

Sustainable Tailored Integrated Care for Older People in Europe (SUSTAIN): Challenges to Implementation at UK, Austrian and Catalanian sites

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On behalf of the SUSTAIN Consortium

Thematic panel

Co-production between new care arrangements and informal practices for chronic conditions

Abstract

This paper discusses the contextual and organisational challenges in the co-design of integrated care initiatives as part of a major European project: Sustainable Tailored Integrated Care for Older People in Europe (SUSTAIN). Case sites from the United Kingdom (UK), Austria and Catalonia are presented. The aims of SUSTAIN are to improve established integrated care initiatives for older people living at home with multiple health and social care needs, ensuring that they are person-centred, prevention-oriented, efficient, and safe, and to ensure that improvements to the integrated care initiatives are applicable and adaptable to other health systems and regions in Europe. A core element is the co-design of initiatives with key stakeholders, users and other members of the community at these sites. SUSTAIN employs a case study design (Yin, 2009) using the Evidence Integration Triangle as the theoretical framework (Glasgow, 2013,) which emphasises a participatory implementation process. Contextual issues of policy, governance arrangements, leadership, organisational issues and collaboration, and availability of resources are explored. The engagement of stakeholders on equal terms, at strategic and operational levels, is key for success integration. Leadership requires a shift from a control process to a focus on building communities of practice. A shared commitment to person-centred care and an understanding of different staff roles, responsibilities and cultures provide a foundation for collaborative working and the co-design of services. However, in a cold financial climate, lack of resources, especially the availability of staff, can be a significant barrier to implementing new ways of working. The engagement

of users and carers in co-design and co-creation both on an individual and system level, requires ongoing support.

Introduction and Background

SUSTAIN examines integrated care for older people living at home and is funded by the EU Horizon 2020 programme (2015-2019). It is carried out by a multidisciplinary consortium of 13 partners from nine European States: Austria, Belgium, Estonia, Germany, Ireland, the Netherlands, Norway, Spain, and the UK.

Due to population ageing, health and social care systems face the challenge of offering care and support to an increasing number of older people. This is a key challenge identified by the European Commission (2013). Many people age in good health and remain active participants in society throughout their lives. Still, the prevalence of frailty, (multi) morbidity and disability increases with age, eventually leading to multiple health and social care needs. Complex needs require the involvement of a large number of providers in the care process and there is often insufficient alignment between different health and social professionals. Health and social care systems for older people can, therefore, be poorly planned and co-ordinated, leading to fragmented, incomplete, inefficient, and ineffective care, which in turn may lead to poor health outcomes. In addition, older people with frailty, disabilities or multi-morbidity are disproportionately heavy users of high-intensity, high-cost services such as hospital care and other forms of institutional care, which puts pressure on budgets. Sustainable systems, addressing both health and social care needs, are necessary to optimally support older people to remain active participants in society for as long as possible, enhancing person-centredness while restricting expenditure.

Integrated care is widely acknowledged to be the way forward in care delivery to support this vision although studies across the EU identify continuing structural, organisational and professional barriers to implementation (Leichsenring et al, 2013). Integrated care, from a user's perspective, can be described as:

“My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes” (National Voices, 2013).

The aims of SUSTAIN are: to improve established integrated care initiatives for older people living at home with multiple health and social care needs, ensuring that they are person-centred, prevention-oriented, efficient, and safe; to ensure that improvements to the integrated care initiatives are applicable and adaptable to other health systems and regions in Europe. A central proposition of SUSTAIN is to ascertain what works for whom, in what context and with what outcomes. Two sites have been selected for improvement initiatives within each of the seven partner countries (n=14). A core element is the co-design of initiatives with key stakeholders, users and other members of the community at these sites. Co-design, is an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership (The Kings Fund, 2017). Our approach to implementation involves developing partnerships between researchers and community

stakeholders who are the potential recipients of the intervention, or responsible for implementing it, including patients, health care providers, managers and policy-makers. This approach seeks to empower participants to tailor an intervention to suit their own contexts. Interventions aim to be responsive to the community and the participants they serve. Ideally, collaboration occurs between researchers and end users from the onset (Goodyear-Smith et al, 2015). Co-design, therefore, places the values of the service user at the centre and aims to involve users as equal stakeholders in the process. It encompasses co-production as a model for health services, which is based on the sharing of information and on shared decision-making between service users and providers (Bettencourt et al, 2002, Needham and Carr, 2009).

