



SUSTAIN

Sustainable tailored integrated care
for older people in Europe



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

 **CLICK FOR KEY MESSAGES**



Person centered



Coordination



Empowering an interprofessional workforce



Safeguarding dignity

START



KEY MESSAGES



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.

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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 misled 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.**



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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



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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**



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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, **in 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.



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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.



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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].



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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 statuses, and people's capability to self-manage their condition when compared to usual care [7].



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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].



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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.



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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.



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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



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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].



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FEATURE 2 Coordination

ESSENTIAL ACTIVITIES

- Case management
- Joint care assessments
- Care transition management

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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 Pfliegewerk 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



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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 be 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**.



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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



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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].



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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.



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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 interprofessional 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.



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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**



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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 **'interview 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



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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).



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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 .



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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.



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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 introduced**. 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



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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].



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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.



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COMPETENCY-BASED RECRUITMENT AND PERFORMANCE MANAGEMENT

- Walk-about 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.



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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 constraints, 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



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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**



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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.



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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



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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).



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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.



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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.



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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].



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