and care home admissions, length of stay, and re-admissions rates; improvements in recovery and quality of life [19-21]. Evidence suggests that better coordination of **vertical programmes of care** (e.g. disease management) enables improved access to care, greater community satisfaction and improved health outcomes [22].

Evidence also suggests that coordinated care using multiple interventions (i.e. case management, supported self-care, polypharmacy management etc.) can significantly improve the care experiences and care outcomes of older people and their **informal carers,** as well as enable more cost-effective care in certain localities [23].

FEATURE 2 Coordination

ESSENTIAL ACTIVITIES

> **Case management**

> **Joint care assessments**

> **Care transition management**

CASE MANAGEMENT

WHAT DO WE MEAN BY CASE MANAGEMENT?

Case management is an established approach for coordinating services around the needs of older people with **long-term conditions** living at home. It may be best described as a collaborative process of assessment, planning, facilitation, care coordination and advocacy for options and services to meet a user's and family's comprehensive health and care needs (Case Management Society of America). A key aspect of the approach is that it improves continuity of care for people with complex needs through a named case manager. This **case manager** works closely with the user, their carers and family, and coordinates the necessary range of services from across health and care teams, as well as between care providers. However, the role of case managers is far more than simply navigating older people between care providers. The case manager or care coordinator role is multi-faceted, and includes [27]:

- providing **relational continuity of care** to the older person and their informal carer, acting as the key point of contact for care over time;
- being the **advocate** for the older person in navigating across multiple services and settings;
- providing care **directly in the home** environment (e.g. by case managers with advanced skills);
- ensuring that care professionals within the interdisciplinary team are **kept informed** of the older person's/informal carer's situation;

- taking **accountability** for the provision of care and ensuring that care packages are put in place and delivered; and
- communicating with the wider network of providers (outside of the core interdisciplinary team) so that **information about the older person is shared** and any actions required are followed up.

At Pflegewerk in Berlin, healthcare therapists, known as "therapy-pilots" were given the role as case managers. This enabled therapists to define and prescribe medical devices and therapeutic appliances – a right usually reserved for doctors. By **placing therapists in the drivers seat**, there was improved communication and collaboration between doctors, nurses and therapists, as well as more timely person-centred care for the user. In the 'Good in One Go' project in Arnhem, Netherlands, **care coordination** involved a specific set of tasks and skill-sets that were undertaken by a geriatric care specialist. Whilst in other settings, case managers are often community-based nurses, or even non-clinical 'link workers' as well as social care professionals and even volunteers.

There appears to be a continuum from the non-clinical approach – primarily providing personal continuity to older people and acting as their advocate to ensure that care is coordinated around their needs – to the clinical approach, in which a case manager would also be able to provide clinical care directly in the home. No matter the choice, it is important that the care coordinators are respected and provided a clear mandate to assume this role. This was the frustration at the Medendi site in Estonia, where the role

CASE MANAGEMENT

of care coordinator was introduced as a nursing role but a series of factors limited their ability to maximise this role, including professional cultures, rules guiding referrals and prescriptions. As a result, this role has struggled to serve the purpose it was intended to serve.

Case management also requires the effective targeting of people who might be 'at risk' (e.g. of a fall, or of a hospitalisation) and so can be enhanced by the use of risk-stratification tools (in combination with the experience of care professionals and the role of community workers and volunteers) in identifying those in need of case management at the earliest opportunity. An example of this can be seen at the Sandgate Road Surgery in Kent, UK, where the **Dalhousie Frailty Screening tool** is used to classify users according to their potential care needs and guide care professionals and the voluntary sector in their provision of services.

WHY IS CASE MANAGEMENT IMPORTANT?

Case management is an essential tool of care coordination for older people with complex health and social care needs. It requires bringing together many formal and informal care providers to deliver services in the home environment, but also to help users navigate their way between different care providers for their different needs. The role of a case manager has been shown to crucial to the success of implementation projects seeking to coordinate services for older people and those with complex medical problems [28, 29].

Case management is particularly suitable for older people who are less able to manage their own care and require intensive support to remain as healthy and well as they can be. The approach seeks to **provide safe, high quality, cost-effective care** for the older person by improving continuity of care and ensuring good care coordination. In so doing, it can enable older people to remain at home for longer, reduce the frequency of visits to care facilities, avoid unnecessary hospital admissions and delay the need for long-term care within an institution such as a care home.

The evidence for the effectiveness of case management is mixed. However, where it is implemented effectively it has been shown to improve the experiences of users and informal carers, supporting better care outcomes, **reducing the utilisation of hospital-based services,** and enabling a more cost-effective approach to care [30-32]. Case management has also been associated with reduced rates of depression and improved self-management of physical health [33]. Case management works best as part of a wider programme in which multiple strategies are employed to integrate care. These include good access to **primary care services**, supporting **health promotion** and disease prevention, and coordinating community-based packages for **rehabilitation** and **reablement**.

NEXT

JOINT CARE ASSESSMENTS

WHAT DO WE MEAN BY JOINT CARE ASSESSMENTS?

A joint care assessment is a **standardised protocol to explore the health and social care** needs of the older person and their informal carer. Together, care professionals work with the older person and their **informal carer** (and often the wider family) to explore a range of issues beyond health needs such as how difficult it might be to carry out everyday life activities (i.e. washing or dressing), and whether people are able to live safely in their home.

Shared care planning assessments have helped health professionals at Medendi in Tallin, Estonia to understand comprehensive needs of the user by looking at their needs at home and how to respond in a joint manner. However, while the care planning is engaging more professionals, more engagement of the user is required to ensure the joint care plan is built around the user's goals and better serves their stated needs. This may mean conducting the joint care assessments differently, as was done in Osana, Catalonia where a case conferencing strategy was put in place to gather professionals (primary health care, health specialists and social workers) to perform a **joint comprehensive assessment** of the user's needs. Based on their assessment, a draft care plan was produced and presented by at least one health and one social professional to the user in his/her home environment. The draft care plan is adjusted and adapted **based on the user's personal goals, needs and preferences**. Given the complexity of needs, and to provide a more enabling experience to the older person and their informal carer, a joint care assessment eliminates the need for people from different agencies to go through multiple assessments. In the Swale 'Home First' service in UK, for example, a key

element of the improvement project was to conduct a shared assessment at the user's own home, rather than multiple assessments both in and out of hospital. This reduced duplication in assessments and helped to reduce unnecessary time spent by the older person in an acute setting. Moreover, a joint care assessment accounts for the views and goals of the older person themselves as co-producers of their health and wellbeing (see Box 2). Undertaking joint care assessments **requires trained specialists** who are able to assess health and social care needs. This might typically be a skilled nurse or social worker working individually or in teams. Ultimately, the assessment process results in the stipulation of '**care outcomes**' which subsequent care coordination activities will seek to address.

Issues that may be covered in a Joint Care Assessment [adapted from Ross et al, 2011, p.5]33

Key issues for a comprehensive joint care assessment include:

- clinical background and current health status
- current level of mobility
- current ability and needs in terms of activities of daily living
- current level of cognitive functioning
- current formal care arrangements

- current informal care arrangements
- social history
- physical care needs
- medication review
- social care needs
- wider needs, including housing, welfare, employment and education
- the health and wellbeing of the informal carer

BACK

JOINT CARE ASSESSMENTS

WHY ARE JOINT CARE ASSESSMENTS IMPORTANT?

Once an individual has been identified through case-finding, it is important that both their current level of ability and their physical and social care needs are assessed. Most older people requiring care coordination have complex health and social care needs, so it is important that any assessment is not restricted to health needs only. The 'Over 75 Service' at Sandgate Road Surgery, UK, uses a **simple-to-use frailty screening tool** to **identify the clinical, social and environmental influences** on frailty. This tool is used by any health, social care or voluntary sector worker who has contact with an older person in the community. Users considered 'moderately or severely frail' are referred to the Practice Matron for further assessment of all their health and social care needs and care planning. Søndre Nordstrand in Norway employs **checklists and digital tools** in its work. As part of its activities including those linked to GPP1, Søndre Nordstrand performs commencement conversations with users new to its services, and uses checklists at these initial and follow-up assessments. The conversations are aimed at discussing users' needs, **clarifying expectations** in terms of the services provided by EMT2 and Søndre Nordstrand, and identifying with the user an appropriate time and place for providing services.

Single assessment processes, for use by both health and social care professionals, are designed to determine a **personalised package of care** tailored to an older person's needs and, increasingly often, that of their informal carer. The assessment stage seeks to identify all of the older person's needs, and how they can best be met. Trials and systematic reviews have shown that such comprehensive joint assessments are associated with improvements in older persons' self-rated health and wellbeing, reductions in depression scores, reduced numbers of falls, and improved quality of life for those able to remain living in the community or at home [34, 35]. Other research has shown that – when **combined with regular home visits** – multidimensional assessments of older people can help reduce mortality, **slow the process of functional decline**, and reduce nursing home placements [36]. Such research concludes that the most effective approach requires multi-dimensional assessments using a standardised protocol combined with a rigorous follow-up process of care planning.

Since comprehensive assessments are time consuming and expensive, targeting people with highly complex needs and higher functional impairment (especially those recently discharged from hospital) may be associated with improved cost-effectiveness and greater likelihood for improved outcomes [37].

CARE TRANSITION MANAGEMENT

WHAT DO WE MEAN BY CARE TRANSITION MANAGEMENT?

Care transition management is a specific approach that seeks to support users make a seamless and well-managed transfer to home following **discharge** from a hospital. The purpose of the approach is to ensure the person's transition from hospital to home is well coordinated, but in addition help the older person (and their informal carer) with the knowledge, skills and confidence to cope in four key areas: **managing medications; maintaining and sharing personal health records**; enabling **follow-up** appointments and **visits at home** or in primary/community-based settings; and building knowledge and setting in place procedures to respond to 'red flags' if a person's condition deteriorates. In contrast to chronic case management, transition management is shorter (usually weeks) and has the clear objectives of preventing readmission, shortening hospital stays and reducing delays in transition to post-acute care [39].

WHY IS CARE TRANSITION MANAGEMENT IMPORTANT?

One of the biggest barriers to effective care coordination is the poor management of users, and particularly older users, transitioning from hospital into home-based settings. This issue is not just about poor discharge planning, but also about inadequate **rehabilitation and re-ablement** support to provide necessary follow-up care. Poorly managed care transitions can significantly diminish the health status of older people, reduce their ability to live independently and at home, and increase costs. Transition programmes that focus on keeping older people at home have been associated with shorter hospital stays and better functional clinical outcomes [40, 41]. Care transition interventions delivered by advanced practice nurses have been associated with lower readmission rates after 30 and 90 days [42]. Lower hospital costs and lower readmission rates for the index condition have also been reported [42].

Inadequate management of care transitions leads to significant and unnecessary delays for older people within hospitals in the post-acute phase of their illness, leading to poor outcomes, wasteful spending and the inappropriate use of hospital facilities. Conversely, improved transition management can help **reduce readmissions**. For example, in one large integrated delivery system in Colorado, a Care Transitions Intervention reduced 30-day hospital readmissions by 30 percent, reduced 180-day hospital readmissions by 17 percent, and cut average costs per user by nearly 20 percent [43]

At the SUSTAIN site in Swale, UK, the improvement project aimed to support transition management both by reducing unnecessary time spent in hospital (by shifting the comprehensive care assessment to the home setting, rather than conducting multiple assessments in hospital), and by delivering a **more integrated** health and social care **'wraparound' service** in the person's own home for the first few weeks after discharge. Although Swale failed in their attempt to create an integrated wraparound service -largely because of extreme lack of capacity in the health sector and a lack of engagement of the voluntary sector- in other localities in Kent, the integrated wraparound service was achieved by commissioning a private provider to look after newly discharged 'Home First' patients.

FEATURE 3 Empowering an interprofessional workforce

3.1 WHAT DO WE MEAN BY EMPOWERING AN INTERPROFESSIONAL WORKFORCE?

The SUSTAIN sites have all been characterised by a group of people - professionals and non-professionals - who aim to support users and their informal carers to receive more coordinated, prevention-oriented and safe care . While the other three design features – **people-centredness**, **coordination**, and dignity – clearly outline what is expected from the **workforce**, the design feature of 'empowered interprofessional workforce' is devoted to outlining the activities that are necessary to ensure the workforce is supported, or enabled, to provide optimal integrated care services. The goals of integrated services will be achieved if it is understood that one cannot support users without also motivating and increasing the capacity of the workforce.

3.2 WHY IS THIS IMPORTANT?

An empowered interprofessional workforce is known to help overcome four main divides that exist when caring for older people [28]:

1. Divide between **health and social care**, as well as the divide between social support, housing, work, and social participation;
2. Divide between **informal and formal** care;
3. Divide between care **at home** and in **institutional settings**; and
4. Divide between private and public provision of professional care.

For users and their informal carers, the interprofessional workforce must be **empowered** by a combination of the **workforce's education and training**, as well as their managers and colleagues, to ensure that the various needs of users and their informal carers are met. In the SUSTAIN sites, empowering of professionals has been seen to be highly dependent on the workforce's ability to both build trusting relationships with users [29, 30] and their informal carers while also providing professional, high quality and safe services.

For managers of services, the inter-professional workforce is important to achieving service goals and maintaining the quality and value of the service.The SUSTAIN sites have shown that close collaboration between managers and the interprofessional workforce was important for **shaping the design, and improvement** of services because the workforce has unique exposure to the lived experiences of users, their families and communities. An empowered interprofessional workforce is equally important for ensuring that resources are used and managed safely and cost-efficiently.

FEATURE 3 Empowering an interprofessional workforce

A supported interprofessional workforce results in improved user experiences and use of resources [31], costs savings through increased productivity, motivation and reduced staff turnover [32-35].

Ultimately, an empowered interprofessional workforce can improve trusting relationships between members of the workforce, and between the workforce and users to mobilise more person-centred, respectful and dignified, and coordinated services.

ESSENTIAL ACTIVITIES

> **Trust building and strengthening care networks**

> **Interprofessional culture of care**

> **Continuous interdisciplinary learning**

> **Leadership opportunities**

> **Competency-based recruitment and performance management**

> **Fostering integrated practice environments**

TRUST BUILDING AND STRENGTHENING CARE NETWORKS

Trust building and the strengthening of care networks is at the core of enabling integrated care. Trust refers to an older person having **positive expectations of a care** provider's competence but also that those professionals and/or non professionals will work in their best interest [44]. Trust and the need to build trust is particularly relevant in situations of uncertainty and risk, where there exist asymmetries in knowledge, access to information and resources. In SUSTAIN, trust was raised as a fundamentally important process to **build and strengthen relationships** not just between users, their informal care givers and the professional or non-professional providing care, but equally between the professionals and non-professionals providing care (i.e. the care networks). Trust is something that **takes time and several interactions** to build and all SUSTAIN sites, agreed that this has been a challenge to build where time allocated to interact with other professionals, users and their informal care givers is cut back or limited.

WHY ARE TRUST BUILDING AND STRENGTHENING OF NETWORKS IMPORTANT?

The essential role that trust plays in relationships between users and providers has long been recognised [45]. Trust has been shown to be a critical factor influencing a variety of important therapeutic processes including user acceptance of therapeutic recommendations, adherence to recommendations, satisfaction with recommendations, satisfaction with medical care, symptom improvement and patient disenrollment. Several studies have identified trust as a quality indicator [46, 47]. Investments in trust building are therefore possibly one of the most **valuable investments** managers can make to secure both improved patient experiences and improved health outcomes.

