SUSTAIN
Sustainable tailored integrated
care for older people in Europe

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

Lessons learned from improving integrated care in Catalonia (Spain)

## Colophon

# Acknowledgements

# Key points

- Two local Catalan cross-sector initiatives have co-designed a new work method for needs assessment and care planning for 65+ users living at home with complex social and health needs, as they had a common understanding that the participation of users and carers in decisions on their care was needed in order to obtain a more person-centred, prevention-oriented and efficient approach.

- Standard care planning tools were produced: multidimensional joint comprehensive assessment of needs (case conference in Osona; primary care triad assessment meetings in Sabadell) and a care plan document reflecting the shared-decision approach.

- The improvement projects were disruptive with usual working procedures and roles, and helped to change work cultures through co-responsibility of care provided to users and enhanced understanding of user reality thanks to visiting their home environments.

- Although the participatory approach for care planning was challenging in some cases due to the cognitive capabilities and cultural attitudes and behaviours of the target group, both improvement projects appear to have improved the perceived person-centredness, prevention orientation, and coordination of the services they provide. A specific workshop for users, addressing aspects related to growing older and enabling reflections on their situation and preferences with peers, was highly appreciated by the 65+ participants.

- A committed group of professionals who believed in the person-centred approach and were supported by managers was a key strength of the improvement projects. Joint leadership of the project between professionals of different institutions and work profiles, with managers acting as facilitators and equals facilitated successful implementation.

- Main challenges limiting the continuity or scalability of such approaches relate to: the lack of time in constricted health care and social services systems; difficulties prioritising care planning activities without allocating additional professionals to the care planning activity and / or reorganizing professional roles and teams; the need to include wider networks involved in the continuum of care; and the convenience of further developing a regional integrated care policy, that would help overcome the traditional fragmentation between care sectors.

# CONTENTS

# 1.  INTRODUCTION

## 1.1  Integrated care in Catalonia

In Spain, the organization of the healthcare system mirrors the political organization and is devolved to the autonomous regions, which has led to the development of seventeen separate regional health services (Ministry of Health, 2012). Mainly financed through taxes, regional health services in Spain provide primary and specialized care, free of charge for those citizens who displayed the status of insured (Cantero MJ, 2014). Healthcare providers at all levels of care are predominantly public, and most health professionals are employees with civil servant status. In general, public healthcare providers in each region are owned by a public organization, which centrally oversees the regional health service. The coordination of healthcare and social care, which is often required for users with chronic conditions, is particularly hindered by the diversity of institutions involved in the care. In most Spanish regions, long term and social care for 65+ population and disabled falls outside the remit of the health authorities, making its coordination and integration with health care quite difficult (Nuno et al., 2012).

As health and social competences are devolved to the Autonomous Community level in Spain, the way the integration of health and social care provision is carried out should be approached at this level. The Catalan government (or Generalitat) has competences in both sectors, but basic social services (including home aid for older persons) are run by the local governments (e.g., at the municipality level). In 2007 a charter of social services was approved by law in Catalonia, including support for older persons living at home, to be funded through general taxes. Further details on how health care and social care are funded and provided in Catalonia can be found in the European baseline report produced by SUSTAIN (Arrue et al, 2016). Comparing the two sectors, significant differences appear. Some social services have co-payment (e.g., family carer, telecare devices, among others) while in the health care sector there is free access to all services and some co-payment of pharmaceutical products. A wide proportion of the social services covered publicly by the regional government (specialized social care, such as nursing homes) and by local authorities (basic social services) are provided by the Third Sector or private providers. In contrast, 80% of primary health care in Catalonia is provided by the Institut Català de la Salut (ICS), owned by the Generalitat (Agustí et al., 2006). Moreover, whereas the Catalan health system shares a common IT-system through which electronic health records are accessible, local social services have fragmented IT-systems. Furthermore, there is no common IT-system accessible to both sectors.

In 2011, the Catalan Department of Health and Department of Employment, Social Affairs and Families jointly created and developed the "Chronicity Prevention and Care Programme" (PPAC) with the aim of creating better conditions to achieve better outcomes for users with chronic conditions. As a result of this program and to strengthen social and health care integration, the Catalan government created the Interdepartment Social and Health Care Interaction Plan or PIAISS (Catalan Department of Presidency, weblink), under the Department of Presidency with the participation of the Health and Social Affairs departments. PIAISS' mission is to promote and participate in the transformation of the social and health care model to ensure integration and continuity of care and reinforce the value of comprehensive care for people. It also provides the definition of a network of services focused on the healthcare continuum to ensure the efficiency and the use of resources, highlighting person-centredness and a shared leadership among people and professionals. The PIAISS is now the policy framework for the impulse of an integrated care model in the Catalan territory.

In addition, PPAC enhanced the use of a tool for individualised care planning for users with chronic complex needs shared between different health sector levels through the common electronic health records (HC3), the Shared Individualized Care Plan (PIIC; Pla d'Intervenció Individualitzada Compartit). The information of the PIIC comes from an assessment performed by the general practitioner (GP) and/or by the nurse, who introduce this to the electronic health records for further consultation by other health professionals (e.g. in acute or intermediate care). Its objective is to be a communication tool among professionals in case the user is seen by health professionals other than her/his referent team (GP and nurse). The PIIC has a fixed format with basic information on main diagnosis, list of current medication, actions to be taken in case of specific crisis (fever, pain, dyspnoea, loss of consciousness), recommendations in front of a vital crisis, a list of specific resources that the 65+ user may receive (telecare, case-management, residence user, home-care nursing, etc.), and two quantitative indicators (number of discharges and number of emergency reports in the last year).

## 1.2  The SUSTAIN project

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

The SUSTAIN-project is carried out by thirteen partners from eight European countries: Austria, Belgium, Estonia, Germany, Norway, Spain (Catalonia), the Netherlands, and the United Kingdom. With the exception of Belgium, in all other countries two integrated care initiatives per country were invited to participate in the SUSTAIN-project. The initiatives were already operating within their local health and social care systems. Criteria for including these initiatives, also referred to as 'sites', were  defined by SUSTAIN research partners and drawn from the principles of the Chronic Care Model and related models (Epping-Jordan et al., 2004; Minkman, 2012; Wagner et al., 2005). Accordingly, initiatives should:
• Be willing and committed to improve their current practice by working towards more person-centred, prevention-oriented, safe and efficient care, which, in line with the European Commission's stipulations, are SUSTAIN's four key domains.
• Focus on people aged 65 years and older (referred to in this report as '65+'), who live in their own homes and who have multiple health and social care needs.
• Support people to stay in their own homes (or local environments) for as long as possible.
• Address older people's multiple needs, in other words, they should not be single disease oriented.

• Involve professionals from multiple health and social care disciplines working in multidisciplinary teams (e.g. nurses, social workers, pharmacists, dieticians, general practitioners).
• Be established, i.e. preferably operational for at least two years.
• Cover one geographical area or local site.
• Be mandated by one organisation that represents the initiative and that facilitates collaboration with SUSTAIN research partners.

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

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

In the second phase of the project (starting spring 2016), local steering groups were set up. Steering groups consisted of stakeholders who participated in the workshops together with additional local stakeholders considered relevant to the initiative. These steering groups were created to design and implement improvement plans, that is, sets of improve-ments that apply to local, site-specific priorities. Each steering group agreed to implement their plans over the 18-month period from autumn 2016 to spring 2018. In the case of Catalonia, study protocols were elaborated in collaboration with AQuAS, and ethics approval from relevant local committees was obtained. In each initiative, implementation progress and outcomes were monitored by SUSTAIN partners using a multiple embedded case study design, in which each initiative was treated as one case study (Yin, 2013). A hallmark of case study design is the use of several data sources, a strategy which also enhances data credibility (Creswell, 2009). SUSTAIN partners therefore used a set of qualitative and quantitative data collection tools (see Annexes 10.1 and 10.3), allowing us to collect data from different data sources, being: surveys to users,

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

surveys to professionals, interviews with users and carers, professionals and managers, care plans/clinical notes, field notes, notes of steering group meetings, and templates to collect efficiency data from local services, organisations or registries. Data were collected at agreed and specified times during the 18-month implementation period, using the same procedures and tools for all initiatives. In addition to a core set of data collection tools applied in all initiatives, sites were encouraged to select site-specific tools tailored to their site-specific context and improvement priorities.

Data were analysed per site, guided by the principles of case study design. There were three steps in our analyses: 1. all data sources were analysed separately using uniform templates for analysis which were generated through a discussion among research partners; 2. for each data source, data were reduced to a series of thematic statements (qualitative data) or summaries (quantitative data); 3. an overarching site-specific analysis was done, in which all qualitative and quantitative data were coupled and underwent a process of pattern-matching across the data. This is the approach of choice for evaluating complex community-based interventions which are context bound and noted for their differences in application and implementation (Billings and Leichsenring, 2014; Craig et al., 2008). In order to be able to do a site-specific overarching analysis, we created an analysis framework which was used by all SUSTAIN partners in order to create uniformity of approach. Data were analysed against the propositions and analytical questions presented in Table 1.

(Programa PCC/MACA/avançats), and the North Sabadell Social and Health care integration initiative. Both had a long-track experience in cross-sector collaboration in order to integrate care for older persons with complex health and social needs, with professionals employed by health care institutions and by local social services working together and identifying opportunities for consolidating formal integrated working methods and enhancing person-centredness.

The Osona site is a hospital-based integrated care programme at the population level in which different health care levels are coordinated (primary care, acute care, intermediate and long-term care). The specialized care including the acute care, the intermediate care and long-term care have redesigned and reorganised their service delivery model under common agreements. Social care is provided from the different care levels and it is well articulated with basic social services provided by local councils of the county. It can be considered as a proactive primary and intermediate care initiative focusing on older persons, commonly above 75 years, with complex health and social needs, who live either in Vic city (the largest town of the Osona county) or in the surrounding rural towns or villages. North Sabadell Social and Health care integration initiative can be considered as a proactive primary care initiative, offering health and social care to the population living in the northern area of Sabadell, which grew as to accommodate population migrating from other parts of Spain during the 30s-60s, and currently is one of the more deprived areas of this industrial city.

## 1.3   SUSTAIN sites in Catalonia

Two local sites in Catalonia were identified, contacted and engaged in the SUSTAIN research project: the Osona Program for chronic complex / advanced / geriatric care

The key feature of the initiative is that social workers employed by Sabadell's City Council are located within the primary health care centres (PHCC), facilitating cross-sector collaboration through a shared agenda in which the case of older persons living at home that could benefit from a greater coordination of services are signed up to be discussed in monthly basis meetings.

## 1.4  Reader's guide

This report will now present the case stories for each of the Catalan initiatives participating in SUSTAIN (Part 1- Osona; Part 2 - Sabadell). A common structure will explain: a) which improvement projects were adopted and the rationale behind the established goals and tools; b) details on the type and amount of data collected to assess these improvement projects; c) findings of the overarching analysis of data identifying what seemed to have worked and with which outcomes, explanations for success and (less) success, factors that are particularly strong in each site, and transferable aspects. Part 3 of the report will reflect on each case study and draw a common message that may have implications for the future provision of integrated care for older persons living at home in Catalonia or elsewhere, also reflecting on the methodological challenges encountered, which apply to both Catalan sites. This final chapter also provides recommendations for policy makers and service providers.

# PART 1
## Osona

# 2. OSONA: CHARACTERISTICS AND IMPROVEMENT PROJECT

## 2.1 General description of the site

The Osona Program for chronic complex / advanced / geriatric care (Programa PCC/MACA/avançats) is a joint venture of Vic Santa Creu University Hospital (intermediate and long-term care), the Hospital Consortium of Vic (encompassing hospitals and nursing homes providing acute, intermediate and long-term care), primary health care centres and corresponding local basic social services of Vic (capital of the Osona County) and smaller towns located south of Vic (Tona, Malla, Seva, St. Miquel de Balenyà, Collsuspina, El Brull, Muntanyola). They serve a population of approximately 155.000 inhabitants, of which 2.58% are users with complex health and social needs (as estimated by the Osona initiative).

This unique configuration brings together local public sector entities involved in the care continuum of 65+ users with chronic health conditions and complex social and health needs: primary health care nurses and GPs delivering home and ambulatory care; social workers assessing home environments and social-relational networks; specialist doctors for several chronic conditions, and acute and intermediate hospital staff caring for these users both as outpatients and inpatients. It is worth noting that home care services supporting basic and instrumental daily activities (personal hygiene, house chores, etc.) included in the charter of local social services (and therefore ultimately provided by the local councils) are currently provided by Third Sector entities, meaning that personal assistants or family workers are not directly employed by the local social services, although they are required to meet the established quality criteria set up for these publicly funded services.

## 2.2 Rationale for improvement project

The Osona initiative has been working for years as to optimise the services delivered to its users, by providing support at home and minimising destabilization of conditions or accidents, and developing a clinical pathway. Osona had taken up the use of the PIIC (the individual intervention plan shared between health professionals), designed and implemented at the level of the Catalan health system as part of the Chronicity Prevention and Care Programme (PPAC), allowing professionals to collect and share a fixed set of social and health information of users with chronic complex or advanced health conditions through the electronic health records, since May 2015.

Several barriers for better integration and person-centredness of care in Osona were identified in SUSTAIN's preparatory phase. First, PIICs were previously completed only by primary health care professionals, without involving all professionals treating the user (specialists, social workers, etc.), and thus not providing a complete interdisciplinary joint assessment. These were mandatory documents to be completed for all chronic complex users, and mainly served as a communication tool between different levels of health care. They did not contain information on user needs assessment, goals or resources. In addition, social workers from social services are not able to see this information as the HC3 is only shared among health sector professionals. Osona's Steering Group found that some improvement was needed, especially to give this electronically shared tool (the PIIC) a more personalised and participatory approach. Another limitation was the fact that users and their informal carers were not actively involved in the definition of PIICs, and therefore could not validate the extent to which planned actions met their needs and preferences. Finally, there was no formal procedure enabling exchange and joint assessment between health care and social care institutions, ensuring a standard approach.

## 2.3 Aims and objectives of improvement project PIIC Plus

The PIIC Plus improvement project co-designed by the Osona initiative has a twofold nature: it is an educational/training intervention that introduces a more participatory and person-centred care planning approach, favouring a progressive acknowledgement on the side of the professionals of the importance of discussing complex cases in multidisciplinary meetings and ensuring user needs and preferences are reflected in care solutions. PIIC Plus is also a cross-care provider collaboration that pursues greater integration by consolidating a common work method for performing joint multidimensional needs assessment and elaborating integrated individualised care plans.

Specific objectives are:
1. To elaborate a new version of the PIIC –PIIC Plus- (known by the team as Document de la Conferència de cas i Pla d'Atenció).
2. To consolidate the case conference as the working method to carry out multidimensional interdisciplinary assessments of chronic complex, advanced or geriatric users (target 36 cases over the 18-month implementation period).
3. To write a manual on how to transfer relevant information obtained by means of the case conference and PIIC Plus to the electronic health records.
4. To transfer information collected in the implementation period PIIC Plus care plans into the PIIC's electronic fields, and to save a copy of each PIIC Plus document in the user documents folder of the shared electronic health records.
5. To provide specific training to approximately sixty health and social professionals employed in involved organisations.

## 2.4 Explanation of the improvement project

The improvement project comprised the following actions, to be designed by the core Steering Group (composed by two managers and eighteen professionals) and implemented by the wider group of professionals recruited in SUSTAIN, with up to 36 users recruited in the frame of the research project:
1. Elaborating an expanded Care Plan document –PIIC Plus-, building on the PIIC and further developing its content in order to: ensure a multidimensional assessment of needs (health and social); that the user and carers views and objectives were explicitly included; and that the plan contains the specific care actions agreed by the different actors and institutions involved. In particular, the following fields were added: opinion/view of the user about his/her social and health situation; general goals agreed with the user; work plan with actions and person in charge; assessment of carer's needs; user situation and relation with the environment; information about advice on medication adherence, safety and autonomy/ independence.