A number of definitions for co-production exist, for example, *“it involves people who use services being consulted, included and working together from the start to the end of any project that affects them”* (Think Local Act Personal, 2011).

The Social Care Institute for Excellence (SCIE) (2015) recommend a ‘whole-systems’ approach for co-production comprising culture - the beliefs and values that define an organisation and the way that it works; structure - the way the organisation is arranged and the systems it has set up; practice - how the organisation and the people who work for it carry out their work and review - the outcomes and impacts that result. Culture is described as key to determining whether co-production can take root. Culture that is supportive of co-production is open to change and comfortable with well-managed risk. However, co-production is time-consuming and requires resources for building the project and ongoing support (Bruce et al, 2011).

Nies (2014) argues that integrated care should include non-professional and community resources and structures in order to achieve sustainable care. Within SUSTAIN, co-design of services includes health and social care providers, users, carers, third sector and voluntary organisations and community groups. Person-centredness is a key theme and aims to involve older people and their informal carers in decision-making and planning their care through, self-management, for example. However, the context within which services are designed and delivered has a dramatic effect on the ability of teams to co-design and implement integrated care initiatives.

This paper focuses on the contextual and organisational challenges in the co-design and implementation of integrated care in SUSTAIN sites in the UK, Austria and Catalonia. These sites have been chosen as they each face complex challenges to implementation, and diverse contextual tensions.

Introduction to the SUSTAIN sites

‘Home First’ is a UK service which aims to discharge users from acute and community hospitals as soon as they are medically fit. The service operates within the South East of England in a locality with high deprivation. An initial triage assessment is made by the hospital occupational therapist to assess the user’s suitability for Home First. New social care packages or a re-instatement of care is activated at this point. A Rapid Response team is contacted to indicate that the user is being discharged from hospital. Their discharge triggers a two-hour response target for assessment by home by an occupational therapist from the

Rapid Response team and any further referrals are made. The intention is that ward staff no longer default to a delayed or community hospital discharge for users with non-complex, active recovery needs. Instead, the assessor can identify and seek to address barriers to care within the context of users own homes, by calling on and co-ordinating existing health and social care support services. The objectives are that patients will be discharged from hospital more efficiently, be diverted away from community hospitals and into their own homes, and be provided with integrated health and social care wrap-around services, assessments and therapies.