Further, comprehensive managed care models seeking to provide integrated care across the home, community services, ambulatory and emergency care to hospital care rely on a high level of trust across the interdisciplinary team. It is therefore important that these teams **meet regularly** to build trust [48]. This was the experience in West Friesland, Netherlands where regular '**intervision meetings**' were implemented where professionals (home care nurses, practice nurses from the GP's offices, a social worker, case managers for people with dementia, and a '**social support consultant**' from the municipality) met to reflect upon their personal and professional development. Not only did these meetings increase their awareness of the roles, responsibilities and expertise of professionals from other organisations, but they helped to build personal relationships and trust between professionals.

Such networks, strengthened by professionals spending time together, can allow for better virtual integration over the long run and can improve the effectiveness of care by reducing delays in access to expertise [39]. Furthermore, studies have found that where investments are made in the **trust across care networks**, more non-medical and non-professionals can be engaged in the network and are even associated with improved functional outcomes [49].

Experience with Home First in Swale, U.K demonstrated that trust between hospital staff and professionals in the community was not easily established. Hospital staff, asked to forgo care planning assessments and discharge patients quickly, had to trust that the patients' needs would be identified in the community. However, it was hard to establish

TRUST BUILDING AND STRENGTHENING CARE NETWORKS

trust in the community when services were fragmented, under-resourced and lacking capacity.

What is important is that all stakeholders involved are **continuously building** reference points that help, not deter individuals from building trust and that in the long run this helps facilitate quicker and more efficient communication among all involved (users, their informal care givers, professionals and non-professionals).

INTERPROFESSIONAL CULTURE OF CARE

WHAT DO WE MEAN BY AN INTERPROFESSIONAL CULTURE OF CARE?

Interprofessional culture of care refers to an organisation and even network-wide belief among those receiving and delivering care, that interprofessionalism truly benefits users and their informal carers. This culture of care **values the insights** from a range of **professionals and non-professionals** working in the **health and social sectors.** It is important to distinguish this from an approach to care that respects a series of professionals and non-professionals working alongside each other but do not exchange or collaborate in co-creating and delivering care together (i.e. setting goals with the user based on input and discussion with other professionals/non-professionals) [50].

WHY IS AN INTERPROFESSIONAL CULTURE OF CARE IMPORTANT?

Chronic and complex conditions are permanent, non-reversible conditions that are, in essence, gradual and long-term. They often require extended supervision, observation and support across a range of settings and providers [51, 52]. Interprofessionalism therefore offers the opportunity to engage with non-health professionals and non-professionals who can help solve problems and deliver services to attend to the multiple and varying needs of older persons in their homes. Such a broader understanding of the workforce allows services to attend to all of the **user's medical needs** but also to their **social and emotional needs** [52, 53].

SUSTAIN sites have been working with a range of non-health professionals engaged in the building of an interprofessional culture of care. One such example is West Friesland, Netherlands where health professionals increasingly work together with the **municipality's social community team**. One of the target areas of the intervision meetings was to **eliminate misunderstandings** between professionals regarding what the other could be expected to deliver. In the 'Over 75 service' at Sandgate Road Surgery, **UK, voluntary sector agencies** are an integral part of the service. Non-professional staff include care navigators, health trainers, personal independence coordinators and carer support workers. In this way the social and emotional needs of users and carers are also addressed. By engaging in an interprofessional culture of care these professionals have been able to decrease social isolation but also provide more proactive and preventative care for users and their informal carers.

Various studies in Europe and abroad have shown the benefits of integrating health and **social care** through interprofessional teams [54]. Systems most successfully responding to the needs of people with **longterm conditions** are able to build on continuum-based approaches that proactively identify populations with, or at risk of, chronic conditions and translate these into specific programmes of care tailored to individual needs, while taking a comprehensive perspective [52, 55-57]. Interprofessional teams are more effective in defining and sustaining clear pathways for users [54] and have decreased costs for services in the long run .

CONTINUOUS INTERDISCIPLINARY LEARNING

WHAT DO WE MEAN BY CONTINUOUS INTERDISCIPLINARY LEARNING?

Education and training are required to strengthen the knowledge, confidence, skills and competence of users, families, volunteers, communities and all staff involved in delivering integrated care. Continuous interdisciplinary learning refers to management-supported learning opportunities that take place in the **service or off-site to learn** together **about users, user communities**, the challenges that professionals commonly face either across the group (communication, collaboration) or in **managing complexities in care**. This learning also aims to foster a better understanding among professionals of their different sectors, roles and responsibilities but also channel their respective expertise. This process can be challenging, as it takes time to build new relationships and to teach health and care professionals to practise. Innovative, person-centred educational approaches should include the design and delivery of training by people who have lived the experience of receiving care.

WHY IS CONTINUOUS INTERDISCIPLINARY LEARNING IMPORTANT?

Despite the best intentions and major advances in transformative education [58, 59] SUSTAIN sites have often found that the skills of new recruits and their ability to work in teams in a **person-centred** manner have not been adequately developed during their initial training. This is exacerbated by the findings that lessons learned during their initial education are often out of date [60]. It is therefore particularly important for managers to assume the responsibility to put in place a range of learning opportunities to develop and improve the capacity and capabilities of their employees [61].

Initial training programmes often do not capture the complexities of integrated care services for older people. The different paradigms taught in schools [54, 62] and the siloed approach to professional training often does not accommodate the wide range of skills, motivations and understanding required to care for older people. To some extent this is changing – in the U.K for example, where prequalification interprofessional training, especially for nurses, social workers and allied health professionals is increasingly common. Being able to perform within networks of carers, manage conflict and ensure a mutual understanding of what older people need is central to **continuous learning activities** [63].

Evidence has shown that the closer learning opportunities are to practical realities, the better the workforce can master **competencies** [58, 64-67]. Learning should be **inquiry-based**, **practice-based** and **problem-based** to promote reflection, problem solving, self-directed learning, and professional responsibility, as well as focused on the relevant issues faced by the workforce [68-70]. New ways of learning facilitate **interdisciplinary** team work and encourage health and social care professionals to get involved in service delivery planning [66, 71]. Systematic reviews of interdisciplinary and professional learning have found that there are several ways to improve this learning. In Sabadell, (Catalonia) for example, professionals came together around joint assessments not only to learn about users but also to learn more about each others roles.

This also turned out to be a valuable opportunity to identify that some professionals, more than others were experiencing burnout, garnering a team response to improve team working so this would not happen.

CONTINUOUS INTERDISCIPLINARY LEARNING

Case conferencing is also a strategy used in Austria where nurses and doctors from different units shared their knowledge with each other. Hospital units for instance had the opportunity to discuss cases/patients with a mental health nurse or psychiatrist which fostered a more person-centred care approach and supported the staff in their daily work. Furthermore, hospitals which participated in SUSTAIN worked together with a community based integrated care centre specialised in geronto-psychiatric conditions like dementia called "Viennese GerontoPsychiatric Centre -GPZ". The GPZ held trainings sessions to **raise the awareness and knowledge** regarding dementia in its **early stages**. The hospital staff appreciated further dementia education and was glad about the opportunity to recommend users suspected of dementia and their informal carer to the integrated care facility.

Other opportunities include moments **when new diagnostic tools are being introduce**. This was the case with the introduction of the Dalhousie scale for the 'Over 75 Service' in Sandgate Road Surgery, UK. The scale was introduced to a wide range of professional and non-professional staff so that all were **aware of its use and benefits.** The learning opportunity allowed staff to share insights on how they would use the tool and subsequently how their expertise could contribute to providing a more comprehensive assessment of the user. Furthermore, the hospital staff in Austria were introduced to a short and easy to use screening test for dementia – the **colour-coded Mini-Cog**, (also known as "Schneller-Uhren-Dreier"). This tool is short enough to perform the required screening without adding unnecessary work load for the practitioners. The challenge however was to maintain such learning opportunities over time due to staff turnover.

It is important that in developing these opportunities staff are engaged to develop and/or select priorities for this continuing learning. Other tools include: **staff information boards** that include reminders and teaching aids to gather professionals from different sectors in a common space; engaging professional associations to **develop learning opportunities**; engage users and user associations in learning activities to ensure user needs and perspectives are included; occasional online quizzes and certification courses; regular staff-led in-services on relevant topics provided during working hours.

LEADERSHIP OPPORTUNITIES

WHAT DO WE MEAN BY LEADERSHIP OPPORTUNITIES?

Some SUSTAIN sites have benefited from a range of leaders at the front line who support the change process. While some of these individuals have been officially mandated to assume leadership roles, others have assumed these roles impromptu and often these leaders have stepped up on their own initiative. Here leadership opportunities therefore refer to offering users, their informal carers, or front-line professionals and non-professionals the opportunity to take on a short term or long-term role in guiding their peers through a **change activity.** This can be on the scale of a practice change or establishing a new committee or designing a new service.

WHY ARE LEADERSHIP OPPORTUNITIES IMPORTANT?

Enabling leadership facilitates agency (i.e. a sense of ownership). Fostering opportunities to lead among front line staff and users can help perpetuate and strengthen a culture of caring that encourages providers to seize and seek opportunities to deliver more efficient and effective **person- centred** care.

There is evidence that where control is delegated to **front line staff**, carers and even to users, the result is more efficient and effective person-centred care. However, the full benefit of providing more leadership opportunities is only realised where individuals and groups have been supported by managers of services to effectively utilise structures and systems that support integrated care delivery. The improvement project at the Alutaguse

Care Centre in Estonia was characterised by a strong leader whose approach involved three important strategies: maintaining a **high degree of communication** with staff to gather their input, introducing **continuous learning** environment to support staff and **sustaining engagement** through new roles and responsibilities.

Medendi (Estonia) has become particularly effective at linking health and social services for users. Management argues that one of the main reasons for this is that they place high value on the role of nurses in delivering their services and are increasingly expanding their roles and responsibilities. This implies **good cooperation** within the health care sector and between the **health and social sectors**. In Berlin, Pflegewerk management saw that doctors were over-burdened (not least due to administrative requirements), not able to tend to their patients' needs, and that other professionals might be suitable to fill this gap. Pflegewerk's management turned to its therapists and not only asked them to help by being part of the team, but also notably decided to entirely **transfer prescribing rights**, responsibilities and leadership to a number of highly competent therapists known as "therapy pilots".

Where health service staff report they are well-led and have high levels of satisfaction with their immediate supervisors, users often report that they, in turn, are treated with respect, care and compassion [73]. Overall, the data suggest that when health care staff feel their work climate is positive and supportive, as evidenced by coherent, integrated and supportive people management practices, there are low and declining levels of patient mortality. These associations are consistent across all the domains of health

LEADERSHIP OPPORTUNITIES

care - acute, mental health, primary care and ambulance. Engagement also appears to be higher in health care organisations where leaders create a **positive climate** for staff, so they feel involved and have the emotional capacity to care for others [73].

COMPETENCY-BASED RECRUITMENT AND PERFORMANCE MANAGEMENT

WHAT DO WE MEAN BY COMPETENCY-BASED RECRUITMENT AND PERFORMANCE MANAGEMENT?

Competency based recruitment applies to those services where managers oversee the hiring of their staff. Where managers do not (i.e. Catalonia) competency-based recruitment may not be relevant however performance management may be more relevant. Ideally both should be pursued and complement one another.

Competency-based recruitment is a process of recruitment that focuses job advertisement, candidate selection, the interviewing and the selection of new staff as closely as possible around the desired competencies needed to support integrated care. This means engaging with users and their informal carers to identify what qualities are required among the workforce.

Competency-based performance management is the **continuous process of identifying**, **measuring** and **developing** the performance of staff and teams and aligning their performance to the goals of the organisation. It is led by managers and occurs on an individual basis. It is a vital process that ensures the effective use of scarce resources [71, 74] through making sure the workforce is performing to the very best of their abilities. Effective performance management involves working closely with the individual's **strengths and weaknesses** on a periodic basis in order to build on strengths and challenge weaknesses in a way that promotes learning and **behaviour change**.

WHY ARE COMPETENCY-BASED RECRUITMENT AND PERFORMANCE MANAGEMENT IMPORTANT?

The recruitment process is an important time to identify the new employees' strengths and weaknesses and to identify what the new employee can bring to the organisation or service. This helps managers understand how to maximise the new employees' strengths as well as the support they will need to counterbalance the weaknesses. It is an equally important opportunity for the service/organisation to declare its vision and goals and to have an open discussion about what this means in practice.

Systematic reviews of recruitment processes have found that there are several ways to improve competency-based recruitment. These include:

- Job descriptions that clearly **identify the user** population and the integrated care qualities needed
- Interview panels that include users and staff members that bring to the table the **practical realities** of delivering integrated services
- Multi-format interviews that include role playing or **scenario descriptions** that address required competencies. These can include users and representatives from different professions. They should be followed by **debriefings** that clearly emphasize the relevance of the exercise to competency expectations.

COMPETENCY-BASED RECRUITMENT AND PERFORMANCE MANAGEMENT

- Walk-abouts to introduce new staff to the various facilities, staff and resources to ensure new staff are **familiar with the many resources available** to them.
- Cross-training new staff with different team members and services to ensure new staff are familiar with the roles and responsibilities of other team members.

Once recruited, performance management becomes important to foster a workforce that is aligned in its strengths and weaknesses with the goals of the organisations. By recognizing individual strengths managers can better match employees with responsibilities in ways that maintain and increase the employees' motivation, challenge them in a non-threatening manner to address their weaknesses that may be affecting the rest of the team and encourage them to make use of all resources. A key part of performance management is that employees define their **personal professional goals** and relate these goals to the service's or organisation's **vision and mission**.

In cases where performance management has been applied, organisations seem to fare better in retaining their staff. There are several reasons why regular performance management not only benefits managers but also benefits the workforce. When performance management is focused on **improving the support** available to staff, staff tend to feel more comfortable identifying what they need to better perform their work, which in turn allows management to address these needs. For staff, these can be important opportunities to **receive feedback, discuss their concerns** with their own performance but also be recognized for any achievements. For managers these have proven to be important opportunities to reinforce the goals of the organisation and improve **alignment with organisational values**.

FOSTERING INTEGRATED PRACTICE ENVIRONMENTS

WHAT DO WE MEAN BY INTEGRATED PRACTICE ENVIRONMENTS?

Working in an integrated way is very demanding. It is therefore important that working environments reinforce the goals of working in an integrated manner. An integrated practice environment refers not only to the **physical structures** (co-location of services, single entry points to access services, direct telephone access to relevant services) but also to the **electronic infrastructure** (IT platforms) and the **non-electronic tools** (paper documentation) that are part of caring for the user.

WHY ARE INTEGRATED PRACTICE ENVIRONMENTS IMPORTANT FOR SUPPORTING THE WORKFORCE?

Physical and electronic integration of the environment of care can improve communication, trust, efficiency and coordination of care and help staff to learn from each other. The availability of information and communication technologies that support the management of people's care makes it easier to ensure continuity and **care coordination** [75]. The goal here is not only to improve care for users but to ensure seamless, safe and effective care is provided without increasing the burden on the workforce. The more barriers in their way, the less likely the workforce will be able to meet the users' needs. For example, separated offices for different professional groups may hinder communication and collaboration. In Surnadal, Norway, the managers expressed that it would have been beneficial if municipal service units (e.g., Homecare services and the safety or information technology units) were strategically co-located. This might have encouraged collaboration in goal setting and problem-solving.