2. Elaborating a PIIC Plus Manual, with instructions on how the content of the PIIC Plus could be transferred into the pre-existing PIIC sections of the electronic health records of each user. This manual was especially relevant, as the inclusion of the wider information included in the PIIC Plus to the electronic records was key in order to enable any health professional (either the usual team caring for the user or other professionals) at any moment to access the users care plan.
3. Consolidating the case conference: a formal, planned and structured interdisciplinary meeting involving relevant professionals for each particular user with complex social and health needs (Department of Health, New York State; 2013), held in order to provide integrated and coordinated care through the different care providers. In Osona, it would be a face-to-face meeting space for primary health care, specialised health care and social services, where the users' needs, preferences, and objectives would be discussed in depth taking into account the perspectives of the different profiles involved, and care plan actions would be proposed.
4. Consolidating meetings of the care team with users and carers to present, discuss and validate draft care plans resulting from the case conference, in order to ensure user participation in the care planning, acceptance of the actions to be undertaken and, overall person-centredness of the care provided. These meetings would be in a comfortable and secure environment for the user, their own home.
5. Training the staff who potentially could participate in elaborating a PIIC Plus in the new care planning approach, emphasising dimensions such as shared-decision making and person-centredness, but also introducing the specific new tools and procedures (needs assessment instruments, case conference document, validation meetings with users).
6. Establishing a formal mechanism to obtain user consent for jointly carrying out a case conference leading to an individualised care plan. Informed consent for professionals from both health and social sectors to exchange information and design an individualised care plan, which would then also be built into the electronic health records, was to be obtained from all users involved in the PIIC Plus activity.

The intervention would be applied through the following steps (illustrated by flowchart in Annex 10.2):
- Step 1: Users meeting inclusion criteria (65+, living at home, with complex health and social needs, cognitively capable) are identified by professionals working in one of the involved care providers and proposed as a participant.
- Step 2: The user (and carer) is visited by one of the professionals (or a team of nurse-GP-social worker), informed of the initiative and agrees to participate (providing informed consent).
- Step 3: The multidisciplinary team of professionals (primary health care, health specialists, social workers) perform a joint comprehensive assessment of the user needs, in a case conferencing format. In order to do so, they use the standard PIIC Plus assessment and care planning tool. Based on this assessment, a draft care plan is produced.

- Step 4: At least one health professional and one social professional meet with the user (and carer) in their home environment, to jointly discuss and validate the draft care plan. In an interview format, professionals ask the user which are their personal goals concerning their health and wellbeing, which would be their preferences concerning care options, and then validate the care plan, adjusting it to the user (and carer) needs and preferences. As a result of steps 1-4, all users have a comprehensive assessment resulting in an individualized intervention care plan agreed with the user and carers.
- Step 5: information collected in the assessment and care plan document is transferred to the electronic health records. This information is therefore available for further care planning, revising treatment and resources according to user goals, preferences and changing situation.

# 3. FINDINGS OF THE IMPROVEMENT INITIATIVE IN OSONA

## 3.1  Introduction

Between November 2016 and April 2018 Osona implemented the PIIC Plus improvement project in an iterative process, first piloting the co-designed work method with six users (two per PHCC), and then scaling up to eleven and nine users (and their informal carers) in two consecutive iterations. The Steering group was provided feedback on and discussed the pilot and iteration 1 experiences (in March and November 2017, respectively), in order to detect room for improvement and apply changes. The intervention reached the targeted number of users set at Consortium level and established in the study protocol approved by local ethics committees, within the given timeframe. Annex 10.3 provides further information on the type, amount and method of data collection.

Twenty users evenly distributed among men and women were recruited for Osona's improvement project in iterations 1 and 2. Half of them were 75-84 years old, and the other half 85+ years. Users were either married or widowed in an equal share (45%). Nearly half of users lived at home with a spouse; the rest lived either at home alone or with other family members, except one, who lived with a privately paid carer. Only one user had completed secondary or further education. Concerning the main clinical conditions, over half of the users reported suffering heart failure, problems with vision, wearing of the joints of hips or knees or persistent back pain (either combined or alone). Diabetes, insomnia, headaches, breathlessness, and urinary tract infections were also quite common. On average Osona users reported having 6.6 medical conditions each.

Twelve of the twenty users in iterations 1 and 2 had carers identified by care team members as providing regular care to the users, and recruited for the SUSTAIN improvement project. Female carers were either relatives of the user (3)

or paid carers, sometimes caring for both members of an older couple (3). The male carers were adult sons of the users (4) and the user's spouse (1). Half of the carers were older than 55, (20% of them 75+), half were married, and half lived with the user. Approximately 60% of carers had completed secondary studies or further studies (usually the younger carers, such as adult children or privately paid carers), whereas 40% (usually user spouses) had not completed secondary education. Six of the eleven carers combined caring for the user with a paid job, devoting on average 23 hours per week to care-giving.

## 3.2  What seems to work?

**Improvement project components**
**Multidimensional and interdisciplinary comprehensive assessment of needs**, to fully understand user (and carer) needs, using a case conference format were undertaken for all twenty users recruited in iterations 1 and 2 of the improvement project. A tailored set of validated instruments was used to explore different health and social needs. Case conferences always comprised the primary care nurse and general practitioner, a social worker from local social services or from the primary health care team, a social worker specialised in geriatric care, a geriatrician and the 1-2 other most relevant health specialists (most commonly internists or nephrologists). Professionals considered that the case conference format increased their understanding of the user situation as a whole, allowed advocating for user and carer preferences and needs when discussing care options with the multi-disciplinary team, and therefore facilitated proposing a more integrated and better **coordinated** combination of resources, increasing the **person-centredness** of their service.

*"The difference in those cases has been that I've been able to say to them "I will meet with the nephrologist, with the ones [specialists] from the hospital, I'll be your wishes advocate, I mean we'll discuss about this and that, tell me what you want me to say, right?" And of course, in fact, we explored this already, but to tell them [the users] clearly that [we want] their opinion, [we want to know] what they want, that it would be an opinion that will be heard in the [case conference] meeting through us, they liked it."* (Professional51)

In addition, the fact that the wider group of care professionals all participated in the case conference enhanced a feeling of co-responsibility for the care proposed and implemented to users.

*"What the [improvement] project brought along is a responsibility of everyone; I mean, from the moment you have done a well-performed case conference for an ill person, there is no longer the attitude of "this patient is mine or yours"; you become co-responsible of what happens to that person because you have participated in the decisions, and therefore, what happens, if you are dealing front line or second line doesn't matter, because you are co-responsible of what happens, because you have participated."* (Manager1)

**PIIC Plus Individualised integrated care plans** were produced and validated with twenty participating users (and carers). The care plans reflect user goals, and generally give informal carers and users active roles within their own possibilities and according to their own preferences. The resulting care plans specify which professionals have been involved in the care planning process and who will be in charge of each action to be undertaken, facilitating follow up and coordination between care team members. The most common type of actions were those related to improving monitoring and control of the clinical condition of users, tailoring it through an individualised combination of primary and specialist consultations/check-ups, enabling living at home with stabilised conditions. The second group of actions were related to enhancing **self-management** of health and reducing safety risks at home, including extensive advice provided to the user and / or carer in their home setting on **safety**, maintaining independence and medication adherence. The third most common type of actions were those increasing support at home for daily basic or instrumental activities when needed.

The fact that a **standard comprehensive tool and working method** for the new care planning process had been **co-designed by professionals** implementing the improvement project enhanced **prevention-orientation and safety**, as it facilitated systematic medication reviews, identification of risks (economic difficulties, carer burnout, architectonic barriers at home, etc.), and routine advice on maintaining independence, promoting healthier habits.

M: *"It forces...I mean, the method makes you go over a series of risks that are very common and you have to revise them."*
I: *"So, it has come a bit more systematic, has it?"*
M: *"Of course. This method obliges you, obliges… The method itself of the case conference and elaboration of a therapeutic plan forces you to go over a series of aspects that are relevant."* (Manager1)

**Joint interviews between professionals, users and carers in their home environments to validate care plans** were undertaken for all participants in iterations 1 and 2. Professionals considered these visits enhanced identification of risks, in-depth understanding of user needs and preferences, and in turn improved the quality of the advice they provided to users, as it was based on the user's real home environment, and could be also provided to informal or privately paid carers if the user had difficulties understanding their recommendations. Being visited at home by the care team during the care plan elaboration also increased user's perception of the interest in their situation and level of support, also allowing a better visibility of the care team.

*"I think it is important, one, to see them [team of professionals; GP, nurse, social worker] together because you also see the way they talk to each other. Someone who works in a team, or that is a team, when speaking to their people, has another way of speaking than when they speak to someone they don't deal with. I, the perception I had, was that these people talk, and they see each other, and they are used to communicating with each other."* (Carer8)

Osona's improvement project also provided **training for professionals on the person-centred approach and shared decision making**, as well as the specifics of the new PIIC Plus document and case conferencing format. Although fifty professionals attended a training session in the first month of the implementation period, and a summary guidance document was circulated as a reminder at the beginning of iteration 2, professionals considered the extent and content of this training did not meet their needs. In particular concerning interviewing and communication techniques that would have facilitated discussions with users, especially on delicate matters, in turn enhancing their involvement in decisions.

*"There are some communication skills, for instance that we might not have acquired that well… And we are talking about people with whom we have to make [shared] decisions and… and sometimes you lack the communication skills, and besides they are not used to what we asked them about: wishes, preferences, which values do they have… those things.. I do believe we did that but not in such a way … following protocols like now, we ask them, we consider it, and we try to represent them [at the case conference] like "what would you like us to talk about?" But sometimes, it depends how you explain it, there are patients that either we don't know how to bring up the subject, or it is not the moment to do so…"* (Professional10)

*"Specific specific training hasn't been done."* (Professional38)

*"And I would say we have learnt by doing."* (Professional44)

An added difficulty was the perceived learning curb of the case conferencing approach. Nurses in particular stressed that elaborating a PIIC, or a PIIC Plus, was not an easy process, but rather required time and expertise. However, the improvement project gave professionals the opportunity to accumulate necessary experience in this new method, learning by doing.

*"And concerning specific training for professionals, I think that those who have participated [in case conferences] have learnt a lot by doing….I mean, I think that those who have repeated in several case conferences have learnt a lot as ongoing training, because you can only learn this by doing it… In other words, they can explain to you one day… four things, but really there isn't an instruction manual or anything suitable… What is important is that when it is done there is someone supervising the method, to participate and learn by doing."* (Manager1)

### Results in terms of person-centredness

Users are generally satisfied with the care and treatment received from Osona care team, considering it is **person-centred**. Baseline and follow up data of users replying both measures indicates that although a higher perceived control of health care is not detected (according to the PCHC), user perception of the level of person-centredness and coordination of care has increased, from a general P3CEQ score of 15.07 to 19.5 (of a maximum 30 points).

A core element of person-centred care is the **way professionals care for people**. Users and carers in Osona generally consider that care professionals treat them with kindness and respect, listening to them, giving them enough time and being empathetic, treating them as a whole person rather than an illness. Bonds of trust exist between users, professionals and carers, and this is key for users and carers.

I: *"So you're satisfied with the way she treats you, respects you, .. the sensitivity…?"* U and C: *"Very much."*
I: *"With respect, sensitivity..?"*
C: *"[Name NURSE]….is…I don't know which score to give, how high can it be? If 12, 12…"*
U: *"Or a 15, I promise you."*
C: *"No, no, no…the maximum. Because [Name NURSE]. She's awesome…"* (User17 and Carer17 in dyad interview).

*"I believe they dedicate [to me] enough time. [Name NURSE] and mainly the nurses, they care for you… they do it very well. They treat me, dress [wounds]… they do whatever they have to do. Very well. I am very pleased. And [name GP] too. She does not come so often because… of course… she does not need to come so often because she already knows what I have, and if not, the nurse informs her how things are going."* (User10)

*"I trust them [third sector paid carers] completely, and with [name paid carer], who stays at midday, I have to trust her completely, because if not I would not leave her with my [user], 3-4 hours alone with him/her."* (Carer8)

In this sense, expertise in geriatric care of the team carrying out the care planning process facilitates understanding that, for older persons with complex social and health needs, following advice on healthy habits or safety may not always be possible; that not all users feel confident or capable of managing their own health; that adapting to complications may not be easy; that users may be reluctant to ask for or accept professional or informal care; and that decisions to be made on care options are not easy for all users or may not coincide with carer preferences. The PCHC survey results reflect these difficulties. Therefore, exploring future scenarios in case more complex care is needed may have been attempted in order to identify preferences, but not fully built into care plans if the user was not prepared to discuss this.

I: *"Given the case your situation gets worse, have you discussed what would you do…or how would you organise it?"*
C: *"I can't talk about this with [USER]… You've already seen he/she doesn't want to talk about it."* (Carer17)

Although users are generally satisfied with the way they are treated by care teams, some report occasional negative experiences, referring to specific events with professionals who are usually not part of their primary care team.

*"I only found one…I have only found one at [Type specialist health care]… That one was definitely…was totally insensitive and just did her own thing. It is the only one [professional] that I have found that was …"* (User10)

Carers consider care teams have helped them to adapt to their caring role with information, rapid access to the care team (at home, in care centres, by telephone and / or by email), and recommendations on looking after their own self that are expressed as important to avoid feeling guilty when taking time out.

C: *"…but when a health professional says "No, no, devote time to yourself as then you will feel better when you are with [USER]", you believe it more, and you don't feel so bad. "Because at the beginning, if nobody tells you this, you think "Damn! Here I am sat on a bench doing nothing when I could be at home…" You say "Ah, ok! If the professional says so, then I am doing the right thing."* (Carer8)

However, carers still express lack of practical support, since they are not offered training on providing care and may only have their needs assessed at a certain time-point, but not on an ongoing basis nor adapting to the changing situation of the user. This was not a main aim of the improvement project, but has limited its impact, as it undermines **safety and prevention**.

*I: "Have you been offered any training in practical aspects of being a carer?"*

*C: "No. What I know about looking after [USER] I learnt at [Name Hospital] because every night I was there asking nurses "How do you do this? What is that for?" and so on. In the end I knew that sooner or later the nurses of [Name Hospital] wouldn't be there. Because [Name Hospital] at the beginning seemed to be the hardest part, but now, in perspective, it was the easiest." (Carer8)*

*"It was only that day [assessment visit from professionals] and that test [carer scale]. But know I think it would be important, hey, to keep an eye out for the carers because… it is a continuous exhaustion. If you do not learn how to regenerate yourself it is very hard for you to be caring for a person well." (Carer8).*

A second pillar of person-centred care is the level of **user and carer involvement in decisions**. Users in Osona do not have access to the care plan document (i.e. a printed copy), and have not always done care plan validation visits with at least one social and one health professional, despite this was the agreed standard format to be applied by teams implementing the improvement project. This appears to diminish user and carer understanding of the care planning process or outcomes. In addition, the complexity of the care team from the user perspective -multiple institutions and professionals involved, unclear distribution of roles between professionals with similar professional profiles (e.g. users can interact with up to three different social workers in Osona)- can also be overwhelming or generate mistrust.

*I: "If I said to you, let's see if you remember something about… If I said whether you talked about something we call care plan, does it ring a bell to you?"*

*U: "A plan about… is in order to see where I would rather want to be [home/care home] or how I would like to be cared..?… To the [social worker] I remember I answered, "well, here at home as long as I am able to", but if a day I no longer…""*

*C: "Now I remember! A [social] worker came. It is since a lot of people came…"*

*I: "Sure… And did you talk about goals or things you would do, like "look, Mrs [name of user], we will do this?"*

*U: "No, this I don't remember." (User23 and Carer23)*

Users have mixed views on the extent to which they have been involved in decisions on care options, sometimes feeling decisions have been made for them, or that information is discussed with their close ones rather than with them (lack of a user-first approach). The shared decision-making approach may have worked with users who were cognitively capable and willing to discuss and receive new care options, and / or when users were happy with delegating care decisions to informal carers. However, it has proved challenging for certain user profiles, such as older couples who mutually care for each other, who may have different preferences on care options or difficulties verbalising their views in a joint discussion (as to not generate a conflict, because culturally they do not want to complain and are not familiar with a participatory approach,

etc.). Nevertheless, users and carers in Osona generally recall discussing what was more important for their health and wellbeing with care teams and perceive that the combination of resources has been designed taking into account user needs and preferences.

*I: "Have you talked about or agreed a care plan?"*

*C: "Yes. With the general practitioner yes. We spoke that, well, that the lifestyle that [User] follows is the one he/she should. It is now tranquillity… In the moment when something happens we should go to emergencies and from there to [Name Hospital] and from [Name Hospital] back here, and so on. This is what…it is keep maintaining… And this is fine with me!" (Carer9)*

When users have wanted care teams to discuss care options with close persons caring for them, they are happy with the extent to which professionals have involved them. The number of users perceiving this was so increased from 7 to 11 (out of 14 users responding both baseline and follow up P3CEQ) at follow up. Therefore, it would seem that the care team has improved their capacity of checking who the user would prefer to be involved in decisions on care options and then bringing them into the conversation, being aware that a family-first approach may not always be the preferred option.