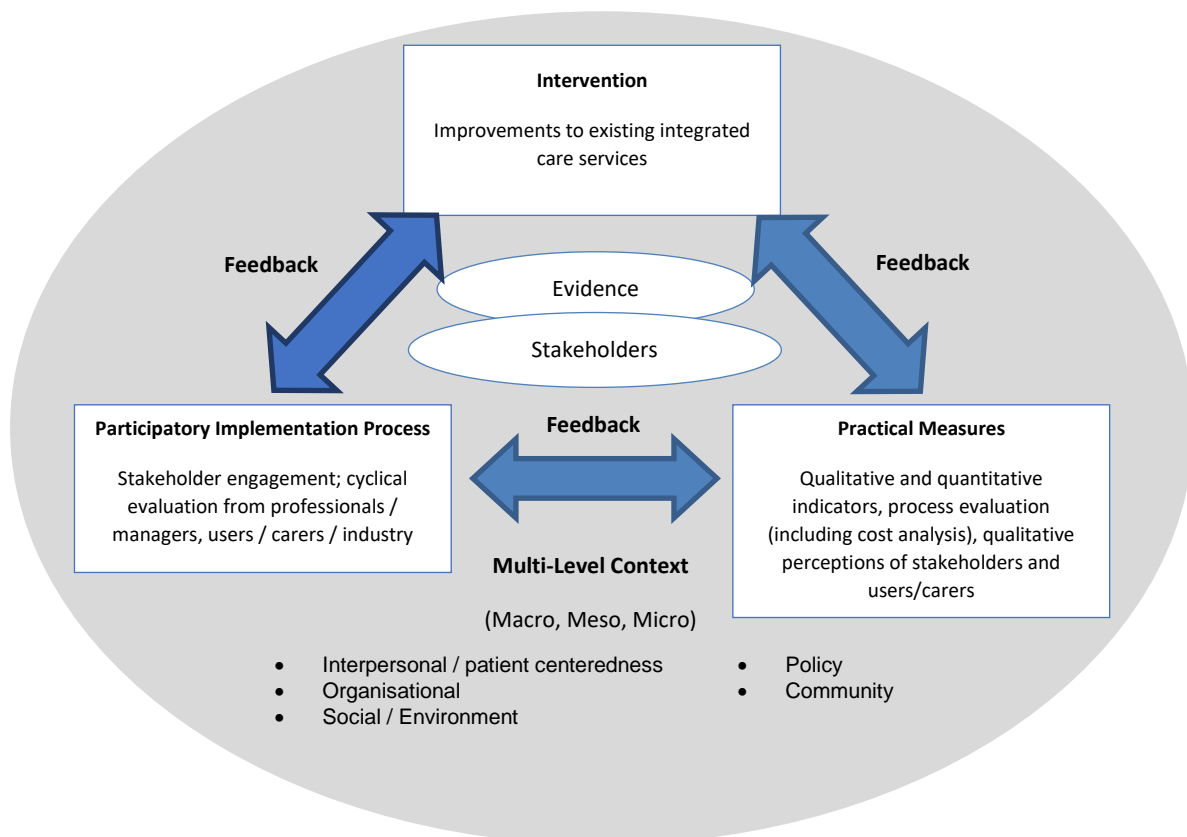
‘Co-ordinated Palliative Care’ started as an Austrian initiative to provide structured care to palliative-geriatric patients living at home. However, this site subsequently withdrew from the SUSTAIN project early in the development as a result of insurmountable financial and resource challenges. The main objectives were to define a set of criteria and improved communication methods for a structured and co-ordinated care process between the palliative care teams and other social and health care providers involved in home care services for older and chronically – mostly terminally ill – older patients people living at home. The team identified a need to define the responsibilities of partners involved, in a seamless care process including informal caregivers. The initiative aimed to involve volunteers as part of the team, and cooperate with a wide range of partners from hospitals to primary care, including home care and residential facilities. Currently, a follow up evaluation as well as alternative forms of engagement for improved integrated care at this site are planned with members of the management team.

In Catalonia, two integrated care initiatives are discussed; the first addresses the needs of users with severe chronic illness, over 65 years of age and living at home. This is a hospital-based initiative in which different care levels are coordinated (primary health care, acute care, intermediate and long-term care). The specialized care centres have redesigned and reorganised their service delivery model under common agreements. Social care is provided from the different care levels and is well articulated with social services at the City Council level, which manages legal aspects of care. All patients have a comprehensive assessment using a case-conferencing format, resulting in an individualized intervention care plan which is agreed with the patient and their family. The second initiative addresses over 65 year old people living at home with multiple social and health care needs and is primary care based. Social and health care professionals jointly defined eligibility criteria to identify the target population. This includes those with chronic diseases, complex pharmacological treatments, and lack of a skilled, informal caregiver. This initiative is carried out in three Primary Care Centres, from which both health and social care are provided to the local population. Integration results from health and social care professionals sharing an agenda in which eligible individuals are identified, recruited and jointly assessed following a multidimensional tool previously defined by the social and health professionals. Care plans are designed and agreed with patients and family.

Methodology and Methods

SUSTAIN employs a case study design (Yin, 2009), with each site representing one case study. Case study design provides a methodological framework that supports the analysis of quantitative, qualitative and a mixture of both types of data to investigate complex

phenomena in their everyday contexts and across multiple contexts. Issues are explored through a variety of lenses which allows for many parts of the phenomenon to be revealed and understood. It enables 'how' and 'why' type questions to be answered, while taking into consideration how a phenomenon is influenced by the context within which it is situated. Case study design has been used in SUSTAIN as it examines implementation processes as they unfold in a structured way. Glasgow's (2013) Evidence Integration Triangle is used as the theoretical framework in which a participatory improvement process is emphasised along with practical evaluation measures including process evaluation.