Templin, Germany, the newly created service-center will foster the integration of services by providing a single-entry point to access services for the whole care-process in the region. In the service-center specially trained nurses, legal and financial experts will work together to support users in decisions for their care-process.

Studies have also confirmed that electronic health information positively influence user's perceptions of continuity of care [76]. Comprehensive programmes for multimorbidity or frailty that include quickly accessible decision supports for professionals and non-professionals have shown evidence of improving health-related quality of life, functioning and satisfaction with care [76]. Whilst also reinforcing learning and contact between providers on a regular and efficient basis.

Tools deemed particularly helpful in creating integrated care practice environments include [77]:

- **interdisciplinary** and **comprehensive assessments** of users,
- coordinated care transitions documents,
- **co-location** of services,
- electronic data exchange,
- **tele-monitoring**, and e-health applications,
- shared user registries and/or methods to track care,
- support interventions for informal carers, and
- support services for the workforce to anonymously debrief and seek support from counselling services.

NEXT

FEATURE 4 Safeguarding dignity

4.1 WHAT DO WE MEAN BY SAFEGUARDING DIGNITY?

In consultations with older people across Europe (e.g. consultation by AGE Platform Europe), older people discussed the ways in which a focus on dignity in care can enhance the design of integrated care services beyond the design features already discussed (**person-centred, coordinated** and **empowered interprofessional workforce**). Participants expressed that dignity in care for older people means going beyond person-centredness by taking pro-active measures to address society-wide misunderstandings about ageing, and to maintain standards of care that are often lowered when caring for older people. These considerations apply to all settings – whether care is being provided in institutions or at home[37]. Users have identified **key aspects** important in maintaining dignity: (i) respectful communication; (ii) respecting privacy; (iii) promoting autonomy, independence and a sense of control; (iv) addressing basic human needs such as nutrition and personal hygiene needs in a respectful and sensitive manner; (v) promoting **inclusivity** and a sense of participation by providing adequate information to support decision-making; (vi) promoting a sense of identity; (vii) **focusing on the individual**; and (viii) fully respecting human rights [38]. In addition, preserving an older person's sense of identity is important; they wish to feel needed as a useful resource all of their life, not as a burden to society. Protecting an older person's dignity goes beyond the responsibility of professionals - it is the duty of society as whole to protect older people against ageism.

4.2 WHY IS THIS IMPORTANT?

Older persons often find themselves in situations that can qualify as a breach of dignity (i.e. frustrations with care, the lowering of standards in care for older persons, and maltreatment; for instance, the inability to make decisions about their own lives, wrong assumptions of care professionals and informal carers about their needs, insufficient access to care, etc.) [42]. Factors that drive **breaches in dignity** during care are diverse and complex. Several studies looking at the breach of dignity have identified time constrains, lack of resources, a lack of qualifications or skills, and stress among those caring for older persons [45] . Studies have pointed to a lack of knowledge of human rights obligations by care professionals and managers and difficult working conditions as drivers of the breach of the dignity of older people in care.

As stated in the European Charter of the rights and responsibilities of older people in need of care and assistance, "human

FEATURE 4 Safeguarding dignity

dignity is inviolable. Age and dependency cannot be the grounds for restrictions on any inalienable human right and civil liberty acknowledged by international standards and embedded in democratic constitutions" [39, page 3]. When people's **dignity** is compromised in care settings, emotional reactions such as anger, anxiety, humiliation and embarrassment may follow [39, 40], which hinder the safety of all involved and the well being of the older person. Across the world, older people with care needs, and especially those whose needs are complex, are confronted with situations where their dignity is at high risk of being undermined. **Elder abuse** is "a single or repeated act or lack of appropriate action which causes harm or distress to an older person or violates their human and civil rights" [41]. It "may include physical abuse, psychological abuse, sexual abuse, financial exploitation and neglect. Elder abuse happens everywhere, including at home within the family, at home with services, or in care [settings]. It can be intentional or unintentional ('bad care')" [42].

Limited emphasis on dignity in care has already been shown to contribute to continued violence, abuse and neglect of older people in various care settings (**acute care**, long term care, primary care etc.) [43]. As a result, it is estimated that elder abuse is a widespread reality in health and social care services, with an estimated 25% of older persons with high care needs suffering **maltreatment** every year in Europe [44].

Dignity is therefore a design feature that needs to be continuously discussed and integrated into the provision of care by both professionals and non-professionals.

ESSENTIAL ACTIVITIES

> **Conflict management Communication and active listening**

> **Ensuring access to information about health and wellbeing**

> **Fostering dignified environments of care**

> **Community consultation and outreach**

> **Promoting reflective practice and positive attitudes**

CONFLICT MANAGEMENT COMMUNICATION AND ACTIVE LISTENING

WHAT DO WE MEAN BY CONFLICT MANAGEMENT?

Conflict is inevitable in any work environment due to inherent differences in goals, needs, desires, responsibilities, perceptions and ideas. It is particularly prevalent in times of stress and vulnerability. Conflict management is the process of **resolving differences** in a fair and professional manner. Conflict is not inherently negative, but can be an opportunity for growth, learning, and change.

WHY IS CONFLICT MANAGEMENT IMPORTANT?

Conflict management is important to maintain the quality of relationships between staff but also between staff and users. It is also important for **achieving positive outcomes** for users and user satisfaction [78]. Effective conflict management can make the difference between difficult situations and intolerable ones.

Interpersonal conflict among members of the care team or with users creates subtle **unpleasant experiences** that result in negative attitudes and behaviours, which can lead ultimately to situations of neglect, violence and abuse. In turn, this can create a stressful work environment with negative consequences such as job dissatisfaction, weak organisational commitment, lack of involvement, low morale, poor working relationships, a diminished sense of well-being, emotional exhaustion, a lack of trust and sense of support in the workplace, absenteeism, burnout and turnover [79-85].

In addition to these negative consequences, persistent interpersonal conflict also results in reduced coordination and collaboration and low efficiency for health care teams [86, 87]. Although none of the SUSTAIN sites specifically dealt with conflict management, the **intervision** meetings in West-Friesland in the Netherlands encouraged discussions to increase understanding of each others' roles and to limit misunderstandings between professionals – which often cause conflict.

ENSURING ACCESS TO INFORMATION ABOUT HEALTH AND WELLBEING

WHAT DO WE MEAN BY ENSURING ACCESS TO INFORMATION ABOUT HEALTH AND WELLBEING?

In the SUSTAIN sites, many users expressed needing more access to information about their health status and care. Ensuring access to health information means **enabling users to freely access**, use and determine who this information is shared with. Decreasing current administrative barriers that are focused on protecting providers is one important consideration. Some good examples include the Estonian example of users deciding who in the health sector can view users' records. However, from an integrated care standpoint this was a point of frustration in the SUSTAIN case site in Medendi where nurses and social workers **struggle** with getting access to each other's records as a result of little interaction between these sectors.

WHY IS ACCESS TO INFORMATION ABOUT HEALTH AND WELLBEING IMPORTANT?

The accessibility of health and wellbeing information is an important factor for users to maintain control and responsibility over their health which in turn enables them to tend to their care needs. When users are able to access their health and wellbeing information easily, they are also able to read about their health and wellbeing in an unpressured manner which allows them to contemplate its content and meaning.

When it comes to complex conditions for older people, access to information is particularly challenging given the range of people and services involved in the user's care as well as age-related factors (i.e. hearing and vision difficulties, cognitive impairment, dementia). Access to information is particularly important for users and the range of professional and non-professional staff in order to have as complete a set of information as possible about users. For example, research shows that having access to their records can help users in communicating with professional staff, **enhance users' knowledge about their health**, improve self-care, allow users to actively participate in the quality of their care, and help users decide when to seek care [88].

FOSTERING DIGNIFIED ENVIRONMENTS OF CARE

WHAT DO WE MEAN BY DIGNIFIED ENVIRONMENT OF CARE?

Environment of Care relates to the context in which the care is given and the activities that may lead to users feeling their privacy or dignity has been violated. It includes issues of privacy in care or **privacy** for examinations for example. SUSTAIN projects have identified several examples whereby attention to the environment of care has been a contributing factor to improving user's **dignity** and respect.

WHY ARE DIGNIFIED ENVIRONMENTS OF CARE IMPORTANT?

Daily activities are predominantly performed in the home and its close surroundings. As people grow older, they spend relatively more time in their homes; on average, very **old people tend to spend 80% of their time at home** [89]. Strong cognitive and affective ties to the home environment are formed as people age, and, as a consequence, ageing in place and preventing relocation are among the strongest needs of older adults as well as their families [90]. Thus, as **activities unfold in the home setting** it is important to maintain the user's comfort in that place. An unsatisfactory environment of care implies a failure to recognise the worth or value of the user.

Several activities are particularly prone to causing violations of a dignified environment of care in the home setting. Where there are gaps in curtains, lack of privacy for examinations, insufficient access to toilets and bathrooms, care provided by the opposite sex, and leaving homes littered with supplies or health information that can be found by non-care related visitors are all examples of activities that can compromise the dignity of the user. Violations of personal space and humiliation, as outlined by Mann [91] are also potential dignity violations.

Very old individuals, particularly those living in single households, have been described as particularly sensitive to "**environmental press**" [92], because of sensory, mobility, and cognitive declines [93]. At least six key aspects of a positive environment of care which challenge user's sense of dignity were identified by Gallagher and colleagues [94]. Older people have reported not having **enough privacy when receiving care.** The environment is important here, ensuring that curtains and private rooms are available and also protecting privacy of information. The **lack of assistance** available or time allocated to service users to eat meals has also been a factor pressing the user to feel more like a transaction than an individual with unique needs/preferences. The insufficient access to and location of lavatory/bathroom facilities with staff unavailable to help, and the alternatives offered, such as commodes, found to be embarrassing and undignified by older adults. The importance of using **proper titles** and not calling people 'love', 'dear', 'poppet' and so on has also been identified as critical regarding this sense of dignity in the care giving environment. Elsewhere, lack of care, time and resources and laundry damage have been identified as contributing to people not appearing well-groomed. Finally, the lack of **stimulation** and opportunity to engage in the community can speed decline and make people feel isolated, therefore, having stimulating activities and

FOSTERING DIGNIFIED ENVIRONMENTS OF CARE

supporting the full participation to society and community life is essential as to boost the sense of purpose (when in a care home or at home alone).

In the 'Over 75 Service' at Sandgate Road Surgery, UK, volunteers provide a befriending service and users are **encouraged and supported to engage in community activities**. In this way users become less socially isolated and are more confident outside their own homes. The experience in Swale, UK with the 'Home First' project showed that in order to maintain dignity in care, there is a need for professionals to be **flexible in their approach** to the user. Several service users felt strongly (and quite negatively) about enablement service at home, feeling that some of the professionals lacked compassion. Whilst the project began with the aim of conducting an assessment within 2 hours of the patient's return home, they realised that for some patients, this was not necessary or important (perhaps because they had a family member with them), and for some patients it was not appropriate (perhaps because they were too exhausted from the transfer home to endure a full assessment).

COMMUNITY CONSULTATION AND OUTREACH

WHAT DO WE MEAN BY COMMUNITY ENGAGEMENT AND OUTREACH?

Community engagement here refers to the measures taken by services to investigate the **needs of the populations** that the service serves – be it **ethnic, geographic, sexual** identity or **economic.** It is a form of outreach to the community to explore ways that care can be expanded, strengthened and improved based on community input. In Catalonia the professionals at the Sabadell primary care clinic have been working together with the community to identify various resources that can be engaged to decrease isolation of older people. Another example is the work of the **AGE Platform Europe**, a non-governmental organisation that works closely with national, regional and local organisations of older persons to define the needs of users and what can be improved in care services.

WHY ARE COMMUNITY ENGAGEMENT AND OUTREACH IMPORTANT?

As the current and potential recipients of services users and their communities are instrumental in identifying what arrangements in the services– in terms of human and physical resources - will ensure respect, dignity and overall an integrated experience. It is therefore important that services engage directly with and **involve the users** and the communities that they serve in order to ensure that the **services are tailored** as closely as possible to these needs, contributing to the co-creation movement [95]. Engaging with users and communities, however, deserves and requires careful planning, resources and a continuous monitoring and follow up. It also requires that roles and responsibilities for users and community representatives are clearly defined – both what the expected contributions are and the resources (i.e. time, space, networks, supplies, technologies, financing) available to support these contributions.

There are at least **three ways** in which to **engage users and the larger community** for improving integrated care so that the goals of integrated services can be achieved:

1. community consultations
2. user representatives included in the governing bodies of services
3. designate staff to network and build relationships as well as intelligence about the community

Consultations with community are an opportunity to engage user groups but also the wider population (i.e. voters and taxpayers) to **discuss** common health and social care needs. These consultations can gather feedback and input from the wider community but also serve as a means to relay important developments to the community. Special attention and resources need to be secured by services and organisations to ensure necessary follow up to community consultations or discussions with community representatives occurs. Community consultations are a chance for the community to meet the manager(s) of the service/organisation.

COMMUNITY CONSULTATION AND OUTREACH

Some sites have had experiences engaging user representatives on their service governing bodies. User representatives can become or may already be in place as the primary person(s) to collect and process input for services. When properly and effectively engaged, **user representatives can also help with planning and rolling out changes**, defend and justify strategies, priorities and developments to users and the community.

Designating staff to network and build relationships with the community are also a common means of engaging with the community. In Estonia's Alutaguse site, the **manager takes an active role in providing input to the local authority** on the needs of the service to thrive but in turn also benefits from the input from other services attending those consultations to gain insight into resources for the Alutaguse care home.

PROMOTING REFLECTIVE PRACTICE AND POSITIVE ATTITUDES

WHAT DO WE MEAN BY REFLECTIVE PRACTICE AND POSITIVE ATTITUDES?

Reflective practice here is intended as a way for providers to think about their activities, practice and experiences on a daily and case by case basis to improve the way you work. It is about going back over the events of the day and **critically examining and analyzing** how one ensured the experience of the user was positive, ensured user safety and the effectiveness of the care provided. It involves drawing instructive conclusions about these experiences, such as areas for **personal improvement or skills** that need to be further developed in order to create more successful outcomes in the future. It involves providing staff and teams with opportunities to take time out of their caring or treatment roles to reflect on and improve their practice. It should be distinguished as one form of **continuous learning**.

The steering group process, supported by SUSTAIN, was a key way in which reflective practice was encouraged. In each meeting, different services would talk through cases, describe the experience from their point of view, and identify what worked well and what worked less well. Positive attitudes were also highlighted by staff in interviews as being important in driving the improvements.

WHY ARE REFLECTIVE PRACTICE AND POSITIVE ATTITUDES IMPORTANT?

Reflective practice is particularly important in learning during complex **problem-solving** situations because it provides staff with an opportunity to step back and think about how they solved problems, if they would do things differently upon reflection and how they can improve their problem-solving strategies or the resources available to mitigate complications and strain on both user and themselves as providers.

There are a variety of models and theories informing how to engage in reflective practice, such as **Johns' Model of Reflection** [96], **Gibbs' Model of Reflection** [97], and **Atkins and Murphy's Model of Reflection** [98]. Reflective practice builds self-awareness and contributes to experiential learning and professional development in the workplace [99].

BOOK 2

Setting up Integrated Care

Achieving integrated care for older people at home requires a coherent change management strategy including both implementation followed by an improvement cycle. The implementation steps presented here alerts decision-makers to the key issues that need to be addressed if the improvement cycle is to be achieved successfully.