### Results in terms of coordination

The improvement project would appear to have facilitated **accessible and coordinated care for users**. Osona initiative deploys home health care visits for older persons with reduced mobility and/or who live in rural areas with limited public transport. On twelve weeks follow up from validating PIIC Plus care plans, on average each user was receiving 1.7 new health-related resources (i.e. home visits by GP or nurse, periodic monitoring by specialists) and 1.3 new social resources (i.e. house-keeping, personal assistance). Users are provided written information to track their appointments, clear indications of which professional to contact when and how (also in case of emergency), and advice on medication administration. According to the PCHC, they consider tracking appointments, dealing with medication, knowing when to call on professional care and reaching this care as easy, also counting on an emergency plan.

Users and carers do not have to repeat information when visiting different health care institutions thanks to rapid access to electronic health records, and have an increased perception that different professionals communicate amongst themselves. Comparing follow up to baseline (for users replying both measures) five more users (35.7%) considered their care was joined up in a way that worked for them after the PIIC Plus process; a total of twelve users (out of the fourteen replying at both measure points).

*"In general… they have always treated us well. But maybe since we are in this project [SUSTAIN] all things have a better flow." (Carer9)*

However, interviews and survey data indicate that users have difficulties finding out which new services or resources could be made available to them, and do not always know where to apply for them, especially for social services. In this sense, several users do not identify someone coordinating their care and some had difficulties understanding the complexity of professionals providing their care.

Continuity of care, and also **person-centredness**, was hindered by certain aspects that were not always directly attributable to the team involved in PIIC Plus. Some users identified a lack of coordination after hospital discharge between care providers; others complained about the long waiting lists for specialist appointments; and some express that the timing of home visits may not always be the best for them (i.e. at lunch time or very early in the morning).

*"I sometimes experience bad coordination of the [Home care provider] with the hospital. After being discharged, sometimes nearly a month goes by before the home aid comes to visit me regularly again. For weeks it is rather a disaster"* (paraphrased open comment to P3CEQ of User7)

U11: *"Well, coordinated yes, but they are slow, honey…"*
I: *"They are slow in coordinating? Explain this to me."*
U11: *"They are slow, slow…when you have an appointment…"*
U12: *Yes because sometimes it takes a while to give you the appointment [visit referrals from specialists]."* (User11 and User12)

In turn, the care provided in the frame of PIIC Plus did not always address emotional wellbeing of users, for instance promoting social relations or community activities, but was somewhat focused on maintaining physical wellbeing and planning future care options in case more complex care is needed. When professionals were fed back the results of the first iteration of the improvement project (in Month 12), they acknowledged this was a shortcoming that could limit self-management of health and affect the clinical condition of users. Professionals partly attributed the lesser presence of activities promoting emotional wellbeing and social relations to the advanced condition some of their users presented, limiting the feasibility of such type of activities. In addition, some users weren't convinced of receiving volunteers for company.

I: *"And have you told the nurse or doctor this?" That maybe you would like to go out or take a walk?"*
U: *"No, I have not."*
I: *"Why not?"*
U: *"Well, no, it isn't a great priority for me anyway. And if… if I don't go with people I know and so, then it wouldn't be worth it, you know?… And sometimes you [referring to the care team] have told me about someone coming to keep me company and to chat a while, but no, I don't…"*
I: *"So they have offered you this possibility, but you have assessed that it isn't…"*
U: *"No, not me, it is not for me."* (User10)

However, care plans in wave 2 included a greater amount of activities promoting social relationships and activities enhancing health ageing, also attributing an active role to more users than in the first iteration. It would appear from these results that the team increased the attention paid to emotional wellbeing and self-management, within user possibilities and preferences.

Despite these limitations in the type of care provided and the extent to which it is coordinated, professionals perceive a higher integration of social and health care: local social services professionals have been more involved in the improvement project, which has been co-designed and implemented, representing both the social and health perspectives.

*"The most outstanding thing is that the elements of health and social integration have worked, it has been very present. The local council social workers have been very committed…because experiences of sharing things with GPs we already have, and sometimes it had worked and sometimes not, but maybe this time the issue of sharing, of trying to, to integrate in the PIIC all the social work side, I think this has been the turning point in comparison to previous experiences."* (Manager1)

However, care professionals have experienced some difficulties in obtaining the validated versions of care plans, in particular those participating in the case conference but not in the validation interview with users and carers.

P28: *"Maybe from what I have done, what I have missed the most was a bit of feedback"*
P10: *"Of course. Because you have not had feedback"*
P45: *"It was a one-time intervention and you do not know what has come of it"*
P28: *"I do not know how the story ended."* (Professionals 28, 10 and 45)

An aspect explaining this is the fact that professionals did not routinely transfer the PIIC Plus documents to the electronic health records shared across health organizations, despite the fact that a PIIC Plus Manual with specific instructions on this data transfer was written and shared among professionals implementing the improvement project. This was rather left as a pending aspect, hindering the follow up of specialist health care professionals once care plans had been validated by primary care team members with users and carers.

*"We need a social and health really shared record…we are moving in this direction, but it is still…"* (Professional10)

*"Yes, it is a bit like…we have talked about how to do this, how we send this, who keeps a copy and so…it is an… an add on aspect, so to say."* (Professional38)

### Results in terms of efficiency (costs and potential benefit)

Concerning **efficiency**, this was not a main aim of Osona's improvement project, and steering group members either expected that in classical terms they would not increase

efficiency, or considered that this was not one of the most relevant criteria to use when assessing this person-centred care work method.

*"But, efficient…actually, maybe we improved some results or aspects, but we invested more people to achieve it. So I will say it is not efficient."* (Professional51)

*"I think that in the objective of person-centred care, efficiency should be an add-on, because in the end what we are working for is so that the quality of life of people…"* (Manager1)

Data concerning staff hours invested in the improvement project serves as a strong measure of the **cost** of the improvement project, since no additional funding, equipment or staff was allocated to PIIC Plus. The care planning process, from informed consent to storing the validated version of the care plan, which could range between one to three months, took an average of 13.8 hours per user, with a greater time investment of nurses, followed by social workers, general practitioners, and finally health specialists.

Site specific data was collected in order to have a first indication on the **possible impact or benefit** of the new approach on the service provision (see Annex 10.3 for further details). Data on the use of primary care services of the twenty Osona participants shows that the number of unforeseen consultations (either with a GP, a primary care nurse, a primary health care social worker or a local council social worker) diminishes 45.5% (-15 consultations) comparing the twelve weeks before and after validating a care plan. It would appear that users have had less destabilizations, accidents, crises etc. once the care plan is in place: from having roughly one health complication every six weeks to having one every twelve weeks. Further analysis and data, with longer follow up periods and a greater sample, is needed to confirm or refute this preliminary finding. If held true, it would represent a significant gain from the user perspective. Data also indicates a possible redistribution effect of the use of services, since, on one side unforeseen consultations drop for GPs, primary care nurses and primary care emergencies, but on the other side, total consultations (programmed or unexpected) with social workers increase 33.3% in the follow up period (from 12 to 16 consultations).

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

**Project design (micro level) facilitators**
**Clear and agreed objectives, roles, and governance arrangements**. Osona's Steering Group had on board members of the local primary health care centres, intermediate, long-term and acute hospitals, and local social services. Professionals working on the front line

with older persons with complex health and social needs, specialists providing care at certain moments in time, as well as managers leading chronic care departments or programmes were involved from the onset. Different professional profiles and institutions shared consensus on the need to improve the way they planned and provided integrated care, and believed in the potential benefit of a more person-centred approach. This facilitated the necessary joint effort and prioritization of the improvement project, as belief in the project objectives existed at the institutional level. Institutional as well as professional belief was considered a key facilitator, as institutions supported professionals to develop the project. The fact that equal attention was paid in the PIIC Plus care planning method and document to both health and social sides of user wellbeing facilitated co-ownership of the project by health and social institutions and professionals, as well as a better understanding of the person as a whole.

*"I still think, like most [professionals attending focus group], that it [the improvement project] is really beneficial because when you put in common from all the different dimensions of a user you can see perspectives or views from hospital care, or they [hospital care] can see ours from primary care, and this sometimes helps to sort out and focus the real situation."* (Professional45)

The absence of a hierarchical decision-making process, with managers acting as facilitators, promoting a joint leadership, equal roles and shared decision-making between steering group members, regardless of their formal position, also facilitated agreement with the approach and fine-tuning of tools bearing in mind the reality of day-to-day practice. This enhanced co-ownership and the feasibility of implementing improvement project activities.

**Project method and management**. Osona professionals consider that the SUSTAIN experience provided a metho-dological framework and timeline that increased clarity of objectives, systematization of procedures, better documentation of the work progress, and prioritization in order to meet defined targets within the given timeline. The externally given implementation plan, together with the project management provided by AQuAS researchers, facilitated regular meetings, defining actions to be undertaken and distributing them among team members, meeting of deadlines, as well as identifying and tackling difficulties. It also enhanced methodological rigour and enabled intermediate assessment in order to improving less successful aspects.

*"[Speaking of facilitators] Working with method… The social side can sometimes be very unfocused… So, if you organise it, it becomes less [unfocused]."* (Professional44; social profile)

In addition, strong leadership in each of the three primary care teams, together with the coordinating role of a professional in the intermediate care hospital was highly valued. Whereas the appointed reference person in each primary care centre coordinated their work with other

centres involved and pushed/reminded colleagues in their primary care setting of objectives and deadlines, the intermediate hospital coordinator played a pivotal role between all organisations involved, overcoming agenda incompatibilities to carry out case conferences within the given timeframe (with seldom exceptions). This co-leadership between the intermediate care hospital and the primary care teams was considered a key facilitator in Osona.

*"I think that what was most facilitating were the key persons, the key person in each centre/level/sector. In particular, well the nurses that had this overall coordinating role. Because otherwise it is such a broad theme, isn't it? I think…, if it wasn´t for this person that pushes, that knows, that has the view of what we are doing and what's next and so forth…[without this leading role] it is not feasible."* (Professional38)

**Working environment (meso level) facilitators**
**Supportive working environment, culture and team attitudes**. Despite the comparatively large number of professionals involved in Osona's improvement project (in comparison to other SUSTAIN sites), who belong to an array of different institutions, the team climate inventory scored 4.04 out of 5, indicating a positive environment for collaborative work, innovation and task orientation.

Agreement with objectives and worth of these objectives for their institution were the aspects rating highest both at baseline and at follow up, together with the belief that professionals were making real attempts to share information. Therefore, there was a supportive work culture among professionals from different institutions towards the person-centred approach, which they perceived as more attainable at the end of the implementation period. Team members mutually recognised and respected each other, understanding that sharing different perspectives, listening to each other and working together could improve the care they provide. A key factor stressed by professionals and managers was the level of commitment, the skills and attitudes of the staff involved, enhancing the exchange, innovation and task orientation needed to ensure the success of the improvement project.

*"Key factors have been the previous culture and the people who have got involved in the project, as they have entered in the project… Wow! The own interest that it has generated for them! For instance, the team of [PHCC] that hadn't been very active previously, as soon as they got involved, goodness me! They have considered it was important and wanted to be doing it. […] The teams that have become more involved, they themselves have been a facilitator."* (Manager1)

Professionals were also capable of devoting time and effort to the improvement project, which had to be combined with their usual workloads, thanks to the continuous support of local service managers throughout the implementation period.

**Accumulated expertise and previous collaborative experience**. Osona initiative members and institutions have consolidated experience in dealing with users presenting chronic conditions. Some professionals are especially trained in geriatric care, others hold positions in Vic University School for Health Sciences. This gives them an advantageous position to lead and innovate in this field, both as pioneers in the Catalan Health System, and also participating in international networks on integrated care. In addition, institutions and professionals involved in the improvement project had extensive collaborative experience in order to improve care integration for this target group, so professionals were familiar with the people, work culture and procedures of the different institutions involved. This helped create a common understanding of how to move forward, a shared acknowledge-ment of the relevance of working in a person-centred way, smoother inter-institutional collaboration and distribution of roles.

P51: *"I think there is a factor that…there is already an intention of working centred on the person…"*
P38: *"A previous intention."*
P51: *"That we have been trying to do for years. Therefore, certain things have not come as completely new to them [the professionals]."* (Professionals51 and 38)

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

**Project design (micro level) barriers**
An aspect perceived by professionals and managers as hindering the improvement project was the **different level of engagement of institutions and professionals** in the improvement project. On one hand, professionals who were executing the project, but had not been in the steering group and participated in discussions and decisions, e.g. most specialist health care professionals) were less familiar with the project, the method and may not consider it as relevant as the more involved steering group members. This was reflected in reduced agenda availability hindering the possibilities of doing joint assessments and joint visits with users at home to validate care plans.

*"[Enquired about top barriers] The difficulty to find a common agenda, schedule… Coordination. The difficulty to find room and time to meet."* (Professional38)

On the other, the difficulties encountered when trying to involve certain profiles in case conferences made steering group members wonder to which extent all involved institutions were effectively giving this new approach priority. The PIIC Plus approach was disruptive with previous working routines and roles, and may have not always been well accepted.

*"I would like to attempt for even more commitment from the institutions. I mean, there has been a lot of commitment of the people who have…the reference persons, who, if they have come, it is because their institution has allowed them to… But to have made the improvement project live a bit more in the institutions, because it is very important that institutions…I mean, without professionals there will not be a change, but without institutions, neither."* (Manager1)

A second barrier hindering the impact of the improvement project was the **lack of involvement of additional working profiles providing care to the users** but not employed (directly) by the institutions participating in the Osona Programme for chronic, advanced and geriatric users. Personal assistants employed by third sector entities, privately paid housekeepers, telecare professionals, additional health specialists, community workers were care 'satellites', thought of more as a resource to provide to users than an active agent that could provide insight in the needs assessment, improve tailoring care options to user preferences, or ensure a better roll out of care plan actions.

*[When discussing shortcomings of Iteration 1 at the intermediate feedback session]. "The difficulty of understanding exactly who does what in the whole of the care that a person receives (due to the amount of institutions/persons involved), combined with the fact that not everybody involved in the user's care are participating in the multidimensional assessment and plan proposal (satellites, informal care-givers, entities that are not part of the Osona Program for Chronic, advanced and Geriatric users), and this may undermine the capability of doing plans that are fine-tuned to the needs and preferences of each user."* (Steering Group Meeting notes 17/11)

### Working environment (meso level) barriers
Despite the joint interest in and co-ownership of the improvement project in Osona, with a work culture favourable to the person-centred approach, professionals expressed that the main barrier hindering the implementation of the improvement project and limiting its outcomes was the **lack of time**. No additional staff were hired or exclusively appointed to the new care planning activity, meaning that fulfilment of objectives depended on the willingness and commitment of professionals, and their capability of making improvement project efforts compatible with other workloads.

*"It stresses you, and sometimes I have three admissions. Lack of time, no one covers you [job duties for attending a project meeting]."* (Professional22)

*"It is the ideal way of working. The problem is that we do not have the environment nor the usual working way allowing us to do it. It means an extra effort, extra hours… coordinating with social services, coordinating with… Of course this requires time. Work schedules need to be made compatible."* (Professional1)

A videoconferencing system saving time of professionals travelling from their usual work premise to the inter-mediate hospital to participate in case conferences, as well as time invested in finding compatible timeslots between the 5-10 professionals invited to attend, was lacking and considered as an option to be explored in the future.

### Structural (macro level) constraints
**The current economic constriction suffered by health and social sectors** which impedes increasing staff and undermines possibilities of innovating and carrying out disruptive change processes was identified by professionals and managers as a key barrier. Such a constriction takes place in a **welfare state that devotes scarce resources to older persons and informal carers** in comparison to European countries. This translates in restricted criteria for accessing services (not taking into account multimorbidity, nor the combination of complex social and health needs), long waiting lists between appointments, tests and results, limited hours of home support (cleaning, personal hygiene), and reliance on informal carers who may receive a public benefit, but not practical support or training. In addition, the public sector covers 'essential' care products, but many health and sanitary products (diapers, lotions, latex gloves, etc.) that improve quality of care have to be paid by the user and cannot always be afforded. This limits the person-centredness of care, as the intensity and quality of care may not always be sufficient to meet user and carer needs.