Yin (2009) emphasises that contextual conditions need to be investigated because they are relevant to the phenomenon under study. In SUSTAIN the context of the study is a crucial inclusion, not only is it emphasised through the Evidence Integration Triangle - but because of the dynamic and influential nature of context on the health and social care settings.

In keeping with this approach, SUSTAIN is collecting a wide range of qualitative and quantitative data to evaluate person-centredness, prevention, safety and efficiency as well as process evaluation measures, including the context within which the initiatives occur. Context is being captured through interviews with managers and professionals, focus group discussions with professionals, stakeholder analysis (the people and organisations that influence the improvement process), analysis of improvement and implementation plans, minutes and reflective field notes of steering group meetings, and a questionnaire that measures perceptions of team work. Reflections on the impact of the researcher on the co-

design services will also be identified. Analysis is continuous with feedback given during the implementation phase.

As of June 2017, most of the SUSTAIN sites are in the early stages of implementing the initiatives. This paper presents an interim analysis of the contextual data at sites within the UK, Austria and Catalonia, within which co-design occurs. Data is drawn from baseline reports, minutes of steering group meetings and reflective field notes of the researchers at the sites. An analysis template was developed to capture themes of: governance arrangements including the composition and functioning of the steering groups, leadership, policy and organisational issues, inter- and intra-organisational collaboration and availability of financial and other resources such as staff. The degree to which care is person-centred will be determined through two questionnaires – the Person-centred Co-ordinated Care Experiences Questionnaire (P3CEQ), and the Perceived Control in Health Care Questionnaire (PCHC). In addition, interviews with users and carers will be conducted and care plans will be analysed.

Results and Discussion

Policy issues

In the UK, national policy is pushing both integrated care and the shifting of care from hospitals into the community (NHS England, 2014). This forms a supportive backdrop for Home First. At a local level, there is an urgent policy imperative to free up hospital beds and improve hospital flow. Home First is seen as one way of achieving that. However, the cold financial climate means that at a service commissioning level, there seems to be a 'blanket' policy mantra that 'there is no more money'. This mantra seems to come before a thoughtful investigation of whether existing resources might be shifted around within the system. Health and social care organisations remain independent of each other with separate budgets, commissioning structures and IT systems, for example. In addition, at this site community health services are now provided by a private organisation rather than the National Health Service (NHS) which has introduced new organisational challenges.

In Austria, issues of co-ordination and integration of care both within the health system and between health and social care (long-term care) have been a major challenge over the past two decades. This is due to the idiosyncratic division of responsibilities, rationales of policy domains, information flow and fragmented sources of funding. However, with the rising number of people with chronic conditions and new patterns of care needs (e.g. due to dementia and other cognitive problems), problems at the interface between hospitals and community care, have become evident so that a number of initiatives have been started to adapt organisational structures and processes. This includes information exchange and discharge from hospital, as well as education and training programmes. Still, related reforms remain piecemeal, are often discontinued and not systematically evaluated.

Integrated care models are gradually being implemented in Catalonia. While there is a policy framework for integration (PIAISS), its full deployment has not yet been achieved. Health has been a universal and free service since the establishment of democracy in Spain (1976), with a larger share of public expenditure. Social services have only begun to be a universal right

over the last decade. Social services have a much lower public investment, and the recent economic crisis, has hindered any possibility of expanding the coverage and depth of social services. A common health care policy can be applied across Catalonia but social services are determined locally, leading to fragmentation and divergence in levels of coverage, models, management procedures and IT solutions. Recent cutbacks in the Catalan health budget have had a significant impact on health services, and primary health care has traditionally received a small share of the total health expenditure leading to pressures within the primary care sector, in particular.

Within all sites, there is an historical divide between health and social care which has led to poorly co-ordinated services. Differences in how health and social care services are funded and commissioned add complexity to the co-design and integration of services. In addition, unprecedented financial pressures mean there are limited resources with which to deliver comprehensive, integrated care. However, it is these same challenges that are driving the need for new models of care and integrated working, meaning that there is a policy imperative supporting integration at the sites.