The implementation of integrated care in a specific country or region requires policy-makers, leaders and managers to plan and invest in an effective implementation strategy, with dedicated time and resources.

This part of the SUSTAIN roadmap is focused on the initial steps required to facilitate implementation. It is drawn from the international evidence. The purpose is to provide a simple step-by-step guide for key decision-makers to support the often complex process of initially implementing integrated care for older people living at home before steps can be taken to improve integrated care (Book 3).

Setting up integrated care involves three steps. In order they are:
STEP 1 Assessing needs and priorities
STEP 2 Designing and planning of services
STEP 3 Implementing Integrated Care

1
Assessing

2
Designing

3
Implementing

START

Clarify what we want to achieve by improving integrated care services

Manage and deliver services in a way that supports integrated care

Find out why previous attempts to integrate services have been difficult or unsuccessful

Address or **adapt to challenges** we have faced in the past

Measure success and know what to look out for in measuring our progress

Continue improving over time by learning and adapting as we go

STEP 1 Assessing Needs and Priorities

1.1 UNDERTAKING POPULATION HEALTH NEEDS ASSESSMENT

A critical first step in the implementation process is for the different key stakeholders to develop an **in-depth understanding** of the health and social needs of older people in their community. This step helps to justify the implementation of integrated care services, as well as to define the target group of older people that are likely to benefit most from integrated care.

Assessing population health needs also provides the opportunity to bring different stakeholders together to establish a '**common cause**'. This also begins the process of defining the essential human, technical and financial resources required to meet the population's needs [1] . Population health needs assessment therefore requires different partners in care (e.g. health care

authorities, municipal authorities, home care agencies and others) to come together to jointly examine the current and future health needs of a specific patient population (i.e. of older people who might benefit from care and support in their home environments).

Ultimately, the purpose of a population health needs assessment is to gather the information necessary to understand the type and distribution of services required to support people's needs. This involves **three key steps**:

STEP 1 Assess the level of need for care services in people's homes;
STEP 2 Describe the current pattern of care delivery and/or level of supply to meet these needs; and
STEP 3 Identify the gap between need and supply

The knowledge gained from a **population needs assessment** is then used to help make decisions about how to prioritise allocation of resources to meet the needs that have been identified, alongside other ways in which people's health and care needs are met - such as self-care, home adaptation, or community support. Population needs assessment is also a first key task in the purchasing and planning of services (see Step 2).

Three Approaches
There are traditionally three approaches to undertaking a needs assessment. These are:

(a) *epidemiological approaches*: which use mainly quantitative data to estimate the size and composition of the population of interest, including information on place, over time, and by key population subgroups; the level of need (as indicated for example by the prevalence of disease, disability or adverse

STEP 1 Assessing Needs and Priorities

life circumstances) and the current provision of services to meet those needs;

(b) *comparative approaches*: which use comparisons across time or between different locations or population groups to establish potential needs by identifying areas or groups where there is relative under-provision;

(c) *corporate approaches*: which gather mainly qualitative information to help understand the views of stakeholders (older people and informal carers, public, professionals, policy-makers etc.) about current needs and priorities for future provision.

POSSIBLE SOURCES OF DATA

> **Understanding the needs of older people living at home: possible sources of data**

In general, all three approaches are needed for assessing health and social care needs (see Box 1) and should help to profile the current and future composition of older people who would benefit from home-based care and support. This should include the use of a range of selected indicators, for example related to health status, prevalence of risk factors, functional dependency, and the social environment within which people live (for example, related to income, employment, education, housing, health, crime, and geographical access).

1.2 BUILDING A "VALUE CASE "

One of the most pressing concerns during the first stages is to make a compelling case for integrated care in terms of the benefits to older people, carers and local communities. Building a '**value case**' looks, not only at the potential **financial returns** from the development of integrated care, but at the

benefits to users and the whole community. A value case is important since it helps to develop the shared vision and set of common goals across different providers or teams. Hence, in the this first phase, there needs to be inclusion of all relevant stakeholders, including local communities. This helps to establish a shared understanding, a **shared vision for change** and a degree of mutual respect on each other's roles in the integrated care delivery. Strong leadership and management capacity are essential.

A common method for developing a value case is through 'logic modelling'. The approach is designed to build an in-depth understanding of how an integrated care programme is intended to deliver results. It seeks to assess the strength of the assumptions around proposed models of care and it may help in determining relevant performance indicators.

POSSIBLE SOURCES OF DATA

SOCIAL CARE DATA

- the proportion of older people with intensive care needs and/or lower levels of care needs who are receiving care at home;
- the proportion of older people receiving (free) personal care at home;
- home care provision for older people;
- respite care for informal carers;
- council/municipality provision of supported or sheltered accommodation; and
- information on care homes.

HEALTH CARE DATA

- primary care consultations
- numbers of outpatient attendances
- numbers of emergency department visits
- numbers and diagnoses for emergency hospital admissions and multiple emergency hospital admissions;
- information on unscheduled care;
- length of hospital stays;
- waiting times;
- numbers of surgical procedures carried out;
- delayed discharge from hospital

STEP 1 Assessing Needs and Priorities

1.3 DETERMINING PRIORITY ACTIONS

The results of the needs assessment and the value case will be one important piece of information to inform decisions about priorities. They should give **an indication of the size and impact of a problem in health and social terms**. This needs to be combined with information about the effectiveness and cost-effectiveness of available interventions. Hence, providing integrated care to older people at home requires an analysis of existing capabilities in service provision as a means to **prioritise investments** in, for example, existing human resources; available financial capital; use of new technologies; and the many competing demands of stakeholders, including those of local communities.

Decision makers can be clearer about determining priority actions by describing the gap between current provision and current need. Decisions about priorities will also need to reflect local priorities and circumstances; be informed by available resources; and by what is thought to be feasible in practice locally. Consideration therefore needs to be given on how to manage change towards building the technical competencies for integrated care delivery as set out in Book 3. This will be **significantly influenced** by:

- the *political system* where formal and informal structures of power influence decision-making;
- the *technical system* of existing human, technical and financial resources available to produce more integrated service delivery; and
- the *cultural system* that encompasses organisational values and behaviours of those influenced by changes

A key approach behind successful prioritisation is the use of diagnostic tools to assess the current situation in relation to what is trying to be achieved. These **situational analyses** attempt to yield insights on the 'strategic fit' of new approaches, like integrated care, amongst key stakeholders and are often used to prioritise the focus of change.

Prioritisation of services and entitlements also supports a rights-based approach to care, provides a framework for monitoring, and drives investments that help to re-orient care towards **home-based approaches**. The process of prioritisation will be better accepted and implemented if it is undertaken in a transparent manner (i.e. inclusive of all stakeholders, including the local community) and informed by evidence.

INTRODUCTION
Summary

BOOK 1
Design

BOOK 2
Setting up

> STEP 1
> STEP 2
> STEP 3

BOOK 3
Improving

BOOK 4
Context

BOOK 5
Resources

STEP 2 Designing and planning services

2.1 STRATEGIC PLANNING

The development of a strategic plan has the advantage of committing a range of organisations involved to a collective set of objectives and actions to guide what needs to be done, by when and why. Effective planning for care delivery needs to **shift from organisationally-led**, vertical and silo-based programmes with rigid norms to **"smart" capacity planning**, based on the needs of older people, and how these may be supported through care networks. Smart capacity planning is based on the concept of "teams" and a "set" of resources (human resources, equipment, drugs, etc.) and allows for adaptation of care activities to reflect local health needs, key determinants of health, and health system constraints.

Effective strategic planning can bring partners in care together by setting the terms of engagement between the different parties, their key roles and responsibilities, and the range of outcomes and performance indicators that may be used to judge whether integrated care strategies have been successful.

2.2 MODEL OF CARE DEVELOPMENT

Having conducted a needs assessment, established the value case for integrated care, and a strategic plan new models of care that are most appropriate to meet the needs of older people living at home need to be designed. It is at this point in **implementation** that the core elements, examined in Book 1 of this roadmap (i.e. person-centredness,

co-ordination, empowered workforce, dignity), should be considered to determine what **type of services** should be offered, where, how and to whom they should be provided. The design of new service models must create the right opportunities for **intersectoral action at a community-level** and prioritise comprehensive primary and community care services to support older people's health and wellbeing in the home environment.

STEP 3 Implementing integrated care

3.1 WORKFORCE DEVELOPMENT

Investing in an adequate workforce in terms of numbers, competencies and distribution of key staff is significantly associated with the success of integrated care programmes internationally[2] yet is often overlooked. **Policy-makers need to recognise that new skills and capabilities** will be required for professionals to work with and alongside older people and communities, in team-based settings that **better co-ordinate** care in and around people's homes. This is likely to require enhanced clinical and non-clinical roles in primary and community-based settings [3]. The advanced role of nurses and social workers, and the ability of health systems to maximise the assets within local communities, is likely to be important to promote older people's health and wellbeing.

3.2 STRATEGIC PURCHASING/FINANCIAL INCENTIVES

The purchasing (commissioning) of services will need to move away from line budgeting and/or fee-for service payment to mixed payment systems linked to outcomes. **Payment reform** options range from bundled payments (for specific conditions or across care pathways) to population-based payments where providers assume joint responsibility for older people's health and which support approaches that reward value instead of volume and consider final health outcomes and patient satisfaction as well as costs.

3.3 GOVERNANCE AND ACCOUNTABILITY

Strengthening governance requires a **participatory approach** that is transparent, inclusive, and reinforced by mutual accountability among policy-makers, managers, providers and users. Promoting clinical governance for quality and safety improvement is an important aspect of effective implementation since it requires health care teams to be **jointly accountable** to older people, their carers and the local community.

STEP 3 Implementing integrated care

3.4 ICT SYSTEMS

Evidence demonstrates that information systems are an essential component to the successful operation of integrated care since they improve the planning of services and resource use, **enable monitoring of outcomes** and **cost-effectiveness**, and provide a method for identifying and targeting older people in need of care. Information systems also enable data to be shared between organisations and care professionals to **promote inter-professional working** and the better co-ordination of services. Information systems also act as an essential **interface** between older people and care providers, enhancing approaches to: prevent ill-health (e.g. through forms of supported self-care); improve diagnosis and treatment (e.g. through decision-support tools); and enable the real-time monitoring of people's health status to influence health and wellbeing [4].

BOOK 3

Improving Integrated Care

The SUSTAIN integrated care sites used the Evidence Integration Triangle (EIT) to guide the design, implementation and evaluation of care/service improvements. The EIT emphasizes engaging key stakeholders, using scientific evidence, and attending to the context in which a programme is implemented. It helps us to ensure the intelligence, sensitivity, responsiveness and adaptiveness of our approach to integrated care improvement.

Complex interventions rarely proceed through neatly organised, linear stages. Learning is continual, and progression (or lack of it)

cannot always be forecast. In order to present the learning from SUSTAIN, we identify:

Four phases in the improvement cycle

PHASE 1 preparation
PHASE 2 design
PHASE 3 implementation
PHASE 4 monotoring, evaluation and feedback

We note that there is overlap and interaction between these phases, but we present each in turn below, with first hand reflections from the partner sites.

IMPROVEMENT CYCLE
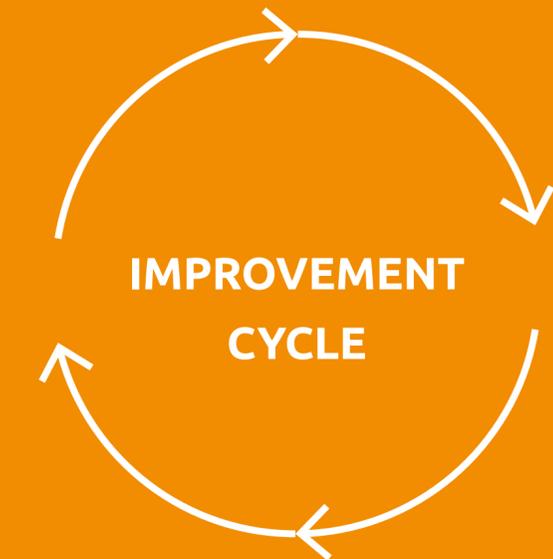
START

KEY MESSAGES

Clarify what we want to achieve by improving integrated care services

Manage and deliver services in a way that supports integrated care

Find out why previous attempts to integrate services have been difficult or unsuccessful

Address or adapt to challenges we have faced in the past

Measure success and know what to look out for in measuring our progress

Continue improving over time by learning and adapting as we go

INTRODUCTION

IMPROVING INTEGRATED CARE: THE SUSTAIN EXPERIENCE

Integrated care is a complex service innovation. It deals with problems and issues at multiple levels. Often, the end point cannot be fully defined since the process **requires partnerships** to explore and co-produce innovative solutions over time. Experience informs us that integrated care evolves as an evolutionary process and so requires time to develop and mature. In the implementation process it is therefore important to build in '**rapid learning cycles**' and improvement measures.

Numerous integrated care initiatives have been rolled out, 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 [1-6]. In most cases implementation is highly challenging and not always successful.

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 [9]. Furthermore, it is necessary to **improve the current ways** of working in existing initiatives, to make them more person-centred, prevention-oriented, safe and efficient [5,8,10-12]. In addition, we need **more insight** into how to **measure and evaluate** (improvements in) integrated care programmes in order to be able to capture outcomes and processes adequately and consistently across different programmes and evaluation studies.

The dynamic and non-linear nature of the improvement process must be recognised in order to take integrated care forward successfully. The environment within which integrated care programmes emerge in their own **contexts change** over time, and the agents (the people and organisations involved) are constantly adapting to such

changes. Improvement processes help to reveal a range of issues that need to be addressed in order to implement services effectively and so achieve the improvement goals that integrated care initiatives seek to make. Whilst some of these issues may relate to minor changes in practice, others may reveal larger cultural or organisational issues that need to be addressed. An approach to integrated care improvement is therefore needed that is intelligent, sensitive, responsive and adaptive. Over the course of the project, SUSTAIN partners identified and piloted many approaches to improvement. This guide provides an account of the improvement methods that were used by the researchers working with the **SUSTAIN sites** and **examines the lessons learned** from these experiences. The aim is to provide a set of insights to others that may be looking to implement similar approaches to improvement in their own contexts.

INTRODUCTION

THE SUSTAIN APPROACH

SUSTAIN researchers applied a range of methods to support case sites in improving their integrated care projects. These approaches supported the sites at different points in their development that can be summarised across four key phases of a continuous **improvement cycle**: preparation; design; implementation; and evaluation and feedback. The approach taken by SUSTAIN researchers in supporting improvement across the sites was naturally limited in scope, so the lessons provided below are not intended to be a **comprehensive and conclusive guide** on what is a highly complex science. Rather, this guide is intended to inform and support those tasked with improving integrated care at the service level with a variety of insights from our SUSTAIN experience.

PHASE 1 Preparation

The first phase of service or care improvement is to take stock of **what is currently being done** in the integrated care service; what is working; what is not working; and what previous attempts have been made to improve the service. Too often, there is not enough **time and effort spent at the start** of an initiative establishing a shared understanding amongst the stakeholders (users and carers, professionals, managers etc.) of the specific objectives for improvement. This makes it difficult to identify and objectively measure progress and successful outcomes [13].

In the preparation phase of an integrated care improvement initiative, it is important to **consider different perspectives** on what progress looks like, as well as how that progress will be monitored and evaluated. A **range of measures** can be used, including: user experience, service utilisation, and staff experience. While it is no less important to

also look at costs of delivering care, that was not the focus of this project.