*"Well, the probe, the globes, all the creams we need for the skin irritation due to diapers… all this it is not covered."* (Carer9)

C: *"What isn't covered are the cleansing sponges, the bed protectors, the latex gloves…"*
I: *"And, are these things important?"*
C: *"For me they are because…First, if you have a paid carer, I don't want the carer to clean, speaking roughly, [USER'S] intimate parts without latex gloves, for instance. For this reason it is important… Then the sponges, we buy those soap-sponges you put under water and produce foam. They use one and throw it… To use and throw because hygienically it is easier than the one you need to clean every single day… If we sum it all, sponges, this, that, it sums up to a bit more than, a bit more than what [USER] receives [referring to pension]."* (Carer8)

The traditional **separation between health and social services** (different ministries with different budgets), together with their different original nature (universal health; social services only for more deprived or vulnerable collectives), implies fragmented non-person-centred care. Multiple institutions are involved, working under separate decision-makers, political agendas and budgets. This hinders further developments of a regional-level integrated care approach. The lack of an integrated IT system shared between all care team members (social sector and health sector) impedes quick storing, sharing and updating of care plans. The stigma of social services in comparison to long-time established universal health service translates into a lack of knowledge of local social services available to 65+ persons since 2007. In this sense, the **uncertain political**

**context** in Catalonia throughout the improvement project affected the mood and energy level of professionals working in a local change process, who were unaware if their local efforts would be aligned with future Catalan-level policy.

*"The political-legal framework is very unsettled."*
*(Professional38, with a general agreement*
*of focus group participants)*

*I:* *"Is this another factor, the framework, so to say,*
*of government or country-level uncertainty?"*
*M:* *"This [political and legal framework] does not facilitate*
*anything. Because of course, now the government, the*
*health system, to get out of the place where it is, needs*
*to innovate. And to innovate you have to be brave and*
*take on challenges. Therefore, the [Catalan] Ministry*
*of Health has a series of very important problems and*
*needs to be brave because it has many challenges. I mean*
*that this will clearly influence the implementation of*
*this kind of projects."* (Manager1)

Finally, the shared decision making approach with this target group may not always work, particularly for **cognitive, cultural-behavioural reasons**, for instance, loss of memory, trusting that 'the doctor knows best', low health literacy, difficulties taking up an active role as not used to expressing preferences or participating in decisions. This can be partly explained by the historical context defining the life trajectory of persons born around the Spanish Civil War and becoming adults in the frame of a dictatorship. These difficulties should be borne in mind when designing interventions for this particular cohort. Professionals considered they **need more training in order to improve their communication and shared-decision making skills** with the target users, as communication issues were identified as a key barrier hindering the improvement project.

# 4.  MAIN LESSONS LEARNED FROM OSONA

## 4.1  Working towards integrated care improvements that could have impact

A large number of institutions (primary care units, four local governments providing social services, and several hospitals) were involved in Osona's improvement project, in comparison to other SUSTAIN experiences. This was not a hindering factor, since, through years of collaboration, institutions and professionals have built a common understanding that the coordination of the care each institution provides is key, both to optimise their resources, and to provide a more person-centred care for 65+ users living at home with complex social and health needs. Therefore, working together and combining their efforts under a **leadership shared between primary and specialised care** (operationalised in the frame of SUSTAIN through the Steering Group with representatives of all institutions and professional profiles) is perceived as a win-win, and thus worthwhile, situation. This facilitates prioritization of all efforts to strengthen coordination and establish common working procedures.

The **case conference** was also perceived as a strength of Osona's improvement project. All relevant care professionals participate in the assessment and co-decide which should be the best care options to propose to the user, enhancing commitment among primary and specialised care staff who feel co-ownership of the project and co-responsibility for its results. It has proved to be a platform where professionals can represent and express user's wishes, expectations and needs to the rest of the health and social team involved in their care.

The **staff commitment** towards the person-centred approach and **expertise** in geriatrics both in primary and intermediate care has also been key for the success of the improvement project. This has facilitated consolidating the

case conference and care planning tool PIIC Plus as a way to optimise and personalize the care provided to this target group, also discussing and personalising future care options with users when they are prepared to do so.

> *"Managing uncertainty is our daily bread, so it does not demotivate us when care plans become obsolete or require constant updates to adapt to the changing situation of the older users."* (Professional45)

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

Both Osona and Sabadell improvement projects share a common set of features that have proved to facilitate the implementation of integrated care, which could be transferred to other initiatives providing care for 65+ users with complex social and health needs.

First, when setting up an improvement project, the **governance style** is key. All key institutions and professional profiles should be invited to participate in the governing board, so that they can agree on objectives and actions to be undertaken, creating a common understanding of what needs to be improved and how this could be best addressed. Managers adopting a facilitating and equal role to front line professionals also favours the feasibility of implementing solutions, as professionals co-own the project and can fine-tune it taking into account the reality of their daily practice.

Selecting professionals that were both motivated by the person-centred approach and best prepared to carry out shared-decision making processes with the target group was a recommendation for initial phases of implementation. Ensuring that the discussions, decisions and tools to be put

in place paid **equal attention to both the health and social perspective** is also crucial for the success of integrated care, as this enables **cross-sector ownership** of the approach, and a comprehensive understanding of user wellbeing.

Another transferable aspect of the two Catalan SUSTAIN improvement projects was the strong **project implementation plan and evaluation strategy**. Methodological and management support (like they had from SUSTAIN methodology and AQuAS researchers acting as external project managers), as well as an evaluation of the improvement project results facilitated attaining deadlines and objectives, as well as tackling difficulties as they were encountered. Besides, keeping records and being organized with all project documentation is perceived as a need when working among different professionals from different PHCC and different disciplines.

**Standard multidimensional co-designed working tools** facilitated the integrated approach. The multidimensional needs assessment and care planning tool that was designed and fine-tuned throughout the improvement project, together with the use of a tailored set of validated instruments helped professionals make the process of needs assessment more efficient and more person-centred. It also improved the prevention-orientation of care, as risks were assessed in a more systematic way, routinely providing advice on medication adherence and safety.

Home visits in the frame of the care planning process (both to recruit users, gather baseline assessments using validated assessment tools, explore user preferences and goals, and then to validate care plans) proved to work both for professionals and users, and could be transferred to other integrated care initiatives.

The **case conference method** applied in Osona could also be transferred to other integrated care initiatives. Case conferences bring primary and specialised care professionals together, enabling a necessary exchange between the different levels and sectors involved in the care continuum, in order to co-decide the most appropriate care solution based on the combined perspectives of specialist health professionals, primary care professionals, users and carers.

## 4.3  Overall reflections and keypoints

Osona aimed to overcome limitations of the pre-existing shared individualised care planning tool available to professionals in the Catalan healthcare system (PIIC), and successfully produced and validated a new care planning tool and work method (specific objectives 1, 2 and 3). By doing so, they improved user perception of the level of coordination and utility of the integrated care they provide, as well as provided greater opportunities for users to be involved in decisions on their care. Osona achieved further involvement and co-ownership of local social

services in the integrated person-centred care planning method comparing to previous collaborations between the health and social care providers of the territory. Some 30 professionals of different disciplines and care levels (general practitioners, primary care nurses, intermediate care nurses, social workers, geriatricians, nephrologists, chest physicians, etc.) learnt-by-doing case conferences and PIIC Plus care plans, a method that was disruptive with common roles and task distributions, and not something easily taught in academic settings. Professionals felt this experience helped them see users and carers in a comprehensive manner, better understanding their needs and tailoring care to their preferences. This also increased co-responsibility concerning the care options to be proposed to the user, as care plans were co-decided by all professionals relevant according to the users' clinical and social situation. It facilitated a greater understanding of the relevance of coordinating and jointly working across care providers in order to provide more person-centred solutions and improved quality of life for the user, and not just to achieve better communication or reduce inefficiencies.

However, Osona's specific objectives 4 (transfer of care planning documents to the electronic health records) and 5 (training of professionals on the case conference method and shared care planning approach) were not accomplished to the desired extent. Sharing of care plans through the electronic health records was not routinely undertaken, but rather considered by team members as an extra task beyond the core of the care planning process. In turn, professionals expressed the need to improve their communication skills with users in order to ensure an adequate understanding of the care planning process by older persons and enable effective shared decision making with this user group. Moreover, professionals experienced significant practical difficulties in order to coordinate work schedules to enable the joint assessment and care planning activities, and expressed that the resources devoted to the person-centred coordinated care planning would need increasing and /or reorganizing in order to allow scalability of the approach.

Despite these shortcomings, Osona's experience is promising: the evidence gathered and analysed by SUSTAIN researchers reflects that users and carers are generally satisfied with the level of person-centredness of their care. Moreover, although involvement in the care planning process of older persons with complex social and health needs has sometimes been challenging, data would indicate an increased perception that care is tailored to needs and integrated in a way useful to users. Furthermore, since the end of the formal SUSTAIN implementation period, the case conference format for multidimensional assessment of user needs has been further applied in Osona. Despite the fact that the work method designed in SUSTAIN has not been strictly applied due to time constraints, all institutions involved in the Osona Program for Chronic Complex / Advanced / Geriatric users indicate their willingness and belief in the relevance of undertaking case conferences to provide more integrated person-centred care.

# PART 2
## Sabadell

# 5. SABADELL: CHARACTERISTICS AND IMPROVEMENT PROJECT

## 5.1 General description of the site

Sabadell is a medium sized city of 209.931 (2017) inhabitants, 20 km north from Barcelona (Spain), being the capital and the largest city of the county of Vallès Occidental (Catalonia). Sabadell is a former industrial city that made its name in wool and textile, mainly during the 50s, 60s and early 70s. For that reason, participants in Sabadell's improvement project come from different cultural backgrounds (e.g. language, region) and have significant different life trajectories (e.g. migrants or locals).

Services involved in the SUSTAIN improvement project include three Primary Health Care Centres (PHCC) in north Sabadell (CAP Concòrdia, CAP Ca n'Oriac and CAP Nord) and the local social services provided by Sabadell's city council. Thirteen professionals form the small team, including: two managers (1 health and 1 social sector) and a triad of GP, nurse and social worker for each PHCC. Health professionals are employed by the Catalan Health Institute (Institut Català de la Salut), and social workers are paid by the local authority (City Council). Members of the triad work together at the same PHCC, meaning that social workers employed by the local council are based at the PHCC settings (and not at the local Social Services premises). Health and social care integration has been happening in Sabadell since 1994, but more actively since 2013, when the Catalan-level Chronicity Prevention and Care Programme (PPAC) favoured the establishment of new objectives and an increased coordination. The North Sabadell Social and Health Care Integration Program was launched for 65+ users with complex health and social needs. When a user met criterion for this program, they were signed-up into a shared agenda, so their case could be discussed and assessed by the triad in their monthly coordination meeting.

## 5.2 Rationale for improvement project

During the evaluation phase of the SUSTAIN project, some barriers were identified concerning providing care in a more coordinated and integrated way for 65+ users with complex health and social care needs (see baseline report Arrue et al, 2016 for further details). Some of these barriers were related to a low attendance to the monthly meetings in which both health and social professionals met to coordinate care services. Difficulties for attending these meetings were attributed to different reasons: lack of clear top-down directives that helped professionals to prioritize the meeting over other pressing matters, and the need of having common procedures and tools to perform joint assessments. Both were identified as essential in order to move forward with integrated health and social care provision. Particularly, professionals identified the need of having common instruments and procedures across the three Northern Sabadell Primary Care Centres (PHCC) involved in the SUSTAIN project.

The improvement project designed in the frame of SUSTAIN aimed to improve the collaborative way of working that the teams had already implemented, but for different circumstances had not been able to make sustainable over time. For that, professionals highlighted the need of developing the common instruments and procedures, receiving professional training on shared decision-making and mapping community and social resources. They believed all will help to support a more integrated and coordinated way of working. A major change within the improvement project was to be the direct participation of the user (and carer) in the process of need's assessment and setting goals and activities within a shared validated care plan. For that reason, professionals decided it would be important to provide specific workshop sessions for users to empower them in shared-decision making, self-care and identifying needs and wishes.

## 5.3 Aims and objectives of improvement project

The general aims of the North Sabadell social and health care integration improvement project are:
1. To improve coordination between health and social professionals of the three PHCCs of North Sabadell.
2. To move towards a more person-centred approach in the provision of health and social care services to 65+ people with complex health and social care needs.
3. To improve 65+ user empowerment and capabilities of self-management.

As specific objectives, this improvement project aims at:
1. Formalizing regular meeting spaces of health and social care professionals (the GP, nurse, and social worker triad) to conduct joint assessments of users aged 65+ with complex health and social care needs.
2. Developing a common multidimensional assessment tool to assist the process of joint assessment of 65+ users with complex health and social care needs.
3. Mapping and making available to 65+ users a number of different community, social and health resources that can provide them with relevant experience and knowledge as to boost their self-management of health.
4. Professional training on shared-decision making and person-centredness of care.
5. Training -*Growing Older workshop* sessions- for 65+ users to enhance empowerment and self-management. Topics of the sessions were active and healthy ageing, empowerment, social and personal development and engagement in self-management of health.
6. Consolidating a fine-tuned validated joint assessment procedure and tool —care plan- that would be validated with users and carers.

## 5.4 Explanation of the improvement project

The intervention of Sabadell's improvement project consisted in the following steps: 1. Selection of users according to inclusion/exclusion criteria (65+, living at home, with health and social complex needs, cognitively capable); 2. Recruitment of participants (users and carers), explaining the project and signing informed consent. Invitation to the *Growing Older workshop* sessions; 3. Joint assessment of the user by health and social care professionals using the common tool developed for this purpose, and initial draft of an individualised integrated care plan. 4. Users attendance to *Growing Older workshop* sessions; 5. Individualized joint meeting between health and social care professionals and the user (and carers) to co-design and validate the care plan. 6. Follow-up assessment of users at months 1, 6 and 12. The improvement project flowchart included in annex 10.2 helps to further illustrate this stepped approach.

It is worth bearing in mind that users' general education level is basic primary school or none, and their socio-economic status is that of low-medium income. Triads in each of the three PHCCs targeted to select one user each for the pilot experience, and then a range of three-five users in both iterations of the improvement project (meaning a total target of 18-30 participants). Identification and selection of users happened both through pre-existing registers (e.g. health records), and by means of day-to-day consultations.

The domain of person-centredness was approached in this improvement project since user's needs were jointly assessed by health and social care professionals and, for the first time, users (and carers) were invited to participate in a joint meeting with professionals to express their needs and wishes, and validate their tailored and individualized care plan. The domains of prevention-orientation and safety were approached by providing advice on medication adherence, healthy habits and safety. By developing and using a common tool —care plan- for performing joint assessments from both social and health care teams, duplication of scales and tests were avoided, helping to make the process of users' needs assessment more efficient.

# 6.    FINDINGS OF THE IMPROVEMENT INITIATIVE IN SABADELL

## 6.1  Introduction

Sabadell's improvement project was undertaken between October 2016 (month 1) and March 2018 (month 18), following the common phases for all SUSTAIN sites, and as designed in the study protocol approved by the relevant local ethics committee. Three users were recruited in the frame of the pilot (one per PHCC), which focused on testing thee co-designed assessment tool. The improvement project was then scaled up to approximately 12 users in the two consecutive six-month iterations. The Steering group was provided feedback on and discussed the pilot and iteration 1 experiences (in March and October 2017, respectively), in order to detect room for improvement and apply changes. Sabadell completed the intervention reaching the targeted number of users set at Consortium level within the given timeframe. Annex 10.3 provides further information on the type, amount and method of data collection.

Twenty-three participants were recruited for Sabadell's improvement project, mainly married women between 75-84 years old. Half of users lived with their spouse, seven lived alone and three lived at home with other family members. Almost all users reported suffering from wearing of the joints of hips or knees and / or having persistent back pain. Half or more of users reported having (alone or in combination) anxiety/panic disorders, hearing problems or heart failure, high blood pressure, weakness in legs, or recurrent urinary tract infections. Users accumulated on average 6.8 medical conditions.

Only seven users had a regular carer identified by the care team and recruited for the research project. Carers were 57% women. Three of them were 75+ year-olds who were spouses taking care of their husbands/wives. The other four were either the son (1) or daughter (3) of the user. The majority of carers had secondary education or less. All were married, half lived with the user and the other half lived nearby. Two combined paid-work and family-care, devoting on average 33.5 hours to care-giving activities per week.

## 6.2  What seems to work?

**Improvement project components**
**Multidimensional and interdisciplinary comprehensive assessment of needs**. A multidisciplinary triad team representing the main primary care profiles (GPs, nurses, social workers) was involved in the new approach, learning by doing through collaborative work. Equal attention paid both to the social and health perspective facilitated a comprehensive assessment of user and carer needs. The use of a tailored set of validated instruments to explore different health and social needs helped professionals make the process of needs assessment more **efficient**, non-overlapping (since assessments were done jointly) and more **person-centred**. It also helped professionals to understand users' (and carers') situation as a whole and identify their preferences concerning care options.