Governance arrangements

In Home First (UK), the steering group has representation from strategic and operational level staff across health and social care commissioning and provider organisations. There is also a representative from Healthwatch which is an independent organisation set up to champion the views of patients and social care users across the County. Healthwatch aim to work to help local people get the best out of local health and social care services and influence the delivery and design of local services. The steering group feeds into a higher, strategic level group involving both health and social care organisations.

In Co-ordinated Palliative Care (Austria), the steering group was composed of representatives from six health and social care co-operation partners. The intention was that the steering group would decide on a detailed work plan for the first months and discuss the implementation in a separate working- or task force group. The baseline assessment demonstrated high motivation of the core management team.

In Catalonia, the hospital-based initiative steering group is composed of health and social care representatives from the Intermediate Care Hospital and Primary Care Centres, Social Workers from the Councils and a manager and Emergency Room Doctor from an acute care hospital. Each organisation appointed a reference person or co-ordinator, to be the contact person with the researcher and the other institutions involved. In addition to the steering group, an improvement project executing team was established which included the health and social care representatives involved in case conferencing and care planning. This is a large group involving 49 individuals. In the primary care-based initiative, the steering group consists of health and social care staff and managers from the Local Council and Primary Care Centres. The improvement project executing team has the same composition as the steering group.

All steering groups, are multi-organizational involving health and social care agencies. However, only one group (Home First) has engagement from a user and carer organization

involved in the co-design of services. Governance at all sites consists of a 'two-tier' system involving health and social care staff at strategic and operational levels. In some cases, the steering group is essentially operational feeding into a higher strategic group (Home First), in others the steering group is largely strategic, informing an operational group (Co-ordinated Palliative Care; Hospital-based Intervention). In one case, the steering group carries out both a strategic and operational function (Primary Care-Based Intervention). What seems to be important is that both functions are carried out with effective communication between groups and organizations (Peck et al, 2004). At some SUSTAIN sites, the researcher Chairs the steering group meetings and facilitates communication between steering group members. In this way, one function is to help drive the initiative forward, if necessary. As the researcher is essentially an independent and external member of the group, they are able to remain impartial and ensure the needs of the project stay centre stage.

Leadership

In Home First (UK,) leadership can be described as distributed, with neither health nor social care organisations taking a strong lead. Everyone is involved in discussions and in seeking resolutions to problems, but difficult decisions have frequently been put off or avoided. During the development phase, the decision was made to implement a simplified and scaled-down vision of Home First. This was due, in part, on pressure to start the service as there was a risk of it becoming a discussion group only. As a result, some key changes that had previously been identified involving resources, staff and processes have not (yet) been implemented.

At both the Catalonia sites, there is a collaborative atmosphere and shared responsibility between the institutions involved. The baseline assessment undertaken in the frame of SUSTAIN indicated that the social sector seemed reluctant to be involved as initial contacts had made through the health sector, and they feared the initiative was perhaps, too health-orientated. However, going forward, this does not seem to be an issue. The equal involvement in developing the multidisciplinary and multidimensional assessment tool for each site has provided the opportunity for collaborative work and exchange, devoting equal attention to both health and social perspectives. Leadership can be described as informal with senior professionals providing a strategic vision and those in operational roles providing "real-world-knowledge" as they are in contact with the patients and know the feasibility of carrying out each activity. Health and social care professionals are able to provide different perspectives based on their different professional knowledge. Over time, steering group members have become more confident in sharing opinions and ways forward, as well as assuming parts of the work to be done, so there is less leadership by a few but rather a collegiate ownership and leadership of the project. Decisions on key issues are brought to the face-to-face meetings to be discussed and agreed upon. Decisions are informed by the different views and realities of all members of the steering group and consensus is achieved. This is possible thanks to a common trust and respect between all members.