Preparing for improvements involves three processes:

1. **taking stock** of what has been done to date and bringing relevant stakeholders together, to define the problem and determine its causes/contributing factors;
2. **developing consensus and clarity** around the need for and purpose of improvements (what are we looking to change and why), and the measures of success (how will we know when we've successfully improved?) and;
3. **establish a team**, made up of all relevant stakeholders, to lead the design and implementation of the improvement project

TAKING STOCK

Different actors need to consider and share their thoughts on the purpose of the improvement initiative, and what success looks like from their perspective. This helps identify how progress towards improved integrated care will be evaluated.

Therefore, this first step in the SUSTAIN improvement cycle involves establishing good working relationships between SUSTAIN **researchers** / SUSTAIN **project team** members with relevant **local stakeholders** (e.g. managers, health and social care professionals, representatives of older people and informal carers, local policy-officers, volunteers) from 13 existing integrated care sites from seven countries across Europe.

PHASE 1 Preparation

Overall, this step of "taking stock" is about (local managers/project managers/policy-makers – depending on the context) **starting a dialogue** around where people stand, what their priorities and perspectives are, and where they see their services to have strengths and weaknesses.

It is vital for establishing an understanding of the situation that is as comprehensive as possible. It helps to avoid a silo mentality by **understanding interrelationships and interdependencies**. And it helps to engage with different (sometimes conflicting) perspectives of the situation. Because the situation is never static, this must be seen as a continuous process that is revisited frequently.

Taking stock also involves some reflection on why current practice is as it is (e.g. what is the history, what are the constraints), and what

are the areas that require major improvement (e.g. collaboration between formal and informal care providers, involvement of older people in care processes). By getting to know relevant stakeholders, discussing the issues with individuals, and **learning about the context**, we form a good foundation for later workshops (see below).

Learning from this process are reported in an EU baseline report which is available at **www.sustain-eu.org**

It is important in this step for the project leader/manager to take the time to talk to a lot of different stakeholders, using a few key questions to gain some insight into their role and their view on the way of working and **potential areas for improvement**.
It is also useful to be able to justify an improvement project by referring to the goals of improvement (in our case, this

related to SUSTAIN's key principles of person-centredness, prevention-orientation, efficiency and safety). This can be helpful for spurring discussions around why improvement might be necessary.

> *"This step is most important to understand where people stand, what are their challenges and opportunities."*
>
> **SUSTAIN CONSORTIUM RESEARCHER**

PHASE 1 Preparation

"Well, of course, when we started we were designing it [the improvement project], and of course, a good understanding between the managers was key, because if not we wouldn't have pulled this forward."

SABADELL, MANAGER

WORKSHOPS AND MEETINGS

Once we have an initial understanding of the situation from our early discussions, we have a good foundation for further exploring the issues in workshops and meetings with key stakeholders. These workshops and meetings are used to **discuss outcomes** of the initial 'taking stock' process and enable sites to determine local improvement priorities.

Stakeholders involved at this stage really start to think about how to practically **improve the services** so as to make process towards more integrated care. They collectively decide what to do and how. Whilst much of the nitty gritty is worked out in meetings of key stakeholders, the workshops are an opportunity to engage a wider range of stakeholders, in addition to mid-level managers and practitioners. They might include **representatives** from:

- Administrative staff
- Service user and carer representatives/advocacy groups
- Insurance companies
- Private sector organisations
- Voluntary and community organisations
- Municipalities (e.g. elected officials)

Workshops are useful for establishing and building stakeholder engagement. It is important, therefore, that the organisers and facilitators are particularly attentive to group dynamics. This can be a challenging step in the preparation phase. The process of engagement and the development of trust and shared understanding may require more than one workshop session. The **purpose** of all workshops should be very clear, for example:

1. To agree upon needs for improvement
2. To agree upon priority and objectives of the improvement project (or intervention)
3. To identify the key stakeholders and establish an implementation team
4. To clarify the resources and time frame available

It is useful to have someone with the time to prepare for the workshop, to facilitate it, and to provide feedback afterwards. Ideally, this would be a neutral person who is not a key stakeholder or member of the team,

PHASE 1 Preparation

but who is familiar enough with the site and who is respected by all participants. **Good facilitation skills are very important**. In SUSTAIN, the researchers were a good fit for this role. Preparation, in particular, can be time consuming – both in terms of preparing the content, and in terms of logistically bringing professionals together for a period of at least three hours. Whilst day-long workshops are desirable to allow sufficient time to build relationships and develop ideas, it is sometimes necessary to be more realistic in order to ensure good participation. They should be carefully designed to select a time and place that works around the constraints of participants.

Overall, workshops – despite the need for time – are extremely useful for identifying priorities and a common vision for various stakeholders. Experiences from SUSTAIN workshops are captured in the EU Baseline Assessment Reports, which are available at **www.sustain-eu.org**.

Alongside, or in addition to workshops, **meetings are essential** for sharing information, making key decisions, and defining, monitoring and documenting key actions that keep the progress on track. They should be chaired by a leader (e.g. a project manager) or a designated member of the group. Participants should be carefully identified to include representatives of key stakeholders, as appropriate for the meeting objectives.

A clear understanding of the **timeframe** and resources available is essential for getting and keeping stakeholders engaged. Given stakeholders include busy professionals, meetings must be **purposeful and efficient** – they should be time-limited and goal-oriented (with a realistic end in sight). However, it is also important to recognise that sometimes stakeholder engagement takes additional time and ongoing effort.

"Steering Group understands the [improvement project] as a useful investment of time to design a plan and then adjust it to the user's changing needs."

OSONA, RESEARCHER FIELD NOTES

One strategy can be to increase the frequency of meetings at the very beginning and then adjust the frequency later based on group consensus. From the early meetings in this preparation phase, a **project steering group** will hopefully emerge (discussed below).

PHASE 1 Preparation

ESTABLISHING STEERING GROUPS

In SUSTAIN, after the initial workshops, local steering groups or committees were set up which were made up of experts who are in the best place to oversee a potential improvement project. Members provide input based on their **direct experience of the issues**, and they should include as many of the key stakeholders as possible (including service users and informal carers), at different 'levels' of organisation (managers and professionals). Steering groups are created to **respond to and act on priorities** agreed upon in initial workshops and meetings, and then to design and implement improvement plans (including all the more practical issues of who will be doing what and when). It is not possible to be prescriptive about membership – they should rather be tailored to the specific improvement project.

The SUSTAIN steering groups evolved out of the preliminary workshops and meetings. Some sites had two or three workshops to determine the priorities and areas for improvement, and the steering group was decided once the intervention areas were clear, while others set the steering group up after the first workshop.

Steering groups usually meet at key stages of a project and influence strategic decisions. It is important not to be too strict on the frequency of the meetings, but at the same time, it is essential to **maintain the momentum of the group**. Members help to build support for the improvement project within their organisation. It is very important to have decision-making power in these groups; members who can influence the organisation and the environment (e.g. provide budget, allocate resources).

"I think the steering group has helped, otherwise it wouldn't have happened. The people in the steering group as well, there were people selected with a special interest/engagement. And very inspiring, especially regarding issues/troubles due to lack of human resources. Without these people, it would have died."

SABADELL, MANAGER

PHASE 1 Preparation

All members should willingly sign up to help with the improvement project, and this role should be recognized and supported by their managers/organizations. It is also important that **membership is stable** (or as stable as possible) and balanced with regards to networks, interests and skill sets, to ensure continuity and support during the project. We recognize that in many contexts, there is a great deal of flux in staffing and **organizational structure**. Steering group members need to be open to this, and need to recognize that representatives will likely change over time. It is easier for new members to join if the group is welcoming, has clear terms of reference, a coherent and consistent membership and meeting structure, and good documentation.

Steering groups require leadership. This could come from a specific and designated staff member (e.g. a project manager), or it could come from a designated member (or members) of the group. However, leaders need the support of their organization, and need **sufficient time and energy to manage** the meetings (including seeing to record keeping, information sharing and logistics), to build and maintain relationships between meetings, and to carry out any additional tasks between meetings that are necessary to keep the momentum going and to help group members see that decisions are acted upon and progress is being made. In some of the SUSTAIN sites, the **researchers played an important support role**, helping with the practical and logistical tasks that professionals didn't have time for.

Steering groups must establish a time-frame for their improvement project. This should be realistic but also challenging – sometimes, particularly when the situation is very complex, a deadline can push a group towards action (even if the circumstances aren't perfect) and away from endless discussion.

INGREDIENTS & METHODES

> **key ingredients and methods for phase 1**

INGREDIENTS & METHODS

KEY INGREDIENTS

Time is an important foundation building stage, so sufficient time should be dedicated to understanding the situation and building relationships

Data a range of information (qualitative and quantitative) should be used to help understand the current situation and the desired improvements. This should illustrate different perspectives on the situation and might include user experience, staff experience, service utilisation data, etc.

Space to bring stakeholders together so they can have protected time to engage in this phase

Facilitation to help establish and build engagement, manage group dynamics and get the most out of the stakeholder workshops

Leadership to manage and chair the ongoing meetings, and to help maintain momentum throughout

Engaged and committed team with representatives of all relevant stakeholders

KEY METHODS

Describe the characteristics of the integrated care situation (e.g. SUSTAIN template)

Map the key stakeholders within the integrated care situation, and assess their levels of interest in and influence over the situation (e.g. stakeholder analysis tool)

Explore the contextual issues relevant for integrated care situations with managers and professionals (e.g. using the SUSTAIN survey)

Gain insight into the experiences of users and carers (e.g. SUSTAIN interview schedule)

Conduct evidence scans to identify existing knowledge and good practice related to the integrated care situation

Hold workshops and meetings with all the key stakeholders so they can collectively define the problem and develop consensus and clarity around desired improvements (e.g. using the SUSTAIN outline for organising a workshop with stakeholders)

Establish a steering group, with representatives of all relevant stakeholders, that is able to meet on a regular basis

Identify the priorities for improvement, using the information gathered (e.g. drawing on allocative planning tools such as Strategic Options Development and Analysis (SODA), option appraisal, prioritization tools)

PHASE 2 Design

The second phase of the improvement cycle is to design the improvement project that will **address the concerns and priorities** of the stakeholders, and achieve the objectives (within the timeframe and resource constraints) articulated by the steering group. This requires a **process of collective decision-making**. The aim of this phase is to have a clear description of the improvements the group are seeking to make (and why), and a good understanding of the actions, resources and changes in current ways of working that are required to bring the improvements about.

> **"Think big, start small, (and then escalate)"**
>
> SUSTAIN CONSORTIUM MEMBER

DEVELOPING IMPROVEMENT PLANS

In this phase, steering groups work together to plan their improvement projects. They go through a process of discussion and decision-making in order to develop an increasingly sophisticated map of where they are going (their objectives), with what resources, how (by which route), and when. The rationale (the 'why') for the improvement projects should be informed both by local priorities and by an overarching framework representing 'higher level', overarching objectives. In SUSTAIN, **the overarching framework was provided by the key domains of person-centredness, prevention-orientation, safety, coordination and efficiency.**

As they develop their improvement plans, and think about how they are going to implement them, steering group members need to increasingly understand each other's perspectives and understand both the current capacity and new resources available for improvement. As a result, they will often have to seek accommodations and compromises to find a plan that is workable, feasible and sustainable. (This is where the relationship building in phase 1 pays off.)

In SUSTAIN, the researchers allocated to each improvement project worked with the steering group to succinctly and consistently summarise the plans (which enabled easy comparison with each other).

A template was used for describing the improvement project and implementation plan at each of the sites. These improvement plans encouraged members to establish clear aims, objectives and rationales; to identify stakeholders and as well as roles and responsibilities; and to establish timelines.

Several documents produced by the SUSTAIN project might provide **inspiration** when

PHASE 2 Design

setting up an improvement project. These include the **seven country-specific reports** on experiences with improving integrated care in seven EU countries; the overarching SUSTAIN report and the reviews on person-centredness (comprehensive geriatric assessment) and safety in integrated care.

FLOW CHARTS

> "It was absolutely pivotal, it was the living breathing way the implementation plan was working. It was dynamic and specific"
>
> SUSTAIN CONSORTIUM RESEARCHER

Flow charts are a useful way of visualising multiple processes and their sequence and can help people to focus on the journey made by the service user. They can also help to communicate the logic of a complex improvement project in a clear and simple way to diverse audiences (including managers, professionals and service users and carers). The challenge, however, is to **produce a visual representation** that does not oversimplify the situation too much, but at the same time does not become complex and clumsy. They can be difficult and time-consuming to construct, but in constructing them, many questions arise, and the answers can help to refine and clarify the project plan. In SUSTAIN, each site developed a flow chart depicting the journey an integrated care service user takes. These flow charts are available in the SUSTAIN country reports at **www.sustain-eu.org**.

In the flow charts, new or modified actions, stakeholders, materials and processes associated with the improvement project could be highlighted. Flow charts also helped steering groups to identify potential improvements in processes and to **clarify the courses of action** for participating professionals. They were often used as a key reference image, enabling the groups to communicate a **full picture of the project** at a glance. They were also used as 'living document' (being continually edited and updated); they were frequently re-assessed and revised as projects evolved.

INGREDIENTS & METHODES

> **key ingredients and methods for phase 2**

INGREDIENTS & METHODS

KEY INGREDIENTS

Steering group with representatives of all relevant stakeholders, who are engaged in and committed to the improvement project

Leadership to manage and chair the ongoing meetings, and to help maintain momentum throughout

KEY METHODS

Develop improvement plans that represent a map of where the steering group wants to go, with what resources, how and when (e.g. using the SUSTAIN template, and/or other resources such as the TIDieR checklist).

Describe the journey an integrated care service user will take in the improved integrated care situation, and identify the new or modified actions, stakeholders, materials and processes associated with the improvement project (e.g. using Flow charts)

PHASE 3 Implementation

The third phase of the improvement cycle is to **implement the improvement plans** designed in phase 2. Here, the steering groups set up the resources and carry out the work necessary to fully implement the plans, in the timeline outlined in phase 2. This might involve securing additional investments (such as financing, staff or equipment), **developing or securing materials** (such as communication materials, training materials, assessment forms or digital information systems), and bringing about changes in current ways of working (e.g. staff conducting different tasks, in different locations, in different ways). This phase also involves establishing monitoring processes and the **collection of data for evaluation** (forming the groundwork for phase 4). In SUSTAIN, the evaluation was conducted by the researchers working with each site.

A strong and realistic plan (phase 2), founded on a good understanding of the situation, will help ensure the implementation phase is smooth. But even the best made plans can face unexpected challenges in implementation, and may require a rethink or refinement. **The context of integrated care** service provision often involves multiple sites, multiple care levels, multiple providers, etc. Changes in this context can either hinder or help improvement projects in unanticipated ways. When plans are threatened, or must adapt to new circumstances, then strong relationships and a good understanding of each other's perspectives (phase 1) can help to keep the improvement project focused on its objectives. A change in circumstances during implementation might require a repeat of some of the steps in phase 1, or a review of the plans designed in phase 2.

Similarly, as evaluation and monitoring data (phase 4) reveal new insights, adjustments might be made in implementation to make further **incremental improvements**.

In SUSTAIN, for some sites, phase 3 was very much entwined with phase 2 – as the groups increasingly understood the complexity of the situation and had to seek accommodations between what was desired (objectives and means) and what was possible (given constraints), the improvement plans had to be revised and reiterated numerous times. As well as the provision of adequate time and resources for this work, a number of more specific activities helped in this phase, including regular steering group meetings, one-on-one '**check ins**' with steering group members and communicating progress to those implementing improvements.