> *"Getting to know the patient in the social context. And to listen more to the patient: their doubts and expectations, which… sometimes we forget what the patient wants and we are thinking for them."* (Professional9)

Identifying risks (home hazards, health situation, economic difficulties, carer burnout, etc.) and anticipating future care scenarios helped to provide a more **prevention-orientated** care, therefore, enabling professionals to provide tailored advice on medication adherence, safety, independence, healthy habits and social relationships. These advices also helped users to acknowledge, understand and cope with their health limitations, enhancing their wellbeing. Professionals provided suitable equipment (when needed) to enable users maintaining independence and **safety** at home, and checked emergency plans were in place and operative.

**Co-designed working method and standard procedures** for needs assessment and care planning, that is, **formalizing the integrated individualised care plan document** as a tool and as a process, facilitated collaboration among professionals and coordination towards the user.

Fine-tuning tools (assessment and care plan document, known to by Sabadell professionals as *QRD i Pla de treball[1]*) based on the pilot test and iteration 1 experiences aimed to ensure that all relevant aspects could be easily included without compromising usability. Care plan shared-decision process helped to set goals and activities, and corresponding roles and responsibilities of the care team.

> *"Well, there are two aspects. It is not just going to their home. It is that I believe that the person-centred aspect is important [to do it] at his/her home, and we have experienced this as a very satisfying element, but I understand person-centred is when you ask to the person: "What do you want to do with all this?"* (Professional6)

In this respect, allocating (more) time and space for triad inter-professional meetings to jointly assess and draft users tailored care plans, was identified by professionals as a 2nd key important lesson learned that helped collaborative work and enhanced **coordination** among professionals.

> *"I think that from all of these goals [they have the summary of goals in a screen they can see], if I have to answer this [goals achievement], I think that there are some that have been achieved in both waves, right? And of course, it has been very beneficial to really improve the coordination among us."* (Professional6)

> *"It has facilitated because in a way the coordination has been institutionalized. Otherwise you did the same or, or not, you tried. If I only look at the coordination, not to everything that SUSTAIN implies, everything that it implies, the plan... is a way to formalize the coordination."* (Professional6)

Keeping records, organising project documentation, and sharing the care plan document facilitated **coordination** among professionals and follow-up and monitoring of users' situation and needs. In addition, the fact that the care plan document itself distinguishes between user and carer goals on one hand, and professional assessment and proposed goals on the other, before specifying which are the agreed goals and actions, is a way to ensure the participatory approach and reflect the shared-decision making process between the care team, users and carers. Care plan actions are assigned to professionals, enhancing co-responsibility and follow up, whereas activities enhancing user's self-management of health and well-being are built into 72.7% of care plans, promoting an active role of users and carers.

A **map of community resources** for 65+ persons was produced and made available to the primary care triad, but was not backed up with staff from the community resources whom they could link to and send users in order to find further information and enrol in specific courses or activities. This hindered the promotion of an active user who was more engaged in community activities, and caused some disappointment among Sabadell pro-fessionals, who were particularly motivated to improve emotional and relational wellbeing as well as health conditions. Professionals felt the lack of **coordination** with the community services hindered continuity of the defined care plan activities.

> *"..Because the idea was also to link them [users] to the territory. So, not having the mapping.. the map of community resources available... Where, when, what they do and what time, this is the part that has been weaker. So, [concerning] our coordination of what we do and how we do it and all of this, yes [was achieved]. But then... linking it to some service or a resource or activity... Well, I think this part is weaker [not achieved], because well, there has been no mapping ..."* (Professional2)

> *"[Speaking of barriers] That we really could have had the figure of a person who, once we had finished this phase, that would be in charge of supervising that activity or with the resource that we have defined."* (Professional6)

The **home joint meeting of the primary care triad** with users and carers enhanced professional in-depth understanding of user needs and preferences. Professionals agreed on the benefits of a person-centred approach in two ways: health and social professionals identified being able to assess users' needs at their home/context as useful. On one side, visiting users' homes allowed professionals to identify barriers or elements that can hinder users' daily routines-activities, assess safety, etc. On the other side, professionals perceived that users highly valued the possibility of being able to express themselves and all their needs to the team of professionals, to discuss what is important to them and be involved in the definition of the care plan.

> *"Completely agree, and with the added value of doing that [multiprofessional assessment] at their terrain [home] which is very important. It is not the same that the patient comes here [PHCC], we are behind a desk, we look at the computer, we pass on a questionnaire, we do the assessment, but that he [user] really could say: "I am not ok, this is what happens to me..." but really the fact that you go to his context, and you go there, and that you are really there, and that he/she can explain to you: "Look, this is the kitchen, this is the bathroom, I do not have that, this is what happens to me, look, there are stairs for getting into the house...", I believe that this is an important added value, we would say, and they ... I think they have perceived it in a satisfactory, very much, as a plus."* (Professional6)

The home joint meeting worked for the users, as it enabled them to participate in their care plan co-design and validation. Being visited at home by the care team was highly valued for users, which perceived being looked after. Users expressed their gratitude for this new team approach and way of providing care.

> U: *"Very well, very well. I didn't expect the doctor to come to my home, because of course, I hadn't phoned him/her. I was very glad he/she came. It was the first time he/she was here. And very well. They were sat there and there, and me here. The doctor there... and very well. We talked/chat, very pleasant, very well ..."*
> I: *"Was it weird they were here?"*
> U: *"No no, no... Well it was the first time they were here, but no, not weird. They came to talk about what I had done at the community centre... We talked about how*

[1] *QRD stands for Quadre de Recollida de Dades, or data collection chart.*

*I felt, how it went ... No, not weird. The one I didn't expect was the doctor as I said."*
I: *"And you felt, that, was it different from what...?"*
U: *"From how they had treated me before??"*
U: *"Yes..."*
I: *"In what sense?"*
U: *"Well ... at home [mmm] no social worker had ever come, had ever come to worry... I felt proud and thought "well, I'm at a place they take care of me in case I need it one day." (User16)*

**Training was provided to professionals** on shared decision-making and person-centredness, through a four-hour workshop conducted by an expert in clinical psychology and health organizational development in the pilot phase (month 5). Professionals felt reinforced regarding approaching empowerment issues with the users, but considered this workshop was limited, as they would have liked to have gone more in depth, particularly obtaining more guidance on how to communicate with users in the frame of the joint care plan validation visits in order to foster (and not hinder) shared decision making.

## Results in terms of person-centredness

Users in Sabadell are generally satisfied with the care and treatment received from Sabadell care team, considering it is **person-centred**. Baseline and follow up data of users replying both measures indicate that user perception of the level of person-centredness and coordination of care has increased 29.5% from baseline, from a general P3CEQ score of 14.78 to 19.14 (out of a maximum 30 points, N=16).

A first core element of person-centred care is **the way professionals care for the population they attend**. Users and carers in Sabadell generally consider that care professionals treat them with kindness and respect, listening to them, giving them enough time and being empathetic, treating them as a whole person rather than an illness.

I: *"Are you happy with the way they treat you; the patience, with respect, are they kind...?"*
U: *"Yes, yes, yes! It goes without saying." (User17)*

Bonds of trust exist between users, professionals and carers, and this is key for users and carers. Continuity of staff over time enabled good knowledge of the case, and enhanced the relationship and trust with/from users.

*"I leave an hour [to go to the gym] and during this hour I'm very relaxed, because I think this girl [family worker] takes care of him..." (User 19)*

Besides, staff training and awareness on person-centred approach helped to overcome the traditional doctor-patient paternalistic approach. Being transparent and clear with users, using a plain understandable language (no jargon) and listening to users and asking them how they believe professionals can help them, rather than telling them what they need and can have (resources), enhanced the co-design and shared-decision process of the care planning. However, some users have difficulties expressing preferences and others do not feel they have discussed future scenarios.

I: *"And in the case that you should need more complex care or that your health situation gets more complicated...Have you spoken with the professionals about how...to plan?"*
U: *"No"*
I: *"When the time comes?"*
U: *"As it should be." (User19)*

A second element of person-centredness is the extent to which users can manage their own health and wellbeing. Concerning how the improvement project may have improved or enhanced user **empowerment** and self-management of health, professionals considered that the training workshop they attended reinforced to some extent their capacity of approaching empowerment issues with the users. Moreover, the Growing Older workshop provided specifically for the users of Sabadell's improvement project, helped them to feel supported, and enabled them to better express their wishes and preferences, thus, enhancing shared-decision making, care planning co-design jointly with professionals, and self-management. Participants were satisfied with the content and especially the workshop facilitator, who was a local expert in gerontology.

*"Well l realise... [mmm] that training [for users] has been a tool focused on prevention, in.... reinforcing individuals' capacities in order to be able to cope to possible future settings. Hence, in this sense, I think it is a very positive thing, right? I mean, this prevention towards something not specific is very positive." (Manager 2)*

I: *"So, let's say, the fact of doing this workshop in the civic centre... the fact they came here at home, has it helped ...?"*
U: *"Very much, very much. And the workshop, brilliant! Actually yesterday, well, the day before, my hip hurt a lot, I sat there, I did the breathing they taught us and after a while, I thought "they were right, it didn't hurt anymore"." (User16)*

In iteration 1, 50% of users participated in the workshop (at least half plus one of all sessions). In iteration 2 the format and content of the workshop was refined, adapting to user preferences and / or convenience, and the participation increased to 91%. Nevertheless, in both iterations some users met difficulties to attend some or all sessions (schedule, distance, care burdens, etc.).

The reported satisfaction and perceived utility of the Growing Older workshop is in accordance with an observed change in P3CEQ pre-post data of users responding both baseline and follow up (N=16): the number of users feeling "more often than not" or "always" confident in managing their own health and wellbeing increased from 10 to 14 of users. This can be interpreted as a sign of greater user empower-ment. An additional sign of a possible improvement in user's capability of self-managing health is that the number of users considering they could "find information about health or care" and "arrange care, aids or services" with ease increased from 6 to 11 and from 7 to 11 (out of 14 respondents) at follow up in comparison to baseline. A third aspect of person-centred care is the **level user**

**and carer involvement in decisions**. The new care planning approach helped to set goals and activities taking into account user and carer needs and preferences, also defining roles and responsibilities of users and carers (within their possibilities). However, one of the main shortcomings of the improvement project was the lack of understanding of the care planning process by users, with the majority not being aware of the existence of an individualised integrated care plan as such. This result surprised Sabadell professionals in iteration 1's feedback session, and led to piloting an "elderly friendly" printed version of the care plan in iteration 2. This poses the doubt to what extent needs and goals reflected in the improvement plan are fully co-designed and shared among professionals, users and carers. For instance, users and carers might believe (or trust) that 'doctors knows best' so they might experience difficulties taking an active role and expressing preferences or participating in decisions. This could be explained by cognitive capabilities and cultural-behavioural attitudes.

> I: *"Did you feel that you participated on deciding what could be done to help you remain at home better and so...?"*
> U: *"No."*
> I: *"No?"*
> U: *"I believe not, or I don´t remember, well...no."* (User 2)

Nevertheless, comparing follow up to baseline (for users replying both measures) five more users, from 4 to 9 (from 25% to 56%), felt involved in decision-making as much as wanted. In addition, a majority of users (from 9 in baseline to 11 at follow up) felt they had discussed what is most important in managing health and wellbeing with care professionals (P3CEQ pre-post analysis; N=16).

> *"Yes, of course. They asked me what else I might need. I said I would need a lift. But this can't be … It is very hard for me to mop the floor. That is what I need the most. Later on I don't know what I might need…"* (User22).

### Results in terms of coordination

The improvement project has facilitated **accessible and coordinated care for users**. The most common type of actions resulting from agreed care plans were those related to increasing support at home for daily basic or instrumental activities when needed, followed by actions promoting self-management of health and healthy habits (such as participating in community activities like soft gym or memory workshops). The third group of actions were related to improving monitoring and control of the clinical condition of users, with monitoring and specialist consultations tailored to each user. The implementation of some of the agreed care plan activities within a month improved users' sense of being cared for.

> *"Well yes. A bit better since the first day I am seeing it. Seeming as I no longer have to think that I have to mop the floor on Friday…Today the girl [cleaner from local social services activated by the care plan] has mopped them [the rooms] all…I am happy; I was thinking that since I no longer have to do the cleaning on Friday, I am going to visit my sister."* (User22)

Being able to access services easily, providing home care (health and/or social) when needed and fluid communication and relationship between care team and informal carers enhanced **prevention-orientation and coordination**. Shared electronic health records avoided repetition for users and facilitated professional's coordination. Knowing there is a team that can be contacted regarding changes in users' situation, needs or preferences, for enquiring about additional or new services, and to discuss about health-related issues, made users and carers feel supported and looked after.

> *"We have more information. In case we need it, well, maybe we know better [now] what door to knock at, right? But, as I said, as [USER] is now, so far we didn´t need [anything else]."* (Carer 6)

At follow-up, four more people rated positively "extent to which care is joined up" (14 out of 16 respondents), and eight more users rated positively the "extent to which they receive useful information when needed" (13 out of 16). However, the delay or non implementation (for several reasons) of some activities or resources agreed on the care plan at the time when follow up interviews were made (approximately four weeks after validating a care plan), made some users frustrated, generating the perception that nothing changed after the improvement project.

> U: *"Exactly. You came [AQuAS researchers] and them [triad of professionals]."*
> I: *"And you met the social worker…"*
> U: *"But nothing else has changed."*
> I: *"The rest is the same?"*
> U: *"The same."* (User17)

In addition, some users shared negative experiences when asked about coordination. These were often related to waiting time or lack of (sufficient) support.

> I: *"Now, talking when you have to go to hospital for XRays or surgery, and then you come back to your GP. Would you say they [professionals] are coordinated and communicated?"*
> U: *"No, no. I think they make us wait too long, to older people, from visit to visit…[pause], do you understand? So that… my GP visits me and then in order to go to the other doctors [hospital specialist] I need to wait 3 months or 4… I find that terrible."* (User13)

An additional shortcoming was the fact that carer needs may have not been thoroughly assessed in the frame of the care planning process, and support at home for users and carers is not always adapted to the changing health situation over time, for instance during users' crisis when carers might need more support. In this sense, some carers expressed a lack of flexibility from health services premises regarding users' appointments in order to better adjust to carer's work schedules. In addition, carers sometimes had to take hours off work to be able to accompany their older sick relative to medical appointments and tests. Increasing support for and monitoring of carer needs was not a main aim of the improvement project, but failing to do so can hinder **prevention-orientation** of the care planning process.

*"And then, when I have accompanied [USER] in the afternoon, it has either been on my day off, or I have asked for permission to arrive later, or I have changed my day off so I could go with [USER]."* (Carer6)

### Results in terms of efficiency

Although it was not the goal of the project, regarding the service **efficiency**, professionals hesitate what to answer. They held the opinion that the team was more efficient qualitatively, but not quantitatively (looking at numbers of visits by users, etc.). Nevertheless, in general they felt more efficient due to the SUSTAIN experience because they had to open their minds and gained effectiveness in being able to identify user needs and address them, despite the fact that more time was required.

*P4: "I would say that it has been efficient because I have opened my perspective."*
*P9: "…On a quantitative level, I do not know."*
*(Professionals4 and 9)*

Concerning **cost**, the project was developed and performed in the regular settings of the three PHCCs involved, without additional staff. The cost of the project in terms of invested hours was a total of 334 hours, distributed equally among the triad, reflecting the shared responsibility and engagement in the care planning process of the three primary care profiles. In total 14.5 hours were devoted to each user on average, from recruitment to validated care plans, a process that could expand over a three month period (of which approximately one month was devoted to 3-5 weekly Growing older workshop sessions).

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

**Project design (micro level) facilitators**
**Implementation plan and timeslots formally allocated to the triad professionals to carry out the care planning process.** Professionals identified that having a good project design, with clear objectives and actions to be done (calendar, pilot + iterations, feedback points), clear roles and governance arrangements (steering group meetings, leadership) facilitated success in carrying out the improvement project. The coordination among professionals was facilitated by following a clear timeline and planning in advance what to do and when, for instance ensuring agenda compatibility and allocating timeslots for joint meetings, assessing and care planning.

**Project managing:** Having an external figure with authority (AQuAS) to act as a project manager, setting deadlines and priorities, and ensuring methodologic rigour was identified as helping to develop the improvement project as designed in the original implementation plan and achieving objectives.