For complex, multidisciplinary integrated care initiatives to be implemented, commitment and motivation from all agencies is required with shared ownership and responsibility and a common agenda. This supports the call of Kelley-Patterson (2012) for a new style of leadership in integrated care requiring a shift from a control process to a focus on building communities of practice leading incremental revolutions to generate transformation at a local

level. Holmes et al (2016), further argue that in a complex system no one person, group or organisation is able to exercise ultimate authority. A key feature is multi-level, multi-stakeholder engagement, requiring inter-organisational and often inter-sectoral cooperation.

Organisational issues

In Home First (UK), there has been some flexibility to change working practices and staff roles in order to introduce the initiative. For example, one clinical staff member was enabled to move from a hospital to a community setting, albeit, on a temporary basis in order to launch the service. However, the organisations' attitude to risk remains challenging. There is a 'risk averse' culture within the hospital which means staff are reluctant to discharge patients before they are assessed by an occupational therapist and physiotherapist on the ward. This has made it impossible to achieve the practice of discharging first, then assessing the patient at home.

The Catalan health and social services sectors were historically created as separate, parallel and differently structured systems (health being of universal access and governed and provided on the regional level; whereas social services were traditionally based on beneficence and a local competence), contributing to the co-existence of diverging organizational cultures. However, efforts to structure and consolidate social services as a universal right across Catalonia, together with the recent cutbacks and higher pressure on the health care system have perhaps drawn organisations closer together. A consensus that care needs to be person-centred in order to improve both individual and system outcomes, and a growing number of successful experiences of cross-sectoral collaboration in local settings, may mean the necessary factors are now in place for advancing the co-design and implementation of integrated care models. However, one aspect still hindering this integration is the need for a legal framework and IT systems enabling exchange of user information between institutions (and thus professionals) between the two sectors. In SUSTAIN, this has been overcome by obtaining informed consent from users, explicitly agreeing to this information exchange, but if this type of initiative is to be scaled up, a new legal framework enabling integrated IT systems and cross-sectoral care is required.

There are significant differences in organisational cultures, particularly between health and social care sectors. A shared commitment to person-centred and co-ordinated care may provide the impetus for integration across divides. Perceptions of acceptable levels of risk may differ between hospital and community settings. Goodwin (2011) recognises that the element of risk in integration does not sit well with the risk-averse culture in health and social care, especially in the current financial climate. Shared responsibility and accountability in managing this risk is required. The ability to share information is also a significant barrier to integration due to incompatible IT systems and a lack of information sharing agreements.

Inter- and intra-organisation collaboration

At Home First (UK), there are good examples of collaboration between health and social care commissioners and providers in, for example, the development of a flowchart which describes the processes of Home First. However, more meaningful integration has been difficult to achieve. For example, there has been no agreement to date to implement a single, trusted

assessor model where the assessment by one professional is accepted and shared across professional and organisational boundaries. Although staff within organisations are all working on the Home First pathway, they are largely working independently of each other. There still exists pockets of a 'blame' culture in which partners are critical of each other in terms of the slow implementation of the service. Most significantly, the change of provider for community health services in September 2016 caused considerable upheaval and significantly slowed progress as the new organisation developed its internal governance and operational procedures and began to engage with Home First.

At Co-ordinated Palliative Care (Austria), structured communication between the mobile palliative care team and providers of community care services (and primary care) was established at the workshop. The intention was for information flow within the acute-care sector regarding admission and discharge and the development of links between palliative care and care homes.

In Catalonia, both sites work in a collaborative manner. Mutual understanding and experience show that all profit from better coordination between different care providers, efficiency in the use of resources and improved care. Responsibilities are shared between the different teams involved, but in a way that enables each professional to contribute. Tasks are distributed to maximise input. One of the factors considered key to the success of the initiatives is that many of the steering group members had previously collaborated together, and thus are aware of each other's procedures, work dynamics, and roles, and have developed trusted relationships. The presence of the research team enables an external, independent element which can counterbalance any conflicts and ensure that decisions always prioritise the project as a whole.

An understanding of different staff roles and responsibilities provide a foundation for collaborative working and the co-design of service. The development of trusted relationships and a 'track-record' of working together greatly facilitates this. External facilitators, in this case, the SUSTAIN researchers can act as mediators in the implementation process. The success of integrated care is arguably significantly tied to the degree of stakeholder collaboration (Janse van Rensburg et al, 2016).