PHASE 3 Implementation

"It is the ideal way of working. The problem is that we do not have the environment nor the usual working way allowing us to do it. It means an extra effort, extra hours... coordinating with social services, coordinating with...Of course this requires time. Work schedules need to be made compatible."

OSONA, PROFESSIONAL

PROVIDING ADEQUATE TIME AND RESOURCES

Change takes time and effort. Busy professionals need to be afforded the 'space' required to meaningfully engage with an improvement project—that is, the opportunity to put other things aside, to align diaries and meet with others, and **the time to develop trust, relationships and an understanding** of what is needed to drive change forward. This all requires the explicit approval from higher management; their support of the improvement project is vital. It is useful for managers to make an **estimation of the time** required by the project and to put measures in place to free up space and time for the professionals involved (e.g. delegation of workloads, flexible working schedules).

REGULAR STEERING GROUP MEETINGS

Steering groups should try to maintain regular meetings to discuss progress. These meetings are a vital time for 'checking in', where members can learn from each other about both progress and changes in context, where they can continue to build trust, and where they can reflect on the process of implementation and the achievement of objectives. The meetings are also important for **keeping members motivated** and focused on the target of improvement. They help to ensure that momentum is not lost during the implementation phase, as well as to address any issues that may need resolution before moving forward. Where time and space are not protected, workloads and schedules can make it difficult for staff to attend these meetings.

PHASE 3 Implementation

"The meetings as the time has progressed, being able to go there and raise any concerns and speak to everyone has really, really helped. I think knowing that you have got someone coming to that meeting that you can talk to and they know what the SUSTAIN is and what we're trying to achieve has been really, really useful"

WEST FRIESLAND, STEERING GROUP MEMBER

Similarly, where service users and carers, and representatives of voluntary and community sector organisations are not supported, either logistically (e.g. through financial reimbursement, or assistance with travel) or emotionally (e.g. by creating an open and welcoming atmosphere), then their motivation for attending may waver.

REGULAR "ONE TO ONE CHECK-INS" WITH STEERING GROUP MEMBERS

In addition to regular steering group meetings, it is useful for a designated leader or **project manager** to consult periodically with **individual members** of the steering group to "check- in" with how they feel about the project's progress. This gives important information that can feed in anonymously to the regular steering groups. In SUSTAIN sites, this role was sometimes carried out by the SUSTAIN researchers (since they often picked up information valuable to the evaluation).

These 'check ins' should be **informal and ad hoc**; in SUSTAIN, they proved useful in building trust and interpersonal relationships, and gaining insights into the progress of the improvement project.

"Key for filling in the gaps"

SUSTAIN CONSORTIUM RESEARCHER

PHASE 3 Implementation

COMMUNICATING PROGRESS

Good communication is particularly important throughout the implementation phase, even though there may be fewer formal occasions for stakeholders to meet together than during phases 1 and 2.

Good communication is sometimes a key aspect of ensuring improvement plans are implemented in the way they were intended – for instance, staff working in one part of the improvement project may find it difficult to understand the contribution they make to the whole; this needs to be communicated to them by members of the steering group.

If we expect staff to make a change in their practice, it is motivating for them **to hear or see the difference** that change makes, in the context of the improvement project objectives. Likewise, it is important for staff (those directly involved in implementation and otherwise), service users, carers and others to communicate back to the steering group how it is going for them. This can help to reveal unanticipated consequences, or minor flaws in their plan (perhaps brought about by a changing context). Good communication is also an important way of **fostering co-ownership** of the improvement project, with a sense of shared responsibility for improving outcomes.

INGREDIENTS & METHODES

> **key ingredients and methods for phase 3**

INGREDIENTS & METHODS

KEY INGREDIENTS

Steering group - with representatives of all relevant stakeholders, and with both management level staff (able to make decisions and take action) and 'on the ground' practitioners

Leadership – to manage and chair the ongoing meetings, and to help maintain momentum throughout

Support of senior management – to help secure the time and resources required for implementation

Support of health and social care practitioners – to make the changes required to implement the improvement plan

Flexibility – to enable adjustments to be made to the improvement plan and its implementation in response to feedback and changes in the context

Reflection – to discuss and reflect on feedback from the monitoring and evaluation phase

KEY METHODS

Hold regular steering group meetings to discuss progress, review monitoring and evaluation findings, reflect on feedback and possibly make adjustments.

Maintain informal and ad hoc communication between steering group meetings to ensure good working relationships, open and honest feedback, and a good understanding of changes in context.

Establish good communication of progress with stakeholders and staff directly and indirectly involved in the improvement project, for instance by sharing 'stories of success' and brief updates, and by holding 'listening exercises' with those involved (e.g. informal drop-in sessions at a particular implementation site where a project leader or designated steering group member can listen to feedback from staff and answer questions).

PHASE 4 Monitoring, evaluation and feedback

Monitoring and evaluation are a vital aspect of continuous quality improvement. It is important not just to study the effectiveness or outcomes of improvement projects, but also to monitor and **evaluate the process of implementation**. And this should be done throughout, so that insights from this phase can inform all other phases in the implementation cycle. If evaluation and feedback are done well, and learning is shared appropriately, it becomes a vital way of securing the **engagement of stakeholders**. A project-specific evaluation framework should be developed by the steering group, in collaboration with relevant stakeholders, and with the active engagement of service users and carers. This process will be easier if there is a **clear plan** (developed in phase 2), with SMART objectives, a clear understanding of the steps required to achieve them, and a timeline to achieve them in. It is important

that the **steering group agrees** on the meaning, value and purpose of evaluation, and dedicates sufficient time and resources to it. Resources will include evaluation skills and experience, which might need to be either sought outside the group, or further invested in and developed within the group.

In SUSTAIN, **we monitored both processes and outcomes of improvement**, as well as changes in context, and we periodically shared and discussed these findings with the steering groups.

MEASURING PROCESSES

Integrated care improvement projects tend to be made up of multiple interacting components, within and across multiple organisations. Improvements can be difficult to bring about as they often require

coordinated action at different levels, and can be highly dependent on timing and context. This means **it is important to understand how things are working in practice** – how actions are achieved, how stakeholders react and respond to changes, what are the unexpected consequences, and so on. This kind of understanding is vital for making conclusions about what works.

> "The strength of SUSTAIN was that they measured different levels and from different perspectives – managers, professionals, users and carers."
>
> SUSTAIN CONSORTIUM RESEARCHER

BACK   ROADMAP   NEXT

PHASE 4 Monitoring, evaluation and feedback

Process measurement should capture how the improvement project is delivered (is it delivered exactly as intended, or not?), how the improvement project produces change (are there some particularly important 'ingredients' within the project, such as training or communication?), and how **the context affects implementation and outcomes** (are there any factors that either facilitate or hinder the improvement project?). Information is likely to include both qualitative data (non-numerical information collected through observations, interviews, focus groups, document reviews, etc.) and quantitative data (numerical information collected through record keeping, questionnaires, document reviews, etc.).

In SUSTAIN, we used a set of **qualitative and quantitative data collection tools** (see overarching report [14]), for evaluating the implementation processes. The selection of measurements and tools was guided by our overarching framework (the key SUSTAIN domains: person-centredness, effectiveness, safety and prevention-orientation). It was also influenced by locally-specific objectives and feasibility issues (such as whether it was possible to access or collect particular data or measurements). Data collection was either overseen or undertaken by the **researchers** attached to the sites, in collaboration with **staff**. We collected data at agreed and specified times over a 12-month period within the overall 18-month implementation phase (months 6-18) using the same procedures and tools for all initiatives.

Our experiences and findings are written up in seven country specific reports (**www.sustain-eu.org**) that include methodological reflections, experiences and challenges of the tools and instruments used.

MEASURING OUTCOMES

People engaged in improvement projects need to know whether their efforts are worthwhile. They need to know whether the changes that they expected to see are actually being realised. And they also need to be able to see whether there are any unanticipated changes occurring as a result of the project (or any particular aspects of it).

"Knowing that what we're doing is having an impact and that service users are benefiting from it, in that you're not just doing something for the sake of doing something, there is sort of a purpose"

SUSTAIN CONSORTIUM RESEARCHER

PHASE 4 Monitoring, evaluation and feedback

The improvement of integrated care is rarely about improving one aspect of care quality or care outcome. **Desired outcomes** are often multifaceted and sometimes quite intangible – such as to improve person-centredness or care coordination. This means that a range of measures are required in order to try to capture a whole range of effects. The specific design of an evaluation will need to be suited to the specific questions and circumstances of the improvement project.

In SUSTAIN our outcomes measurement, like the measuring of processes, was guided by our overarching framework, and by locally specific objectives and feasibility issues. Outcomes measurement should capture what change is produced by the improvement project. So in SUSTAIN, **we wanted to know the extent to which integrated care has become more person-centred, more prevention-oriented, safer and more efficient**. In some cases, an improvement in one aspect (e.g. person-centredness)

may relate to a deterioration in another (e.g. safety), so it was important to be able to capture the interconnections between these domains of integrated care. We did this by using an in-depth case study design, where we could bring a range of qualitative and quantitative data together to reflect on the actions identified in the improvement plans, and on our proposition that these actions would enhance the four domains of integrated care. (See the overarching report [14] for more information on the set of qualitative and quantitative data collection tools we used, and the seven country reports for our experiences and findings).

Where possible, it is useful to use **validated questionnaires** [15-18]. However, data collection should not be too onerous on either the project team or on participants (particularly older users). We should take care to avoid data collection tools that are too lengthy, wordy and repetitive. It may also be useful to collect **'before' and 'after'**

measures, to help identify whether outcomes are quantitatively different following the implementation of the improvement project. This can be very difficult when a project involves incremental improvements of existing services, since it can be hard to distinguish a clear before and after.

FEEDBACK TO STAKEHOLDERS/ STEERING GROUP

Feedback and reflection are a vital part of the improvement cycle. It is a way of linking the different phases of the cycle together, and ensures learning is fed back into continuous improvement. It also helps to maintain and improve the motivation of people involved in implementation, and is important for ensuring accountability both to users and carers and to senior management (across the health and social care systems).

PHASE 4 Monitoring, evaluation and feedback

In SUSTAIN, some sites needed to receive and reflect on feedback at the monthly steering group meetings (e.g. where the steering groups were facing particular challenges with implementation). At other sites, it was only necessary to reflect on feedback during one or two meetings during the implementation phase. This coincided with the **cycles of the evaluation** in SUSTAIN (i.e. at the 12 and 18 month time points).

At key points in the improvement cycle, feedback of evaluation findings can be a time to celebrate the hard work and willingness of the relevant services to have engaged with the improvement cycle. At these points, it is important to **invite representatives** of all key stakeholders, including users and carers, elected decision makers and senior management. Having them in the room also provides an excellent opportunity to **discuss the findings**, and to incorporate them into further changes or improvements.

INGREDIENTS & METHODES

> **key ingredients and methods for phase 4**

"To know that you're doing a good job because you don't often get told that you're doing a good job. But to come to a meeting and know that actually the service that you're providing is having an impact is quite a nice thing"

PROFESSIONAL / MANAGER

INGREDIENTS & METHODS

KEY INGREDIENTS

Steering group - with representatives of all relevant stakeholders

Support of senior management – to help secure the time and resources required for evaluation and monitoring, and to help secure access to data

Support of health and social care practitioners – to help ensure their voices, and the voices of users and carers are heard and incorporated into the evaluation

Information management – to ensure relevant data can be collected, collated and shared in accordance with General Data Protection Regulation

Evaluation skills and experience – to guide the development of the evaluation framework and the collection and analysis of data

Qualitative and quantitative data – to measure both processes and outcomes

KEY METHODS

Develop an evaluation framework, in collaboration with relevant stakeholders, and with the active engagement of service users and carers. This should identify the key questions we want to answer, and the type of monitoring and evaluation required to answer them (SUSTAIN's evaluation framework)

Draw up a realistic data collection plan, identifying what sort of information should be collected, when, from whom, and at what time points.

Collect information that captures how the improvement project is delivered, how it produces change, and how the context affects implementation and outcomes. (e.g. SUSTAIN care plan analysis template, SUSTAIN interview schedules to gain insight in the experiences of managers and professionals, TCI survey measuring vision, participative safety, task orientation and experienced support for innovation of the improvement team, time sheets for recording time allocated to improvement project, field notes).

Collect information that identifies whether the changes the steering group expected to see are actually being realised, and whether there are any unanticipated changes as a result of the improvement project. (e.g. SUSTAIN set of quantitative indicators; SUSTAIN interview schedule to gain insight in the experiences of users and carers; Person Centred Coordinated Care Experience Questionnaire, SUSTAIN care plan analysis template).

Analyse the information collected in order to find answers to the questions proposed in the evaluation framework.

Feedback findings from the monitoring and evaluation activities to stakeholders at key points in the implementation process, to enable reflection and adjustment, and to help maintain/improve motivation amongst those involved (e.g. using SUSTAIN template for feedback presentations).

BOOK 4

Context of Integrated Care

The purpose of integrated care within this context is to deliver person-centred, coordinated care across multiple health and social care professionals, organisations and sectors. Underlying this simply stated purpose, however, is a great deal of complexity. Books 2 and 3 highlighted the importance of context in integrated care implementation and improvement – some of the issues revealed in implementing or improving services may require significant cultural or organisational issues to be addressed. There is a continuous interplay between the objectives or purpose of integrated care, the 'process' (how it is to be implemented), and the context.

Successful improvement will rely on the appropriate interaction between these three dimensions [1].

In this book, we briefly look at three aspects of strategic thinking that relate to the context of integrated care. They are:

LAYER 1 Engaging stakeholders
LAYER 2 Making systemic change
LAYER 3 Creating an enabling environment
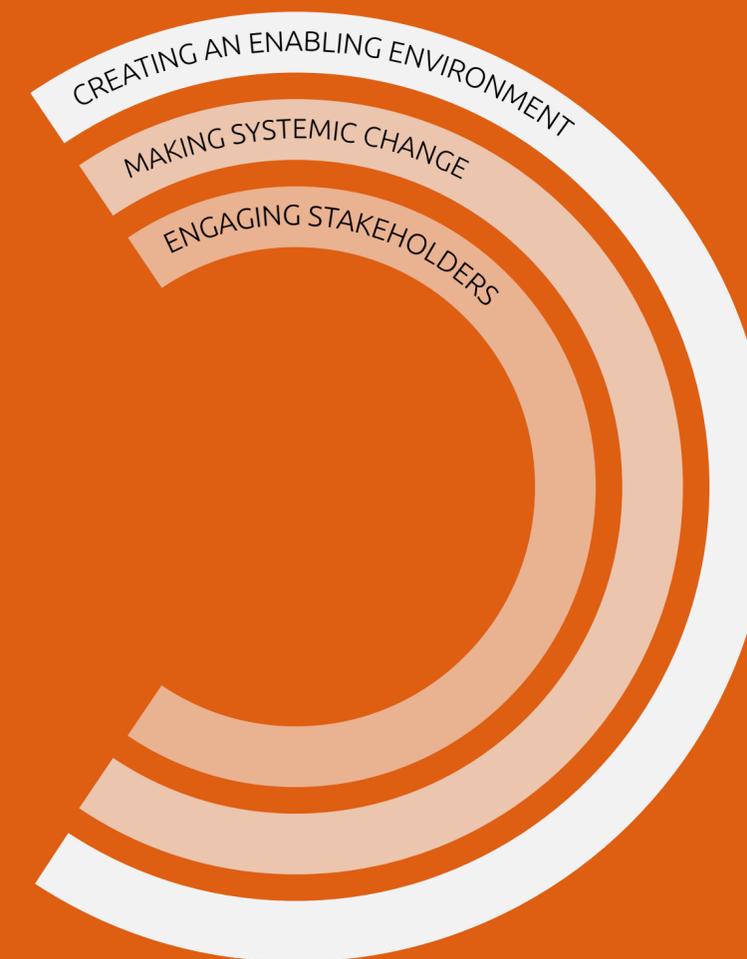
CREATING AN ENABLING ENVIRONMENT
MAKING SYSTEMIC CHANGE
ENGAGING STAKEHOLDERS

Health systems constitute the totality of health and social care organisations which contribute to the delivery of health and social care to a given population.