*"… in this sense I think [mmm] SUSTAIN or AQuAS added methodology. This is an important element. Contributed to share knowledge, in a way you have provided us documents… experiences/practices from other places… you provided us with key people… and also a calendar, right? Continuity.. In this sense, I think it… is very positive. It would not have been possible without it, ok?"* (Manager2)

**Working environment (meso-level) facilitators**
**Team leadership and support from key local managers** of both health and social services, together with a **committed team of professionals** who believe in the person-centred integrated approach and feel co-ownership of the improvement project was a key aspect for implementation success. The presence of champions within the team capable of providing support and leadership to colleagues when needed helped to carry on with duties and actions.

*"I think the steering group has helped, otherwise it wouldn't have happened. The people in the steering group as well, there were people… selected with a special interest/ engagement. And very inspiring, especially regarding issues/ troubles due to lack of human resources. Without these people, it would have died."* (Manager1)

*"Facilitator sure […] I believe we have been very lucky with our steering group. Very lucky with the people that are members of the steering group. I think it has been very important […] Because this group has not been constituted randomly…. I think this group is 'tell me with who you go and I will tell you who you are'. This project cannot move forward… you cannot participate as a steering group member if you do not agree or do not believe [in the project], you name it, right? Therefore, we are not here by a matter of chance. I believe that.. talking about profiles, just as there are patients' profiles, there are professionals' profiles, right?"* (Professional6)

**Team climate and attitude**, that is, supportive team members who mutually recognise and respect each other enhanced exchange, innovation and sharing of workloads. **Shared belief in the benefits of the person-centred approach** (both for their professional performance and for providing solutions tailored to user needs) enhanced collaboration and willingness to learn from other perspectives. Continuous exchange and feedback between implementers to address difficulties, worked as a supporting and motivating factor among professionals. The Team Climate Inventory (TCI) score for Sabadell was already high at baseline, and increased 0.5 points during the project to a follow up score of 4.47 (out if 5). Some of the remarkable increase points were: 'searching for new ways of looking at problems' (growing 0.88; to 4.38); 'building on each other's ideas' (increasing 0.75 points); and the 'we are together' attitude, scoring 4.75 at follow up (an increase of 0.37).

*"I think professionals' dedication has been the main thing, without them, NO [pause]. The other thing, well… the good relationship between them, both social and health professionals, have got on really well and have listened to each other."* (Manager1)

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

**Project design (micro level) barriers**
**Lack of coordination or working collaboratively with additional working profiles** providing care to the users such as personal assistants, housekeepers, telecare professionals, health specialists and community workers, among others. This hinders fine-tuning of the care plans and ensuring its take up. For instance, the specialised professionals (e.g. hospital specialists) are not yet in the picture, not working collaboratively with the primary care teams, not aware of users having a designed care plan and not familiar/applying this particular person-centred approach. This might undermine efforts made in primary health care or local social care services. Moreover, in relation to the first barrier mentioned, the lack of a bond with staff from the community resources for 65+ population limited the effective uptake of activities promoting social relationships and active healthy ageing. This was considered by professionals as the third most important barrier.

*"It was a community thing; a difficulty is [mmm] this division. Health and social care on one side and the community on the other, and we have not built bridges yet…We are still in our consultation premises. We are dependent on the demands of the people that come, and not that connected to the community resources. I mean both the social and the health sector. This difficults this dimension of connecting the user [to the community]; it is an extra effort."* (Manager2)

**Working environment (meso level) barriers**
**Lack of human resources**. The staff participating in the SUSTAIN improvement project had no specific time to devote exclusively to the improvement project and had to do it together with their daily duties, sometimes in extra hours (not paid). Consequently, it leaded sometimes to burdening professionals or they had to ask colleagues to cover them, a fact that may not have always been understood or taken well by work colleagues who were less familiar with the SUSTAIN improvement project. More staff and specific allocated time to devote to the project would enable professionals to work in a better environment, as this was considered the most important hindering factor. Considering that a greater share of care plan activities fell in the social domain, and that each PHCC only had one social professional involved in the new triad care planning approach, a lack of staff in local social services (beyond the social worker of PHCC triad) was considered a factor limiting the implementation and follow up of care plan activities.

*"We had to do it during our working time, therefore it has affected our colleagues. Occasionally we have done it [working on SUSTAIN project] out of our working time, but this was not paid. So, financially nothing…"* (Professionals 2, with 6 and 4 agreeing)

**Structural (macro level) constraints**
**Stigma of social services**. Users of Social Services tend to be stigmatised since traditionally in Spain Social Services focused on collectives at risk of social exclusion or in conflictive situations (e.g. extreme poverty, substance abuse, family violence etc.), and only in the last decade have also provided a charter of services for 65+ population, together with becoming responsible for assessing degrees of dependence. Users and carers generally lack knowledge of the local social services roles and resources that might be available to 65+ persons. The connotations behind being visited by a social worker hindered users and carers' acceptance of the figure of social worker, who were sometimes initially reluctant or hesitating when receiving the social worker visit at home together with their health professionals. In professionals' views, some users might have declined participating in the improvement project due to this. Findings from the project show that some of the users and carers who willingly participated in SUSTAIN improvement project had no clear knowledge or perception of the role of the social worker within the triad of primary care professionals. This triad team is somewhat disruptive with who the population commonly understand as their reference care provider (usually the general practitioner) and therefore challenging to convey.

*"Yes, in this respect [going to social services]; the word may sound a little hard but it is true that it seems like [going to] social services was/is a stigmatization. "I went to social services!" This means [a common connotation] that "I have financial problems, something…". So it is [explaining to users and carers] "No! Look, when there is this [issue], I [social worker] deal with that. Right?". This [project, SUSTAIN] has brought visibility [of social services] and of these more preventive actions that [professional2] mentions."* (Professional6)

**A welfare state with scarce resources for 65+ population** (e.g. that relies on family informal support for 65+ persons, or provides minimum pensions under the minimum wage) hinders access to services or resources that professionals might consider beneficial or that are expressed as a need by users. An example of the scarce resources users have is reflected in the PCHC findings, since the only item scored on average as difficult (1.75 out of 5) was "When I need complex care, coping financially". Not taking into account multi-morbidity or a complex social and health situation in criteria for accessing specific resources, or long waiting lists between appointments-tests-results, are some of the examples users express when asked about how their care could be improved.

*"Because I do not have diabetes, I am not entitled to a podiatrist, but I have back pain and other problems that make it really hard for me to reach down to my feet."* (User4 paraphrase from P3CEQ baseline visit open comment on question *Do you feel treated like a whole person or rather an illness?*)

**Fragmentation and the need of an integrated IT system** shared between all care team members. Health professionals belong to the Department of Health and social professionals to the Department of Work, Social Affairs and Family of the Catalan Government. They have different IT systems. This poses a difficulty when working collaboratively and sharing care plans. In Sabadell improvement project, professionals solved the problem by obtaining informed consent from users in order to do a joint assessment, and by sharing the user care plans by other means, as a provisional solution to be able to carry on with the project (with a low number of users). However, in order to work towards integrated health and social care and make all professionals aware of the user's complete records (health records, social records, care plans, etc.) an integrated IT system is essential.

> *"I mean. Health [sector] has its goals, and go ahead with them… there is times it seems they need the social services, but the social is "another world". It is a very fragmented structure, each City Hall has its competence within the primary health and social care. The Social Services department of the Catalan Government is not focused on primary care…It focuses on homes for the elderly and day centres [specialised social services, which are competence of the regional government] …there is a misfit between who has to mark the policy and who has to mark the play field for professionals, which are the departments [social and health], who don't come to a final agreement. In other words, they don't completely put the energy into considering this [integrated care] as a priority aim…"* (Manager2)

Finally, as found in Osona, **cognitive capabilities and cultural-behavioural attitudes** of the target group hinders the shared decision-making approach. Some of the Sabadell users were between 65-75 years (rather than 75+, as occurred for all Osona users) and may have higher levels of health literacy and self-management. In addition, a specific workshop was provided for Sabadell users to enhance empowerment. However, understanding the new care planning approach and becoming involved in decisions on care sometimes was challenging with users mind set. Sabadell professionals also pointed out the need for additional training on shared-decision making in order to improve their communication with users and carers.

# 7.    MAIN LESSONS LEARNED FROM SABADELL

## 7.1  Working towards integrated care improvements that could have

A first strength of Sabadell's improvement project was that, during the implementation phase, the **triad primary care team** (GP-nurse-social worker) was formalised as the team in charge of doing joint multidimensional assessment of 65+ users with complex social and health needs leading to integrated individualised care plans. Formalization consisted in the fact that the local social and health managers allocated specific time and space for inter-professional coordination and care planning activities to take place. Professionals considered that having time and space for coordination meetings is something 'sacred' that must be respected by all professionals. Formalization of the triad also meant that a cross-sector work force was established to co-design a multidimensional working method and standard procedures for needs assessment and care planning. This enabled co-ownership and equal attention paid to both the social and health dimensions of wellbeing.

Sabadell's improvement project was particularly **concerned about the need to promote emotional wellbeing of users**, understanding that physical and mental health go hand in hand. As a result, actions promoting social relationships and healthy habits (such as participating in community resources for 65+ people) had significant presence in the care plans agreed with Sabadell users.

In turn, Sabadell's Steering Group was particularly aware of the **need to support users in this phase of their life**, improving health literacy and offering practical advice in the form of a support group before inviting them to discuss and agree to care options. Sabadell considered that empowering this particular target group could not be done just by giving the opportunity to decide on care options at a certain moment in time with the care team, but also required increasing user's capabilities of understanding and managing their health situation and care over time.

Both managers and professionals identified that one of the key factors behind Sabadell's improvement project achievements was the **commitment of the group of professionals** involved, combined with their **belief in the person-centred approach**. The fact that professionals in Sabadell were motivated and willing to innovate by working together and learning from each other, enhanced integrated care, since the plans validated with users were based on comprehensive assessments and offered care options tailored to user needs and preferences. The presence of both social and health professionals working front line with users acting as champions facilitated the roll out of the project, as leadership was shared between managers and professionals.

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

Both Osona and Sabadell improvement projects share a common set of features that have proved to facilitate the implementation of integrated care, which could be transferred to other initiatives providing care for 65+ users with complex social and health needs.

First, when setting up an improvement project, the **governance style** is key. All key institutions and

professional profiles should be invited to participate in the governing board, so that they can agree on objectives and actions to be undertaken, creating a common understanding of what needs to be improved and how this could be best addressed. Managers adopting a facilitating and equal role to front line professionals also favours the feasibility of implementing solutions, as professionals co-own the project and can fine-tune it taking into account the reality of their daily practice.

**Selecting professionals** that were both motivated by the person-centred approach and best prepared to carry out shared-decision making processes with the target group was a recommendation for initial phases of implementation.

Ensuring that the discussions, decisions and tools to be put in place paid **equal attention to both the health and social perspective** is also crucial for the success of integrated care, as this enables **cross-sector ownership** of the approach, and a comprehensive understanding of user wellbeing.

Another transferable aspect of the two Catalan SUSTAIN improvement projects was the strong **project implementation plan and evaluation strategy**. Methodological and management support (like they had from SUSTAIN methodology and AQuAS researchers acting as external project managers), as well as an evaluation of the improvement project results  facilitated attaining deadlines and objectives, as well as tackling difficulties as they were encountered. Besides, keeping records and being organized with all project documentation is perceived as a need when working among different professionals from different PHCC and different disciplines.

**Standard multidimensional co-designed working tools** facilitated the integrated approach. The multidimensional needs assessment and care planning tool that was designed and fine-tuned throughout the improvement project, together with the use of a tailored set of validated instruments helped professionals make the process of needs assessment more efficient and more person-centred. It also improved the prevention-orientation of care, as risks were assessed in a more systematic way, routinely providing advice on medication adherence and safety.

Home visits in the frame of the care planning process (both to recruit users, gather baseline assessments using validated assessment tools, explore user preferences and goals, and then to validate care plans) proved to work both for professionals and users, and could be transferred to other integrated care initiatives.

Two final components of the Sabadell improvement project could also be applied in other settings: the **growing older workshop** as a way to enhance understanding and self-managing of health amongst 65+ users, and the **mapping of community resources** for this target group. Despite the fact that a strong link with staff in Sabadell's community resources was not possible in the frame of the implementation period, (the intention of) building bridges with the wider network of care providers could also be beneficial in other contexts.

## 7.3 Overall reflections and keypoints

Health and social care integration has been happening in Sabadell since 1984, but more actively since 2012. The SUSTAIN improvement project -North Sabadell Social and Health Care Integration- helped professionals to achieve a better level of coordination and collaboration between health and social services, improved person-centred care and enhanced user empowerment and self-management of health of a significant number of participants. Moreover, Sabadell's care planning activity became more prevention-oriented, despite the fact that this was not a core aim of the improvement project, as, in addition to the Growing Older workshop offered to users (specific objective 5), advice for users and carers on maintaining independence, safety assessments and safety advice became part of the care planning routine. This in part was achieved through the multidimensional needs assessment and care planning tool that was designed and fine-tuned throughout the improvement project (specific objective 2). Professionals believe the experience has helped them change their mind and work in a person-centred manner, and that the specific training they received (specific objective 4) helped them to do so, but could have gone more in depth, particularly offering more guidance on how to communicate with users favouring shared decision making. Professionals expressed they 'wish they could work in that way always', even that 'it is an ideal way of working', meaning that dedicating more hours to each user in a team way (the GP, nurse and social worker triad) is both necessary for users and rewarding for professionals.

However, both during the SUSTAIN implementation period and beyond, certain difficulties were encountered in Sabadell: preserving the coordination timeslots for the care planning activity (specific objective 1) was not always possible in practice, despite the fact that these meeting spaces had been formally approved by the managerial level; incompatible timetables and short deadlines sometimes meant working extra hours or delegating workloads to other colleagues who might not have always be informed of the reason and only accept to do so reluctantly. In addition, the map of community resources for 65+ persons (specific objective 3) was produced and made available to the primary care triad, but was not backed up with staff from the community resources whom they could link to and send users in order to find further information and enrol in specific courses or activities. This hindered the promotion of an active user who was more engaged in community activities, and caused some disappointment among Sabadell professionals, who were particularly motivated to improve emotional and relational wellbeing as well as health conditions. The improvement project served as proof of concept for providing more person-centred care and empowerment of older persons from primary care settings, but was achieved to a great extent thanks to the commitment and dedication of the team of professionals pushing the project forward. The continuity of this working method remains fragile as it currently depends greatly on the team involved in SUSTAIN, and would need further

support and prioritization, restructuring human resources and professionals' time and workloads. Professionals stressed that the integrated person-centred approach is not just another way of working, but a change of a working culture that they wish could be escalated to other primary care centres and all over Catalonia. In this sense, both local and regional leadership was perceived as key to create a working environment that better supported the integrated care approach.

# PART 3

# 8.   OVERALL (NATIONAL) REFLECTIONS

## 8.1  Introduction

Between autumn 2016 and spring 2018 two Catalan local initiatives implemented improvement projects focused on increasing the level of person-centredness and coordination of the integrated social and health care they provide to 65+ population living at home with complex health and social needs. Osona aimed to improve the pre-existing individualized intervention plans that were shared between primary and secondary health care (PIIC), building in the social perspective through a consolidated work method for joint multidimensional assessments and proposal of current and future care options tailored to user needs and preferences. The adopted format was that of a case conference involving the most case relevant primary health care professionals, health specialists and social services professionals. Sabadell also aimed at improving the coordination of professionals, in this case, primary care general practitioners and nurses with the local council social workers, giving this triad specifically allocated time, as well as a standard method for performing multidimensional needs assessments and drafting integrated care plans. Both initiatives wanted to give users (and carers) greater opportunities to be involved in decisions on their care, Osona perhaps focusing more on stabilising health conditions and discussing future scenarios, while Sabadell paid special attention to enhancing older person's self-management of health and greater engagement in community activities promoting health and wellbeing.

These improvement projects were implemented in an iterative process, first piloting the co-designed work method with a small number of users (3-6), and then scaling up to approximately twelve users in two consecutive waves. Steering groups were provided feedback on and discussed the pilot and iteration 1 experiences, in order to detect room for improvement and apply changes. Both

sites completed the intervention reaching the targeted number of users set at Consortium level within the given timeframe. Parts 1 and 2 of this report summarise the main findings for each of the case studies undertaken, offering insight on how the different SUSTAIN domains (person-centredness, prevention-orientation, safety, efficiency and coordination) may have been enhanced by means of the Catalan improvement projects.