Availability of resources

For Home First (UK), to start, no additional funding was committed by either the NHS or local government social services. All UK health and social care services are currently operating under tight financial allocations as their budgets have been cut considerably since 2010. Lack of staff has been a significant barrier to implementation. A number of vacancies exist across organisations but particularly in community health services. This is primarily due to difficulties with recruitment. As a result, there are many gaps in provision and staff workloads are correspondingly high. As in many UK Health and Social Care Services, there is little or no additional funding for this new initiative. Organisations have some power to move resources within their local system, but the general shortage of funding relative to need makes this difficult. Although contractual arrangements mean that the community health provider has not been commissioned to deliver Home First, the initiative is being supported.

At Co-ordinated Palliative Care (Austria), a lack of new resources and staff within one organization meant it was not possible to support implementation of the initiative, specifically, due to the additional burden of work that would be placed on existing staff. As the staff members of this organization were core collaborators in the provision of palliative care services provided by Co-ordinated Palliative Care, the planned initiative had to be dropped. There was a belief that the involvement in a European research project would be a source of additional means and resources. A clear understanding of the financial commitment required from each member organization is then imperative from the outset.

In Catalonia, training and staff time were identified as additional resources. At one site, steering group members have been offered training on patient-centred care, in order to reassure them in their role in discussing and agreeing care plans directly with patients and care-givers. Neither initiative has been able to recruit staff specifically for the design or implementation of the projects. This means that time has to be found in day-to-day practice in order for the projects to move forward. Implementation needs to occur beside/along with pre-existing workloads. To overcome this, decisions have had to be made at a managerial level to free up time to devote to the projects. In Catalonia, neither initiative has obtained specific funding or resources in order to carry out their improvement projects. This means that the weight of the workload falls upon staff already working in the involved institutions, but also on the research team to help drive the initiative.

The availability of staff is a key factor in the implementation process. No additional staff have been allocated to any of the sites due to resource constraints which means that workloads are increased, at least in the short-term. Coupled with this, at the Home First, unfilled vacancies have increased the severity of the problem. However, re-deployment of staff within and across organisations has been shown to be a relieving factor. A lack of staff time has meant that the researcher has often had to play a more substantive role, beyond evaluation, in the development of the initiative, if stakeholders are unable to provide additional input. The Kings Fund (2014) identify that the development of payment systems that create incentives to integrate care is necessary to move forward at the scale and pace demanded. A statement which is supported by these examples.

Co-design at the SUSTAIN sites

At the SUSTAIN sites partnership working between researchers, health and social care providers and managers, service-commissioners, and user organisations is being developed. Users and carers have been involved in the preparatory phase of the SUSTAIN project, by means of individual interviews exploring their views on current care provision. This informed the development of the initiatives at the sites. Co-production of services therefore, occurred at this early stage of development. At Home First (UK), a representative of Healthwatch, a user organisation, is a member of the steering group and therefore contributes to the ongoing design of the service. However, at the other sites there is no user or carer representation at a system-wide level. There is also limited involvement of volunteer organisations in co-design although this does occur at other SUSTAIN sites. Co-production occurs mainly at an individual level, characterised by user involvement in their own care through identifying goals and self-

management, for example. (Needham and Carr, 2009). Person-centredness is a key theme within SUSTAIN and services have been developed with the aim of enhancing person-centred care. For example, the co-creation of care plans with users is an important component at the Catalanian sites. The degree to which users and carers have been involved in making decisions about their health and social care needs, feel in control, and have support to self-manage will be examined in the final evaluation.

The context within which integrated health and social care services are developed and implemented provides the landscape within which the co-design of services occurs. Governance arrangements, policy and organizational issues, the nature of inter- and intra-collaboration and not least staffing and financial issues are likely to influence the extent to which services are co-designed. Organizational culture which is open to change and able to deal with risk are conducive to co-design (SCIE, 2015). From the SUSTAIN examples, there are significant challenges for organizations to overcome in terms of structures and processes, for example, IT sharing agreements. Co-design, including users, is time-consuming and requires resources in order to build services and provide ongoing support (Bruce et al, 2011). However, this will require creative solutions in terms of re-deployment of existing resources rather than additional staff or funding, in most cases.