Delivering person-centered integrated care is a complex task that requires the accommodation of such systems.

This booklet identifies three core layers of activity that are needed to underpin such approaches: engaging all relevant stakeholders; managing whole systems change; and creating an enabling environment.

Effective approaches to managing, leading and delivering integrated care depend on building inclusive relationships and networks to engage stakeholders and harmonise goals in contexts where hierarchy has a necessarily limited role.

Among many other factors, **barriers to integration** arise from competing interests and different professional views of the world. Hence the importance of seeking to negotiate common understandings of integrated care and service models to improve outcomes for users and carers.

A mismatch between the resources available to stakeholders at any point across a particular health system and the responsibilities they are expected to fulfil will lead to shortcomings and failure in integrated care programmes. An enabling context for integrated care is one which minimises such mismatches and proactively equips local health systems with the external supports and internal resources needed to fulfil individual and collective roles in securing better outcomes.

INTRODUCTION

CONTEXTUAL FACTORS

There are many frameworks, models and taxonomies for context. Most of them boil down to a very similar list of contextual factors that can usually be grouped (broadly) into:

Leadership context (style, method, level of support);

Political context (level of empowerment, locale of decision making, configuration of top-down/bottom up, and so on);

Cultural context (shared mindsets around quality, risk, participation, etc.).

The key contextual themes identified within SUSTAIN as being important for the design, implementation, evaluation and outcomes of improvement projects were: governance arrangements, leadership, accountability, policy issues, organisational issues, collaboration, interpersonal relations, availability of resources, and financial issues. These contextual factors can play out at multiple levels, creating receptive and non-receptive environments for change from the innermost contexts (e.g. interpersonal relationships within a local situation) to the outermost contexts (e.g. global policies, laws and advocacy campaigns), and everything in between.

In order to deal with change and uncertainty, integrated care situations require **strategic thinking**—that is, thinking that recognises the relationships between different contextual issues, that brings different assumptions to light, and that understands that issues do not exist in isolation. Integrated care is about more than different stakeholders coming together to deliver care - it is about more than the sum of its parts. It requires, therefore, to **look at the bigger picture**, to focus on the relationships between the parts, to interrogate the multiple interrelated factors that contribute towards the situation, and to focus on processes as well as outcomes. In short, it requires strategic thinking.

LAYER 1 Engaging stakeholders

The health and social care professionals, organisations, sectors and services users (and their informal carers) involved in an integrated care situation can be described as the 'stakeholders'. **These stakeholders include individuals** (staff, service users, carers, managers, etc.), and stakeholders at local-level (e.g. service providers), regional-level (e.g. specialist service providers or area strategic management organisations), national-level (e.g. policy makers), and maybe even international-level (e.g. advocacy organisations). They will vary, depending on the situation.

Each stakeholder has their own 'stuff' to deal with - multiple issues that need attention at any one time, in any one context. And each stakeholder will have **different perspectives** on both the situation and the purpose of integrated care.

Dealing with and improving situations in which there are many issues, and with often contrasting perspectives held by different stakeholders, will require good stakeholder engagement. Engaging stakeholders helps to avoid:

reductionism - or having a limited understanding of the situation because of silo-thinking or narrow-mindedness, and

dogmatism – or restrictive practice through ignoring other perspectives of the situation.

By engaging stakeholders, we also help to: improve communication between them; develop a deeper mutual awareness of the challenges; enable stakeholders to work together better to resolve challenges; build trust; motivate stakeholders to collaborate more; and develop a culture of collaboration rather than competition [3].

1.1 MAPPING STAKEHOLDERS AND THEIR INTERESTS

A **'map' of stakeholders** and their interests will help to develop a rich picture of the situation – one which enables us to capture the main entities, structures and viewpoints in the situation, the processes going on, the current recognised issues and any potential ones [4]. Clearly, stakeholders involved will differ from situation to situation, but it is important to think about multiple 'dimensions'. In SUSTAIN, we identified **six dimensions** at which contributions to the design and delivery of integrated care have generally been necessary (Hexagon of Integration).
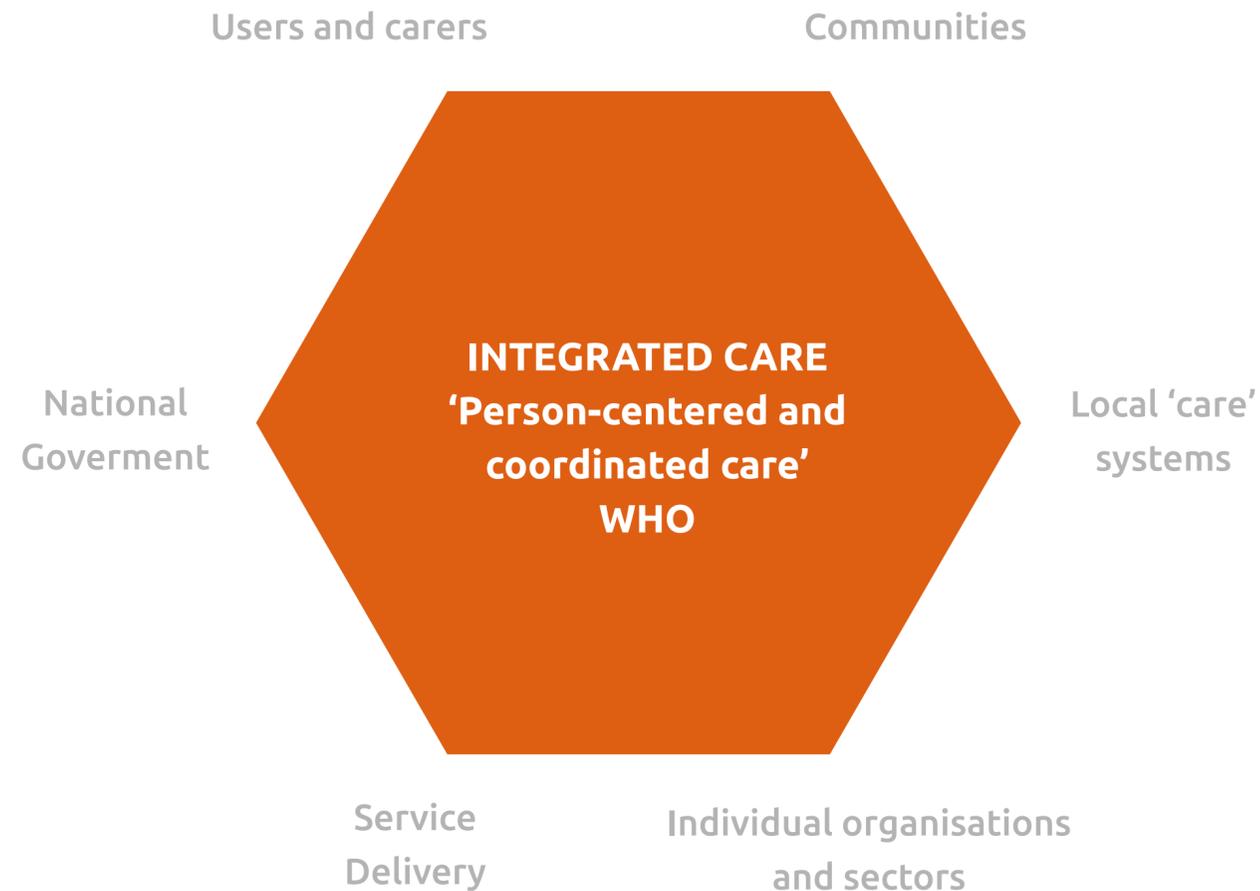
LAYER 1 Engaging stakeholders

Users and carers   Communities

National
Goverment

**INTEGRATED CARE
'Person-centered and
coordinated care'
WHO**

Local 'care'
systems

Service
Delivery

Individual organisations
and sectors

Each of these dimensions represent **different sets of interests** that might be in tune or in conflict with each other. Indeed, even within the dimensions, there may be interests that are either in conflict or at least in a delicate balance. For example, a commissioning organisation (responsible for deciding what care will be paid for) will need to balance the interests of individuals alongside those of others in the local community and society as a whole, and within the confines of an allocated budget. Some interests may be represented less powerfully than others (for example the interests of service users or informal carers), but an important part of strategic thinking will be to **appreciate all interests equally**.

In SUSTAIN case study sites, different interests of stakeholders within the improvement projects frequently came to the fore. It is clear that with different interests, issues and power dynamics, relationships between stakeholders may not always be easy.

LAYER 1 Engaging stakeholders

1.2 BUILDING RELATIONSHIPS

In building relationships between stakeholders, it is important to **create a space that is safe and non-blaming**, and in which tough conversations can be had. Clashing perspectives can be a source of strong feelings, energy, motivation and creativity.

As stakeholders build relationships – not just between each other, but also between common issues and interests – they will begin to recognise each other's positive contributions to integrated care; develop purposeful strategic partnerships, and create a shared vision, strategy and goals. Note our Hexagon of Integration **avoids representing any sense of hierarchy.** The point is to think in terms of 'networked' relationships that will be specific to that situation, in that context, at that point in time.

In many SUSTAIN sites, positive interpersonal relationships were seen to be key to the success of the improvement projects. In UK Sandgate, professional and non-professional staff were seen as equally important and staff valued the direct, personal contact they had with each other. In particular, social care staff felt equal to health partners because of a shared vision of promoting independence in frail, older people and felt comfortable discussing issues and concerns within the team.

LAYER 2 Making systemic change

Person-centred integrated care requires a strategic approach that plans and delivers **change in a 'systemic' way** – by this, we mean thinking in terms of wholes rather than parts and assessing the situation in a broad-minded way that crosses the boundaries that separate and insulate professions and sectors. The four phases of the SUSTAIN improvement cycle described in Book 3 are built, to a large extent, on the technical skills and competences of measurement, analysis and review. They **focus on breaking the process down into manageable parts,** making each of them work and systematically re-assembling them into a coherent programme of implementation. However, making systemic change requires a fundamentally different approach.

Any significant change to the integrated care situation is likely to entail changes to structures, changes to processes or procedures, and changes to attitudes. It is likely to demand additional, or re-allocated, resources. And ensuring all this happens will require excellent stewardship – to secure and manage the engagement, commitment, resources, energy and goodwill required to make systemic change. **Stewardship** is described by WHO as "a political process that involves balancing competing influences and demands". Given integrated care comprises many interrelated parts and is defined by multiple agents, there is likely to be significant resistance to change unless some of the changes are structural or profound. To improve the whole, it is necessary to improve relationships among the parts.

2.1 GOAL HARMONISATION

The Hexagon of Integration emphasises the common concern as 'personalised and coordinated care'. This highlights that integrated care is ultimately a mechanism to **improve outcomes for individuals and their informal carers** – efforts to make systemic change need to revolve around this purpose. However, other concerns will come to the fore at different points in the process. These might include the need to save money, the need to take pressure off one part of a health or social care system, or the need to meet a particular government target or objective. It might not be possible to form a consensus amongst stakeholders on the best way to improve the situation, but it is necessary to find an accommodation, based on common concerns. This process of finding an accommodation will depend upon strong relationships and careful stewardship.

> In the GCM site in the Netherlands, managers talked about the 'binding factor' – which in the case of stakeholders in health and social care is often a shared compassion for the target group – and the trust and understanding necessary to overcome 'cultural difficulties'.

LAYER 2 Making systemic change

2.3 'SOFT SKILLS

The different approach required for making systemic change depends on the skills of building relationships based on trust, shared values and a commitment to improving outcomes for end users. It requires people to **understand the whole picture** (or as much as possible of it) by developing an appreciation of opposing ideas, opinions, arguments or positions. This may require people to put aside enduring and systematic biases or blind spots, and to use a different set of lenses to explore problems and solutions [6].

In the GCM site in the Netherlands, the independent position of the externally hired project manager was an important facilitator since there were no perceived conflicting interests with the participating organisations.

In many of the SUSTAIN sites, the persistence, commitment, willingness and motivation of the individuals involved were a key facilitating factor. Evaluation teams noted stakeholders being able to explore new or different ways of doing things as a result of collaborative exploration of the issues.

In contexts where none of the individual stakeholders has control of the process as a whole, it is important to accept the necessity for leadership through networks (rather than hierarchy). This sense of **shared organisational responsibility** is important, both in terms of developing a shared commitment, but also in terms of developing a 'complete-as-possible' understanding of the situation. Networks help to transfer theories, evidence-based knowledge and insights across disciplines in pursuit of new approaches to making systemic change.

Alongside a shared responsibility is the need for a proactive 'can do' attitude, which sometimes involves taking a risk. In the UK Home First site, where significant barriers (principally associated with a lack of resources and staff capacity) impeded implementation of the group's improvement plans, analysis of data found that the group of people working on the project showed absolute commitment in pushing the project forward and in working together, and developed good working relationships. As one manager put it:

You need to have the right kind of staff. So staffing can be just numbers but it can also be personalities and a can-do approach and certainly [without the staff we had], that project would not have got off the ground if it hadn't have been for them agreeing to take that on and do it and [them] being able to proactively sort the problems.

LAYER 3 Creating an enabling environment

An 'enabling environment' is a difficult thing to define. The **enabling environment** could be thought of as both the backcloth to action, and an interacting part of the action itself (Dopson S and Fitzgerald L. Oxford University Press; 2005) and is constantly changing. We have already talked about the dynamic relationship between improvement projects, implementation and context, and how stakeholders will need to adjust and adapt to changes in their environment as they encounter them. The SUSTAIN final report highlights many contextual factors that acted as barriers or facilitators to integrated care improvement in the project sites. **Implementation will always be affected by context**. But there is also a need to recognise that in implementing integrated care, we should work towards creating an enabling environment that helps to secure improved outcomes. In other words, a part of our strategic approach to implementing integrated care is to consider how we can affect the context in positive ways.

Some factors are beyond the control of local-level leaders and managers. These might include, for example, overall budgets, professional regulation and training, electoral timetables and political change/priorities, performance and accountability frameworks, and public opinion. Sometimes, as we saw in our SUSTAIN sites, this was a frustration:

This [political and legal framework] does not facilitate anything. Because of course, now the government, the health system, to get out of the place where it is, needs to innovate. And to innovate you have to be brave and take on challenges. Therefore, the [Catalan] Ministry of Health has a series of very important problems and needs to be brave because it has many challenges... this will clearly influence the implementation of this kind of projects.

MANAGER INTERVIEW OSONA

However, it is important that stakeholders are **honest** with themselves and each other about the extent to which they are equipped to fulfil their purposes. There needs to be **interaction**, therefore, between the local situation and those with the ability to help shape the environment.