## 8.2  Implications of SUSTAIN for integrated care in Spain (Catalonia)

The SUSTAIN research project provided a window of opportunity for Catalan local initiatives to innovate in the way they collaborate and jointly provide care to older persons with complex health and social needs living at home, especially in a current economic and political context constraining health and social teams. The method and implementation plan fixed at SUSTAIN Consortium level, together with the project management, monitoring and assessment undertaken by AQuAS researchers, served as a frame and driving force that helped prioritize and fulfil care planning activities, amongst usual workloads. According to managers, SUSTAIN's evaluation will serve as an external assessment on whether the improvement projects work, how and why (or why not). Such an account of the benefits of the integrated care approach may be useful for local and regional decision-makers when defining future care models for this population.

In this sense, the SUSTAIN research project has raised the interest of Catalan policy makers from PPAC and PIAISS, who are expectant of the case study findings. Osona and Sabadell's improvement projects have served as proof of concept of how institutions from different sectors and care levels can jointly perform multidimensional assessments of complex health and social needs, providing a tested integrated person-centred care planning method and tools that enhance shared-decision making with users and informal caregivers. The multidimensional person-centred individualized care plan documents produced in Osona and Sabadell are inspiring examples that can be borne in mind when further developing integrated health and social care for older persons in Catalonia. In addition, regional level care providers have also learnt about the SUSTAIN improvement projects and expressed interest in the assessment method and implementation strategy. Nevertheless, an important aspect to acknowledge when exploring the scalability of Osona and Sabadell experiences is the strong belief and interest of the local stakeholders in the person-centred integrated approach, facilitated through years of collaboration between social and health care providers. Such a favourable context has been a strength facilitating the achievement of improvement project objectives, but may not always be found in other local settings.

In turn, some remarks must be made concerning the methodological lessons learned and limitations which should be taken into account when considering the extra-polability of the case study results and scalability of improve-ment project components. First, an essential part of the evidence used in this report depended on the willingness to participate in the project of 65+ users with complex social and health needs and persons caring for them. In most cases this meant receiving AQuAS researchers for (lengthy) interviews and surveys, sharing their views and suggestions for improvement, but sometimes showing signs of fatigue and not being able to complete the surveys. The surveys were given less priority than in-depth interviews in follow-up visits were both techniques were applied, and this has hindered the size of data collected.

The valuable input of users and carers has been useful to assess what was working well or not, but sometimes perceptions could be conditioned by the way users felt (physically or emotionally) at the particular moment they were interviewed. In addition, not all users who were approached by the research team were willing to participate in the research study, but instead reluctant to have a whole team of professionals and persons they are not familiar with (i.e the AQuAS research team) look into their personal circumstances. This selection bias must also be taken into account when interpreting the findings and designing new interventions.

An additional methodological challenge was that of identifying evidence or signs of change that could be considered as partly attributable to the improvement project itself. Multiple factors could explain observed changes in the views or experiences gathered throughout the improvement project, making it hard to establish causal relations between outcomes and improvement project activities. In order to address this, special attention was paid in qualitative interviews on the changes users and professionals perceived to have occurred and how they related these to the new approach they had participated in. A cautious approach was followed when comparing baseline and follow up survey data (see Annex 10.3 for further details). Comparisons between the findings in two sites have not been made, and caution is advised when doing so, since the particularities of each improvement project (user demographics in a small sample size, care providers involved, different timing of follow up period) should be taken into account.

Furthermore, the research techniques applied (lengthy interviews and surveys, on concepts that were rather novel or hard to grasp) implied a selection bias. Persons with cognitive impairment had to be excluded from the improvement project, or could only be included if an informal carer who could also participate complementing the user perspective and providing their own view was available. However, professionals considered that this user profile could potentially benefit most from the new approach.

Finally, it is important to consider the cultural and socio-demographic background of the target population when designing person-centred care. In the case of Osona and Sabadell, the life trajectory of 75+ users (all cases in Osona, and a significant proportion in Sabadell) was marked by the Spanish Civil War, followed by economic hardship and a dictatorship lasting over 30 years. Many migrated from other parts of Spain to Catalonia and had little education opportunities, working since they were teenagers, and afterwards in the case of women, becoming housewives responsible for family duties. This implies complexity in addressing user empowerment, self-management, and co-decision of health and wellbeing care in this specific group, since health literacy may be low, and users are not necessarily familiar with being given a voice, nor feel comfortable expressing their preferences or complaints.

## 8.3  Policy recommendations

Person-centred care means providing users with those resources that most adequately meet their needs and preferences, making the most of available budgets, regardless of which care provider should provide each resource. However, the ideal *continuum of care* clashes with the traditionally fragmented Catalan welfare state, with health services provided universally (funded through general taxes) at the regional level, while basic social services, including home help to 65+ users since 2007, is a local competence, implying a variety of co-payment models (for instance, depending on the political colour of the local council and budget availability), a multitude of care providers, a collection of different information systems, and an array of organizational models. The involvement of basic social services is key in Catalonia for effective

integrated care for 65+ persons living at home, being both the assessors of levels of dependency, and the providers of telecare, cleaning, support with everyday basic activities, etc. This may partially explain why local initiatives such as the Osona and Sabadell sites play such an important role for advancing in the field of integrated care in Catalonia, and how a regional strategy can be created in a bottom-up process, learning from most promising experiences and identifying key elements that could be scaled up to the regional level. Professionals who have undergone the local improvement project experiences perceive the benefits of the integrated care approach both for their own performance and for better addressing user needs, considering it the "ideal way of working". Such a finding alone would support further steps to increase integrated care in Catalonia avoiding institutionalised care in the later periods of life. However, local initiatives currently find difficulties to consolidate or scale up integrated care planning work methods in their own territory. A more supportive environment for integrated care could be achieved, by:

• Institutional leadership, through a Catalan-level strategy for further implementing integrated case and enhancing the scalability of best practices.
• Providing a legal framework enabling social sector professionals and health sector professionals to jointly assess users' multiple needs, when it is considered the user can benefit from an integrated approach. This framework should also define when this latter condition is met, and enable effective channels for users to reject this approach if they do not agree to it.
• Policy makers providing a standard tool for multi-dimensional interdisciplinary needs assessment and care planning, and guidelines concerning how to share this plan across care providers and to monitor or update care plan activities. This tool could be based on Osona's *PIIC Plus* and Sabadell's *QRD i Pla de treball* documents, which already have significant commonalities.
• Facilitating an integrated IT system (or platform) accessible to the multidisciplinary care team members, as to enhance intra- and inter sector- coordination, integrated care planning, monitoring of care plan activities and evaluation of integrated care impact on health and wellbeing outcomes.
• Policy makers and/or service providers offering training for health sector and social sector professionals on the person-centred care and shared decision-making approach, with the aim to increase communication skills, promote active listening, and familiarise professionals with possible work methods for integrated care planning. This training could be provided as life-long-learning, but also become part of the study programmes of nurses, general practitioners, health specialists, social workers or family workers. Such training is particularly relevant when working with 65+ users with complex health and social needs, in order to enhance their understanding and involvement in shared decisions on care.
• Increasing public resources for 65+ persons living at home (more coverage and intensity), in order to prevent health and wellbeing deterioration. This can be achieved through greater support at home for basic and instrumental daily activities; telecare with lower (or no) copayment; by

devoting more resources to home safety assessments, technical adaptions and aids; and promoting community and voluntary sector activities for older persons, such as soft gym, memory courses or Growing older workshops enhancing health literacy and self-management of health. Likewise, greater attention should be paid to informal carers, in the form of practical training, periodic monitoring of burnout risks, support groups, or respite services.
• Supporting research on the global impact on service use of older persons living at home -pre and -post validation of integrated care plans, taking into account the combined use of primary health care, specialist health care and basic social services. Key indicators should be defined and monitored over time (e.g. evolution of unforeseen consultations due to a deterioration of the user's health, accidents, crisis, etc.), identifying potential benefits of the integrated care approach and potential redistribution effects within and/ or across sectors rather than a change in the use of one specific type of services. Such information could enable a system-level cost-effectiveness study, which could serve as a basis when deciding and prioritizing future public expenditure.
• If further research shows a saving effect in the system-level use of resources due to the new person-centred integrated care planning approach, freed-up resources should be reallocated to enhance this care planning capacity, for instance devoting specific staff in local initiatives to the integrated care planning activity. Since the institutional composition, governance arrangements and aim of each local initiative may diverge from one site to another, the work profile and role could be commonly agreed by the local initiative's governing board and the funding institution, in order to best complement and reinforce the pre-existing work team, rather than generating duplicities or conflicting roles. For instance, one site may prefer to hire a project manager in charge of coordinating and monitoring the care planning activity; another may prefer to add expertise in geriatric care; and another may prefer additional social workers who can help older persons better exploit community resources available for them.

## 8.4 Recommendations for service providers

The experiences from Osona and Sabadell, and particularly the reflection process of involved managers and professionals throughout the implementation phase (evaluation feedback and discussion sessions, periodic meetings, in-depth interviews and focus groups) generate the following recommendations for service providers interested in promoting improvements in integrated care initiatives:

• Governance structures between institutions involved in the integrated care improvement should be set up and based on equal rather than hierarchical roles, with managers acting as facilitators but not necessarily core leaders.
• All organizations and staff profiles who will be

implementing the improvement project (both health and social) should be involved in its governance and design, as to achieve agreement with objectives, co-ownership, multidisciplinary perspective and co-responsibility.

- To facilitate co-ownership and enhance the uptake of the new approach, local stakeholders should be mapped and invited to participate in the project governance and design. In particular third sector care providers, voluntary associations or community resources for 65+ population.
- Service providers should adopt a communication strategy to ensure that all co-workers in their service are familiar with the improvement project and understand its level of priority and support from the managerial level.
- Service providers should select professionals who are both motivated and capable of strong leadership when needed to steer the improvement project, as these can act as "champions" driving the project forward.
- The implementation team should include front-line professionals who are skilled in working with users in an equal, respectful and active listening manner.
- Managers should provide training on what professionals perceive as their current weaknesses or limitations, before further implementing or scaling up the improvement approach.
- Key improvement procedures should be developed, discussed and standardised by the steering group, consolidating a work method, tools and guidance that is made available to all involved professionals.
- Service providers should ensure that the time and space to undertake key improvement project activities (for instance care planning joint assessment meetings) are respected, redistributing workloads or allowing flexible work schedules if necessary.
- A figure should be established to act as a project manager and trouble shooter. This could either be an external professional, or someone appointed by consensus of the steering group to facilitate legitimacy. As much as possible, the timeline and objectives agreed at the beginning of the project should be respected, avoiding undermining the project manager's authority.
- An implementation plan with a clear evaluation strategy should be put in place, enabling feedback points and adoption of necessary modifications as the project unfolds. This can be conveyed through further collaboration between local initiatives and research institutions.

## 8.5  Conclusion

Integrated care for the 65+ population in Catalonia implies coordinating a multitude of care providers from three sectors (health, social services, Third Sector) with different levels of political decentralization, funding regimes, work cultures and IT systems.

In the frame of SUSTAIN, two local Catalan initiatives have designed a new work method for needs assessment and care planning for 65+ users living at home with complex social and health needs. The adopted work method aimed to enhance the participation of users and carers in decisions on their care and pursued a more person-centred, prevention-oriented and efficient approach, tailoring services to better understood needs and preferences. The ultimate goal was to provide an optimised set of resources that would maintain independent living at home as long as possible, preventing health deterioration through: increased support at home, personalised monitoring of clinical conditions, promotion of social relationships and active ageing (within user possibilities), and advices and mitigation of safety hazards in the users own environment.

Standard care planning tools were tested and refined as the improvement project unfolded: multidimensional joint comprehensive assessment of needs (case conference in Osona; primary care triad assessment meetings in Sabadell); care plan document, reflecting the shared-decision process of users and carers with the care teams; agreed process to transfer validated care plan documents to the electronic health records, sharing them between care team members and for future consultation or follow up.

The approach was disruptive with usual working procedures and roles. It meant sitting all relevant professionals around the same table not only to share  what they each saw as the most convenient care solutions, but to also reflect on user preferences and situation as a whole, and agree on a draft care plan to validate with the users and carers. This enhanced co-responsibility of care team members for the integrated care they provided to users, changing mind sets from a "my patient-your patient" perspective to a "we are the user's care team" way of thinking. In turn, the fact that the standard approach included interviewing users in their own environment -taking professionals out of the consultation premises- meant a change in the usual way professionals communicate with users. The home visits favoured a dialogue (more than a prescription), also allowing care professionals to better understand user needs and identify specific opportunities to improve safety and wellbeing. The visit at home also helped users to perceive increased interest in their case and support, introducing the concept of a care team (rather than one single profile as a reference person) who worked together and were all knowledgeable of their case. This facilitated to a certain extent overcoming the absence of contact between users and local social services, despite the fact that these are responsible for providing home care for 65+ persons.

Although the participatory person-centred approach for care planning was challenging in some cases due to the characteristics of the target group, both improvement projects appear to have improved the perceived person-centredness, prevention orientation, and coordination of the services they provide. In particular, concerning the extent to which users and carers consider that care is well integrated and useful, and concerning the greater opportunities for users and carers to discuss what is important for their health and wellbeing with care teams.

Tailored advice on maintaining independence, safety and adherence to medication, provided routinely as part of the care planning process in the user's home, increased prevention orientation and capabilities of self-managing health of some users. Providing a specific workshop for users addressing aspects related to growing older and enabling users to reflect on their situation and preferences with peers, was highly appreciated by the 65+ users, and appears to have had a positive influence on user empowerment.

A committed group of professionals who believed in the person-centred approach and were supported by managers was a key strength of the improvement projects. Joint leadership of the project between professionals of different institutions and work profiles, with managers acting as facilitators and equals facilitated successful implementation, which was also reinforced by an external figure acting as project manager following a given timeline and agreed distribution of tasks.

Main challenges limiting the continuity or scalability of such approaches relate to: the lack of time in constricted health care and social services systems; difficulties prioritising care planning activities, without additional care professionals and / or a reorganization of professional roles and teams; the need to include wider networks involved in the continuum of care, such as more health specialists or staff in community resources for the 65+; and the convenience of further developing a regional integrated care policy, that would help overcome the traditional fragmentation between care sectors.

All in all, the improvement projects implemented in the frame of SUSTAIN proved to be a satisfactory and beneficial experience for the Catalan sites participating, and a proof of concept to be borne in mind in future Catalan integrated care policy.

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# 10.  ANNEXES

## 10.1  Annex 1: Practical measures for monitoring outcomes and progress of the implementation of the improvement plans

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

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

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

## 10.2  Annex 2: Improvement project flowcharts

### Osona improvement project: PIIC plus*

**SELECTION CRITERIA**
• ≥ 65 years
• Living at home
• Health and social needs
• Cognitively capable

**Pre-surveys**

**Tool already developed by health & social professionals from the SG**

**Post-surveys (12 weeks later)**

Selection of patients by health or social professionals in their settings (Primary Health Care, Social Services and the Geriatric service)

Patient recruitment by professionals & informed consent signed

Joint and multi-dimensional assessment: case conferencing format

**Care plan draft**

Individualized interview with the patient: validate Care Plan & work plan

**Final joint care plan**

Selected information from the Joint Care Plan is copy/paste in the PIIC*

PIIC Plus**

Addressing patient's needs and goals, according to the plan

**Improving the current work methodology of the team**

**Accessible to professionals involved in case conferencing**

**Accessible to all professionals working in the public health system of Catalonia**

**Adding new steps on the work methodology of the team**

*PIIC (Individualized Care Plan): already existent care plan with a fix format, it was created by the Interdepartmental Plan for Health  and Social Care and Interaction (PIAISS) with the purpose of sharing information with health professionals from different care level settings in Catalonia. PIIC is part of the Electronic Medical Record of the patient.
** PIIC plus: Improved PIIC including patient-centered information taken from the full care plan, developed as a result of the case-conferencing session and the interview with the patient. It is part of the Electronic Medical Record of the patient.