Conclusion

The involvement of all stakeholders, including users, on equal terms from the very start of the project is key for success integration. There is a need to involve professionals at all levels and disciplines at strategic and operational levels. An improvement project requires time as well as drivers or 'champions' in order to maintain momentum. In addition, an open and flexible mindset is a valuable asset that facilitates the co-design and implementation of improvement projects, and is perhaps a pre-requisite for co-production with users that is transformational. Managers and professionals must be willing and prepared to give patients a voice and continuously review their way of operating. Communication between the researcher and staff to inform, share, discuss and participate throughout the process is key to achieving ownership and the motivation to change as well as allowing any difficulties to be identified and addressed in the early stages. It is also important to consider the cultural and socio-demographic background of the population when co-designing person-centred care, in order for users to be full and active participants in the process. The engagement of users and carers in co-design and co-creation both on an individual and system level, requires ongoing support.

Going forward, a full analysis of the context in which co-designed, integrated care occurs will inform the development of a roadmap - a main product of the SUSTAIN project. This will provide support and information for policy- and decision-makers tasked with designing, establishing, and maintaining systems of integrated care that focus on older people living at home with multiple health and social care needs. In addition, a toolkit for professionals will be available to support best practice.

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Questions for Discussion

| | Question | Response |
|---|---|---|
| 1 | <p>How do you see the co-production in your arena?</p> <p>Looking ahead, how would you envisage co-production developing?</p> | <p><i>The concept of person-centredness is established but there is limited consensus on what this looks like or how best to implement integrated initiatives which support it; The co-design and co-creation of services at a system-wide level is still underdeveloped.</i></p> <p><i>In particular, co-production with users of the SUSTAIN project is not straightforward due to the background of the particular cohorts (elderly, with cognitive impairment in some cases or at end of life, with perhaps a different culture towards participation). Further training for professionals to properly understand person-centredness, patient empowerment and co-decision making. Reflecting on how to do this with this particular target group should be a preliminary step to facilitate co-production and avoid risk to this frail.</i></p> <p><i>In integrated care, organisations need to engage users, carers and communities more fully from the outset not just co-design with professionals and other stakeholders. Examples of ‘good practice’ are needed to support how to do this.</i></p> |
| 2 | <p>How would you assess the opportunities offered by this relational mode of producing care?</p> | <p><i>Ensures services really are person-centred; Enables users and carers to be given a voice on how services should be designed and delivered; Requires additional resources which are already limited.</i></p> |
| 3 | <p>What challenges does co-producing care present to participants in the process?</p> | <p><i>Complexity in addressing patient empowerment, self-management, and co-decision making in this specific group, may not necessary mean wanting to participate in decisions, but being informed of options, and the target population of the improvement projects are not necessarily familiar with being given a voice so need to be supported to do this (Appendix 1); A further challenge is how to engage other marginalised groups e.g homeless people, ethnic minority groups, people with learning disabilities.</i></p> |

Appendix 1:

Community profile of older people in Catalonia

- 2017: 77 year old in 2017 with complex social and health care needs. Low income (state) pensioners, relying on wives/sons/daughters for care, or even providing for them (due to high rates of unemployment)
- 2007: Retirement just before economic crisis
- 1997: Consolidation of Spanish Welfare state (strong universal health care and education; social services only provided as beneficence and not a universal right until 2000s'; family services underdeveloped; pensions frequently used as an electoral weapon)
- 1977: Transition to democracy
- 1967: Parents of the Spanish Baby-boom (increase of births between 1958-1977)
- 1957: Incorporation to the labour market in a world without trade-unions, right to strike, low qualified manual class (many abandoning education to work for a living)
- 1947: Educated under the Franco dictatorship: repression (Catalan forbidden, republicans persecuted/ punished/ forced to exile), no civil or political rights (no vote, no organizations, movements or parties, no freedom of speech) catholic values, traditional role of the woman, care provided either by family-women or beneficence, international isolation
- 1937: Born 1 year after the end of the Spanish Civil war (1936-1939): Many personal losses (broken families, destruction, poverty, migration)