There are aspects of change that can only be brought about from above, outside or meta- (at a higher level) to the immediate health system being managed. Ultimately, **national and regional stakeholders** should be involved in ensuring local care organisations are operating in an environment that facilitates integration rather than one that reinforces separation.

LAYER 3 Creating an enabling environment

3.1 RECOURSES

A mismatch between the resources available to stakeholders and the responsibilities they are expected to fulfil will not create an enabling environment. It is useful to think about **two aspects of resources** (which could include financial and non-financial resources, such as staff): **adequacy and location**. Within and across health and social care systems, we often see a mismatch between need and resource availability. In all European countries, for example, acute services receive a much greater share of the funding than primary or preventive services. When implementing or improving integrated care, it is particularly important to **think strategically about the balance of resources** across different locations. Historic patterns of budgetary allocation may not be supportive of integration. There may need to be dis-investment in established services

and/or a shift in the balance of funding corresponding to shifts in responsibilities. This is likely to be controversial and difficult, and to rely on action outside of the local level.

Shortages of resources can be extremely damaging to efforts to improve integrated care. In a number of our SUSTAIN sites, the lack of financial investment, the uncertainties of (short term) funding, and staff shortages and high workloads were found to be explanations

> There is very weak capacity in the community for a number of key reasons: staff vacancies; difficulties in recruitment; change in provider contract; many different pressures on services, particularly during winter pressures; lack of funding.
>
> EXTRACTS FROM ANALYSIS OF MANAGER AND PROFESSIONAL INTERVIEWS

for not succeeding and improving integrated care initiatives. In one of our SUSTAIN sites, for example, which had no financial investment for the project, existing severe shortages in staffing, and an organisational stakeholder in financial deficit, there were multiple impediments to change:

- "[The organisation] had their focus on their **financial situation** which meant they didn't have energy/time to lead/manage/ push [the improvement project] and have not been able to come up with any ideas or solutions for anything."
- "Financial cutbacks in general are harming the ability of the **voluntary sector** to be involved because they need to be financed to be involved."

We note, however, that a perceived limitation of resources can act as a stimulus to the pursuit of integrated care.

LAYER 3 Creating an enabling environment

> **In the DE-PB SUSTAIN site, the widely felt limitation of resources in the healthcare system generally promoted openness and willingness to consider new approaches brought in by the improvement project.**
>
> EXTRACTS FROM DATA ANALYSIS

3.2 PROFESSIONAL REGULATION AND TRAINING

Given that any significant change to an integrated care situation is likely to entail changes to processes or procedures, and changes to attitudes, it is necessary to **pay attention to both the training and the professional regulation of staff**. Some changes may require the expansion of roles among some professionals, especially those working in the community. A key part of creating an enabling environment, then,

is to pay attention to the training needs arising from this. In addition, regulation may sometimes enforce boundaries which confuse and sometimes threaten optimal communication or collaboration amongst professionals. This highlights another **interface between the local level and the higher level**, and suggests that front line staff and managers also have an advocacy role to play within and across their professional organisations – highlighting where aspects of training and regulation act as barriers to integration, and supporting the creation of a more enabling environment.

3.3 INFORMATION GOVERNANCE AND IT

> **It can be a bit scary to the staff on the ground due to 'unknown territory' and change in practice.**
>
> UK HOME FIRST, EXTRACT FROM MANAGER AND PROFESSIONAL INTERVIEWS ANALYSIS

Integrated, continuous care requires the ability to link up and share individual level data. Broadly speaking information systems tend to mirror the boundaries of professions and occupational groups.

Information governance, technical IT barriers and professional protectionism have all contributed to the absence of shared, user-focussed information systems. This is another example of a contextual factor that is often outside the control of local level stakeholders – particularly where the roots of the difficulties lie in regulatory arrangements and data protection legislation. **Local sites generally adopt 'work-arounds', which might be cumbersome and inefficient** (such as manual transfer of information onto different IT systems, or verbal hand-overs of information).

3.4 PERFORMANCE AND ACCOUNTABILITY FRAMEWORKS

Accountability frameworks are mechanisms for determining priorities, allocating resources, monitoring progress and ensuring delivery. They encompass "how people in governance and/or funding roles specify what they are looking for, how practitioners account to them for their performance, and how action is taken when performance is unsatisfactory" [8].

For practitioners of integrated care, accountability frameworks are not always joined up enough, and don't always reflect different local circumstances and changing ways of delivering care. Also, they don't necessarily support innovation, as sometimes governance and accountability can lag behind novel care models. Practitioners of integrated care might have to work towards multiple sets of outcome indicators covering health care, public health and social care. They also feel accountable to the patient or service user in their care, and to their professional standards formally laid down by bodies like the royal colleges. Alongside this, managers are likely to feel accountable to their staff (e.g. for their ability to win resources), as well as to the people commissioning services; elected members and public sector boards will feel accountable to the residents of their area or the electorate. There are different motivations, therefore, that are rarely taken into account within accountability frameworks.

Different countries use different approaches to accountability. Mechanisms might include a mixture of:

- **Market-based systems** of choice, where service users or insurers exert pressure through the threat to take their business elsewhere;
- **Elections**, for the relevant authorities;
- **Direct incentives**, through managerial control, or payment mechanisms designed to improve quality or ensure minimum standards;
- **Professional oversight** and control.

Practitioners of integrated care need to be clear what they are accountable for and to whom. This includes both formal and informal accountabilities. By understanding their multiple lines of accountability, they can shape new innovations or care models within these, and they can use them to evaluate progress and impact. Where accountabilities clash, are unclear, or perhaps produce disincentives for integrated care improvement, practitioners and managers (or those in strategic or 'higher-level' decision-making roles) should seek to change, clarify or resolve them.

LAYER 3 Creating an enabling environment

3.5 CONCLUSION

The provision of integrated care requires a significant and meaningful level of interprofessional engagement and cross organizational cooperation. Creating a very specific notion of a health system allows one to **consider the enablers and resistors** underpinning such a set of processes. An enabling health system will not guarantee but it will support the coming together of health and social care professionals. An enabling health system will not guarantee that services will be integrated, but it should aid the process just as disabling aspects may hinder it.

The summary of the assessment provided in Book 4 is that there appear to be more health system resistors than drivers, **reflecting degrees of institutional inertia** as well as barriers emanating from challenged interests. Administrative and organisational infrastructures effectively lag behind developments in care models and a growing commitment to more personalised and coordinated care at the individual level.

The integration of care for older people is, in all SUSTAIN jurisdictions, one among many **policy priorities** pursued at different levels of political and administrative systems both for health and social care and also in the public policy field more generally. We have identified a number of inconsistencies between the policy and practice implications of extending integrated care for older people and established ways of working and managing local health systems. Explicit and implicit policy conflicts are an inevitable part of the public policy environment. They can however be identified and mitigated.

BOOK 5

Resources of Integrated Care

SUSTAIN, which stands for 'Sustainable Tailored Integrated Care for Older People in Europe' (www.sustain-eu.org), was a four-year cross-European research project initiated to take a step forward in the development of integrated care. During the SUSTAIN project, we learned what integrated care means for older people living across seven countries in the European Union.

In this last book you will find the resources of the four books.

> ADVOCACY TOOL

> ASSESSMENT TOOL

> CASESTORIES OF EACH COUNTRY

> REFERENCES OF EACH BOOK

ADVOCACY TOOL

FOCUS POINTS

1 **The ageing population and accompanying increase in people with multiple chronic conditions has changed and increased the demand for health and social care.**

2 **While the demand on governments to improve the health and wellbeing of their populations is rising [5-7], so is the demand for better care.**

3 **Health care spending is expected to increase.**

4 **Something has to change.**

READ MORE

INFOGRAPHIC

Integrated care seeks ways to better coordinate services by working together around people's comprehensive health and social care needs, engaging individuals and communities in managing their care. It is essential to meet the needs of the ageing population, transform the way that care is provided for people with long-term conditions and enable people with complex needs to live healthy, fulfilling, independent lives. A definition of integrated care, based on the perspective of a user, states that "I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me" [12].

GO TO THE INFOGRAPHIC

FOCUS POINTS

1. **The ageing population and accompanying increase in people with multiple chronic conditions has changed and increased the demand for health and social care.** Integrated care seeks to deliver services that are person-centred and meet these changing needs of the population. Across EU countries, the share of the population aged over 65 has grown, on average, from less than 10% in 1960 to 19% in 2015 and is projected to increase to nearly 30% by 2060 [1]. The share of people aged 80 years or older will more than double by 2080 to reach 13% of the EU population [2]. However, with increasing age comes chronic health problems. Currently, around 50 million EU citizens are estimated to suffer from two or more chronic conditions, most of them 65 years and over, which can lead to multiple health and social care needs. This number is expected to rise in coming years[3]. Further, it is estimated that 555,000 people of working age die prematurely from chronic diseases with an economic loss of EU 115 billion per year [4].

2. **While the demand on governments to improve the health and wellbeing of their populations is rising [5-7], so is the demand for better care.** Exacerbating this pressure is the fact that services are far too fragmented, disease-centred, and difficult to navigate [8]. People are reporting negative and life-threatening experiences due to failures of communication, inadequate sharing of clinical information, poor reconciliation of medicines, duplication of investigations and avoidable hospital admissions or readmissions [5]. This is particularly acute for older people living with multiple chronic or complex conditions that require care and support, and whose needs are being insufficiently addressed. Increasingly citizens are calling on policy makers to improve people's access to care by reducing waiting times, improving the capacity and quality of providers, providing care that is more personalised to their needs, supporting people to cope with their disease burden in and/or closer to their homes , and decrease administrative burdens.

3. **Health care spending is expected to increase.** Growing health demands combined with health care costs, health care inefficiencies and poor performance are putting a strain on national budgets and social security. Health care costs in the EU currently make up between 7% and 11% of overall GDP expenditure [9] and are projected to increase. Public spending on long-term care is predicated to rise from 1.6% of GDP in 2013 to 2.7% of GDP in the EU by 2060[1].With poorer and sicker populations entire economies are vulnerable, as is the health and social care workforce tasked with caring for the sick. This is relevant both for high-income and low- and middle-income countries [6, 7].

4. **Something has to change.** Countries across Europe and the world are seeking ways to improve the quality of care delivered and sustain their health and social care systems. This change involves shifting much of the system and rethinking the way we deliver services so that countries can better cope with the higher demand for quality care and increased complexity in the care needs of users.

ADVOCACY TOOL

TOP 6 REASONS FOR INTEGRATED CARE

1 **Takes the user's perspective** as the organising principle for delivering services– it is easily forgotten that 80% of care is self-care and only about 20% is professional care. Users (and their families or carers) are the true primary health care providers. Hence, a focus on prevention and self-care is essential.

2 **Improves people's experiences of care** – a recent systematic review [13] concluded there is evidence of perceived improved quality of care, evidence of increased patient satisfaction with services, and evidence of improved access to care.

3 **Improves population health** – reviews by The King's Fund and the Nuffield Trust of the evidence from research conclude that significant benefits can arise from the integration of services where these are targeted at those client groups for whom care is currently poorly coordinated [14-17]. People that benefit the most from an integrated approach are frail older people, children and adults with disabilities, people with addictions, and those with multiple chronic and mental health illnesses, for whom care quality is often poor and who consume the highest proportion

of resources [18]. Integrated care is also important for those requiring urgent care (e.g. cancer patients) where a fast and well-coordinated care response can significantly improve care outcomes.

4 **Helps those that are most vulnerable** – those that suffer most from a lack of integration and coordination of care services are people who are poor and/or vulnerable. There is an ethical imperative to help those most in need, ensuring equal access to quality care.

5 **Can represent better value for money through improved coordination** - The evidence on whether integration leads to value for money remains inconclusive and difficult to interpret due to the complexity of evaluating it. Evaluation of integrated care is still an evolving and emergent field and the quality of existing economic evaluations is not yet robust enough [19, 20]. But the lack of evidence does not mean that it does not hold promise.

ADVOCACY TOOL

There is some evidence [5] that better coordination can save money and raise quality for particular patients. The rationale is that breaking down barriers and working as a well-coordinated team leads to more efficient delivery of services. This allows us to make better use of existing resources by avoiding duplication and ensuring people receive the right care, in the right place, at the right time.

Particularly cost-effective seem to be initiatives that use reliable data to identify the patients most at risk of deterioration, and then ensure that they get the appropriate type of coordinated care and self-care services [5]. Essentially, integrated care can save money if the right approach is used, if it is implemented correctly and depending on the context (e.g. financing system) and timescale over which savings are estimated. Successful examples include models of care to prevent hospital admissions and programmes that prevent chronic care and illness.

6 **Fosters a motivated and satisfied workforce** – the workforce is the most vital resource when it comes to delivering care services [21]. Through greater coordination, integrated care can free up valuable space and time for staff to spend more time on what they are good at, extend their skills and their scope of practice. This means patients get better care, but it also means staff's careers are more rewarding, helping to address potential gaps in the workforce[22].

BUT, we need to keep in mind that to make these gains, integrated care must be tailored to local contexts.

GO TO INFOGRAPHIC TOP 6

ASSESSMENT TOOL

INTRODUCTION

In this section a simple self-assessment tool is provided to enable decision-makers to take an informed view of their current capabilities when designing and improving approaches to integrate care that support older people to live at home. The tool brings together descriptors, or core characteristics, in service design associated with the four principle design features of: person-centred care; coordination of care; empowering an interprofessional workforce and safeguarding the dignity of older people. The approach to the self-assessment uses a simple five point scale so that key informants can rate the relative strengths of the current design of their integrated care programmes by listed component. The intention of this simple tool is to help guide decision-makers tasked with implementing integrated care in their thinking.

APPLYING THE TOOL

The self-assessment process should invite representatives of all key stakeholders to contribute to the process. This might commonly be administered through a simple survey tool with the results collated to provide the scores at both an individual and aggregate level. The purpose of the exercise is then to utilise this information to promote discussion and debate on the existing perceived capabilities in the design of their integrated care programmes, for example through facilitated workshops and other discussion forums. In other words, the self-assessment process is not a 'tick-box' approach, but a tool to bring people together and examine and agree where key issues for prioritisation exist that would help to strengthen elements in integrated care design.

INTERPRETING THE RESULTS OF THE SELF-ASSESSMENT

The results of a self-assessment survey across multiple stakeholders might lead to the development of a spider-plot that tracks the average scores within and across the four design-features identified through SUSTAIN's research. This can provide an at-a-glance picture of the aggregate views of informed stakeholders on the relative strengths and weakness of the design components. For example, such an analysis may result in consensus that care coordination tools have been well established, but that the ability to provide person-centred care and safeguarding dignity is weaker. Such a visual picture resulting from a self-assessment enables key stakeholders to discuss their perceptions of design strengths and weaknesses. Its purpose is to stimulate conversations on how to improve the design of care services and so inform future strategies.

CASE STORIES

CASE SITES

| ALUTAGUSE | MEDENDI | GPZ | SABADELL | OSONA | PFLEGEWERK | TEMPLIN |

| SANDGATE | SWALE | SØNDRE NORDSTRAND | SURNADAL | ARNHEM | WEST FRIESLAND |

FACTSHEETS

| ESTONIA | AUSTRIA | CATALONIA | GERMANY | UK | NORWAY | NETHERLANDS |

REFERENCES

> **Book 1**

> **Book 2**

> **Book 3**

> **Book 4**

> **Book 5**

COLOPHON

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On behalf of the SUSTAIN consortium:

- Austrian Interdisciplinary Platform on Ageing (OEPIA)
- Age Platform Europe
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