**Figure 1 -** *Osona improvement project flowchart.*

### Sabadell improvement project: Improving coordination of professionals and patient empowerment

**SELECTION CRITERIA**
• ≥ 65 years
• Living at home
• Health and social needs
• Cognitively capable

**Pre-surveys**

**Applying the common tool developed by health and social professionals**

**Display map with resources**

**Pre-surveys**

Selection of patients by health or social professionals in Primary Health Care settings

Patient recruitment by professionals & informed consent signed

Patient recruitment by professionals & informed consent signed

**Care plan draft**

Group meeting training session/s on patient's empowerment

Individualized interview with the patient: validate Care Plan & work plan

**Final joint care plan**

SUSTAIN Follow-up, 12 weeks later

Ongoing monitoring of the work plan every three months

**Improving the current work methodology of the team**

**Adding new steps on the work methodology of the team**

**PRELIMINARY ACTIVITIES OF THE IMPROVEMENT PROJECT**
• Developing a common tool to systematically assess patient's needs
• Developing a resource map (social, health and community resources of the neighborhood)
• Professional training about patient empowerment, shared decision making and communication skills
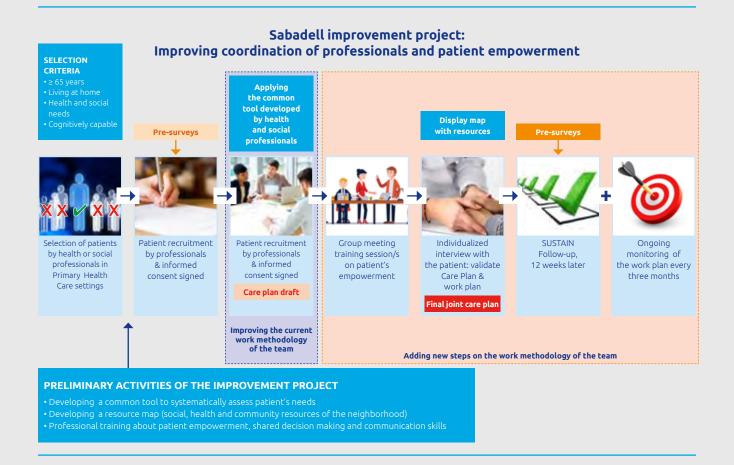
**Figure 2 -** *Sabadell improvement project flowchart.*

## 10.3  Annex 3: Further methodological details

Tables 1-4 provide an overview of the type and quantity of data collected in the Catalan sites. The successive paragraphs offer further insight on the method of data collection.

**Table 1 -** *Details of user and carer data collected in Osona.*

| User and carer information | Data collection | | | |
|---|---|---|---|---|
| | **Iteration 1** | | **Iteration 2** | |
| **Demographic data users + carers** | Users = 11 Carers = 6 | | Users = 9 Carers = 5 | |
| **Person-centred coordinated care survey (P3CEQ)** | Baseline N = 10 | Follow up N = 9 | Baseline N = 7 | Follow up N = 7 |
| **Perceived Control of Health Care survey (PCHC)** | Baseline N = 7 | Follow up N = 9 | Baseline N = 6 | Follow up N = 7 |
| **Interviews with users + carers** | Users = 1 Dyad = 2 Carer = 1 | | Users = 1 Dyad = 2 Carer = 0 | |
| **Care plan analysis** | N = 11 | | N = 9 | |
| **Efficiency indicators (pre-post ER hospital admissions)** | N = 11 | | N = 9 | |

**Table 2 -** *Details of professional and manager data collected in Osona.*

| Professionals and managers information | Data collection | |
|---|---|---|
| | **Baseline** | **Follow up** |
| **Demo. data prof + managers** | Professionals = 54 Managers = 3 | Professionals = 57 Managers = 3 |
| **Team Climate Inventory survey** | N= 51 | N = 34 |
| **Focus group with professionals** | Participants = 11 ( 3 GP, 4 nurse, 3 SW, 1 specialist) | |
| **Interviews with managers** | One interview | |
| **Steering group notes** | 3 steering group meetings and field notes | |
| **Timesheets** | Register of time investment in assessment and care planning process per user elaborated by professional coordinating case conferences in consultation with primary care teams. | |

**Table 3 -** *Details of user and carer data collected in Sabadell.*

| User and carer information | Data collection | | | |
|---|---|---|---|---|
| | Iteration 1 | | Iteration 2 | |
| Demographic data users + carers | Users = 12<br>Carers = 6 | | Users = 11<br>Carers = 1 | |
| Person-centred coordinated care survey (P3CEQ) | Baseline<br>N = 12 | Follow up<br>N = 9 | Baseline<br>N = 10 | Follow up<br>N = 7 |
| Perceived Control of Health Care survey (PCHC) | Baseline<br>N = 12 | Follow up<br>N = 8 | Baseline<br>N = 10 | Follow up<br>N = 7 |
| Interviews with users + carers | Users = 4 interviews with 5 users<br>Dyad = 1 | | Users = 4 interviews | |
| Care plan analysis | N = 12 | | N = 11 | |
| Efficiency indicators (pre-post ER hospital admissions) | N = 12 | | N = 11 | |

**Table 4 -** *Details of professional and manager data collected in Sabadell.*

| Professionals and managers information | Data collection | |
|---|---|---|
| | Baseline | Follow up |
| Demo. data prof + managers | Professionals =10<br>Managers = 2 | Professionals = 11<br>Managers = 2 |
| Team Climate Inventory survey | N = 11 | N = 10 |
| Focus group with professionals | Participants = 4 (2 GP, 1 nurse, 1 SW) | |
| Interviews with managers | Two interviews | |
| Steering group notes | 4 steering group meetings and field notes | |
| Timesheets | N = 13 | |

**Demographic data of users and carers**

*Both sites:* Recruitment was carried out by usual care team members (commonly primary health care nurse, general practitioner or social worker), mostly in user's home environment, but also in care premises. Following informed consent, care team members provided contact details to AQuAS researchers, who then contacted users as to schedule baseline visits. When AQuAS researchers were informed of the existence of an informal carer, baseline visits were scheduled at a time convenient for both user and carer, so they could both be present and provide demographic data face-to-face. In the case of Sabadell, two users replied via telephone, in order to explore this form of delivery.

**P3CEQ and PCHC**

*Osona:* The P3CEQ and PCHC questionnaires were delivered face-to-face by AQuAS researchers at user's homes at two time points; in a baseline visit within a month of recruitment (demographic data was also collected), and at approximately twelve-week follow up from the date of validation of care plans. Informal or privately paid carers recruited as participants of the improvement project were also present and jointly answered the questionnaires with the user. If user or carer showed signs of tiredness or discomfort, the PCHC (delivered after demographic data and P3CEQ) was sometimes interrupted.

*Sabadell:* The P3CEQ and PCHC questionnaires were delivered face-to-face by AQuAS researchers at user's homes at two time points; in a baseline visit within a month of recruitment (demographic data was also collected), and at approximately four-week follow up from the date of validation of care plans. Informal carers recruited as participants of the improvement project were also present and jointly answered the questionnaires with the user. In the case of Sabadell, two users replied via telephone, in order to explore this form of delivery. If user or carer showed signs of tiredness or discomfort, the PCHC (delivered after demographic data and P3CEQ) was sometimes interrupted.

**Qualitative interviews with users and carers**

*Both sites:* Qualitative interviews were undertaken face-to-face with a selected sample of the participants in the follow up visits (mentioned above). When possible, AQuAS researchers aimed to interview at least one dyad (or carer alone) per iteration, and include users representing the other user profiles (e.g. widows living alone, users living with dependent spouses or adult children) in the remaining interviews. Qualitative interviews were done at the first part of the follow up visits, and followed by the P3CEQ and PCHC. If user or carer showed signs of tiredness or discomfort, the P3CEQ or PCHC (delivered after qualitative interview) were sometimes interrupted or not collected.

**Care plans**

*Osona:* Care plans were designed by social and health primary health care professionals, specialist health care professionals and social workers from local social services, in the frame of a case conference, and then later validated with the users (and family or close relatives if available).

Care plans are the key source (document) that care plan indicators derive from, complemented with a 12-week follow up monitoring document (SP-1 12-week monitoring document) that the team of professionals filled in and delivered to AQuAS researchers, with information on the level of implementation of the actions or resources set in the plans at that point, and also the use of resources within the 12 weeks before and after the validation of the care plan. During the analysis of care plans, AQuAS researchers conducted a quality check of the data contacting the care teams to confirm information that could be ambiguous or incomplete.

*Sabadell:* Care plans were designed by health professionals from the primary health care centres in collaboration with local Social Services professionals in the frame of SUSTAIN in order to conduct a multidimensional assessment of the user's needs together with the user and carer(s), establishing goals to achieve, discussing available resources and activities/tasks to do, and roles of both professionals and users/carers to achieve those goals. Care plans are the key source (document) care plan indicators derive from, complemented with a 4 week follow up monitoring document (SP-2 4-week Monitoring document) that the team of professionals filled in and delivered to AQuAS researchers, with information on the level of implementation of the actions or resources set in the care plans at that point, and also the use of resources within the six months before and four weeks after the validation of the care plan. During the analysis of care plans, AQuAS researchers conducted a quality check of the data, contacting the care professionals who filled in the care plans to confirm information that could be ambiguous or incomplete.

**Efficiency indicators:**
**staff hours and cost of equipments**

*Osona:* Register of time investment in assessment and care planning process per user elaborated by professional coordinating case conferences in consultation with primary care teams. Steering group informed that the project was done with no ad hoc cost of equipments.

*Sabadell:* This data was collected either directly from each professional participating in the improvement project, using a standard template, or from one person providing the data for all staff in their Primary Health Care Centre (PHCC). Despite sending several reminders to staff members, both in wave 1 and in wave 2 data was missing for some staff members (wave 1 = 2 missing cases; wave 2 = 4 missing cases). Imputed data has been estimated for these professionals, as follows:
• In wave 1, each PHCC had a similar team implementing the improvement project (GP+nurse+social worker triad) and 4 recruited users each. Therefore, data was estimated for the two professionals with missing data by calculating the average hours per month spent by the professionals of their same profile in the other two PHCCs (i.e nurse missing data from one of the PHCC has been imputed from the mean hours of nurses/per month in the other two PHCC).

• In wave 2, missing data corresponded to the four professionals of one of the PHCC. Users were not evenly distributed between the three PHCCs. Therefore, data has been estimated for the four professionals with missing data by calculating the average hours/per month/per user spent by the professionals of their same profile in the other two PHCCs (i.e nurse missing data from one of the PHCC has been imputed from the mean hours of nurses/per month/per user in the other two PHCC). Steering group informed that the project was done with no ad hoc cost of equipment.

## Site specific information on pre-post use of resources

*Osona:* Data collected specifically in the Osona site in order to assess the improvement project. In particular, Osona's Steering Group decided to explore:
• Number and reason of consultations with primary health care general practitioners. Twelve weeks pre- and post- validation of care plan.
• Number and reason of consultations with primary health care nurses. Twelve weeks pre- and post- validation of care plan.
• Number and reason of consultations with social workers (either with primary health care social worker, or local council social worker). Twelve weeks pre- and post- validation of care plan.
• Number and reason of emergency consultations in primary health care centres (PHCC). Twelve weeks pre- and post- validation of care plan.
• Number and duration of hospital emergency admissions (at least one overnight stay) of users. Twelve weeks pre- and post- validation of care plan.
• Number of hospital readmissions. Twelve weeks pre- and post- validation of care plan.

Osona wanted to explore if the establishment of an individualized integrated social and health care plan had any effect on the level and kind of use of primary care (not explored at consortium level), looking not only at the number of consultations, but the reason behind these visits. Collected data would enable distinguishing between primary health care programmed use (e.g. medication prescription or administration, regular check-ups, informing on test results, care plan visits, etc.) and unforeseen use (e.g. feeling unwell, accidents, complications in chronic conditions, etc.). Reason of consultations was collected as a merely quantitative approach (number of visits) would not offer enough insight into the impact of the improvement project, since a reduction or increase in the number of consultations could have multiple interpretations. However, a reduction in the number of unforeseen consultations due to complications, accidents or feeling unwell, could clearly be a beneficial outcome, particularly from the user perspective.

This data was collected by an appointed person in each of the three PHCC, in two stages:
• Pre- twelve-week data, and Post- twelve-week data was collected in the frame of each Iteration (during months 11 and 17 of the implementation period), by means of the SP-1 Monitoring document that had been adopted to document the level of implementation of care plan actions twelve weeks after care plans had been validated (information required at Consortium level to ellaborate Care plan indicators).
• It Iteration 2, some care plan validation visits were held later than scheduled, meaning that by month 17 (March 2018) the follow-up period had not yet finished. In these cases, the appointed person in each PHCC sent AQuAS an updated version of the SP-1 Monitoring document between April-May 2018.

Some aspects must be taken into consideration when looking at primary care consultations:
• Consultations on the day of care plan validation have been counted within the –Pre period.
• Consultations were classified into programmed visits, unforeseen visits and other visits. Other basically covered all consultations that were held specifically to undertake user recruitment, needs assessment and validation of care plans. Since by definition these mostly fall within the –Pre period, they have been excluded from the analysis as to avoid biasing the comparison between periods.
• Number of consultations does not necessarily reflect the number of times one same user has been visited (e.g. at home, gone to the primary health care centre), since in one same event, several professionals may be involved (i.e. a joint visit at home by nurse and GP, which would be counted as two consultations). Since this analysis wishes to reflect the total pressure on the services (e.g. the sum of all the times each member of staff devotes time to the users), it counts all of the consultations. This means that the number of consultations is not equivalent to the number of interactions of the user with the care team.
• Two outlier cases were detected concerning programmed consultations with nurses, with a considerably higher number of consultations (both in the –Pre and –Post periods) in comparison to the average of the other eighteen users. For this reason, a parallel analysis has been undertaken, in which the number of programmed consultations with nurses of the two outlier cases is adjusted, assigning these cases the average number of consultations observed with the other eighteen cases. When relevant, both observed data and adjusted data were calculated.

In order to ensure consistency, only emergency hospital admissions with at least one overnight stay were considered.

*Sabadell:* Data collected specifically for the Sabadell site in order to assess the improvement project. In particular, Sabadell's Steering Group decided to explore:
• Number and reason of consultations with primary health care general practitioners. Six months pre- and post- validation of care plan.
• Number and reason of consultations with primary health care nurses. Six months pre- and post- validation of care plan.
• Number and reason of emergency consultations in primary health care centres (PHCC). Six months pre- and post- validation of care plan.
• Number and duration of hospital emergency admissions of users. Six months pre- and post- validation of care plan.

• Number of hospital readmissions. Six months pre- and post- validation of care plan.

Sabadell wanted to see if the establishment of an individualized integrated social and health care plan had any effect on the level and kind of use of primary health care (not explored at consortium level), looking not only at the number of consultations, but the reason behind these visits. Collected data would enable distinguishing between primary health care programmed use (e.g. medication prescription or administration, regular check-ups, informing on test results, care plan visits, etc.) and unforeseen use (e.g. feeling unwell, accidents, complications in chronic conditions, etc.). A merely quantitative approach (number of visits) was considered as not offering enough insight into the impact of the improvement project, as a reduction or increase in the number of consultations could have multiple interpretations. However, a reduction in the number of unforeseen consultations due to complications, accidents or feeling unwell, could clearly be a beneficial outcome, particularly from the user perspective.

The Steering Group also decided to broaden the pre-post period set at Consortium level for emergency use of hospital care, from 12 weeks to a six-month period.

This data was collected by an appointed person in each of the three PHCC, in two stages:
• Pre- six-month data, and Post- four-week data was collected in the frame of Iteration 1 (between July-August 2017) by means of the SP-2 Monitoring document that had be adopted as to know the level of implementation of care plan actions four-weeks after care plans had been validated (information required at Consortium level to elaborate Care plan indicators).
• The remaining post- six-month data was provided to AQuAS in January 2018, once the six-month period had been completed, using a standard ad hoc template.

Since the six-month follow up period for Iteration 2 participants does not conclude until July 2018, only a preliminary analysis based on the data of Iteration 1 participants is available at the time of writing this report.

## Demographic data of professionals and managers
*Osona:* Recruitment of professionals and managers was carried out by AQuAS during months 0-3, in the frame of face-to-face steering group meetings or short training sessions. Professionals and managers were asked to sign the informed consent sheet and provide demographic data using the auto-administered paper questionnaire. Demographic data and informed consent sheets of professionals joining at later stages was collected by the appointed reference persons in their institution and handed to AQuAS researchers.

*Sabadell:* Recruitment of professionals and managers was carried out by AQuAS during months 0-3, in the frame of face-to-face steering group meetings. Professionals and managers were asked to sign the informed consent sheet and provide demographic data using the auto-administered paper questionnaire. Demographic data and informed

consent sheets of professionals joining at later stages was collected at later stages (in face-to-face meetings or sent via encrypted email) by AQuAS researchers.

## Team climate inventory survey
*Osona:* The TCI was completed by professionals and managers of the Osona SUSTAIN team initially involved in the design and/or implementation of the improvement project. Baseline data was collected on paper during December 2016-January 2017 (months 2-3) by professionals and managers as they signed informed consent to participate in the study, mostly in the frame of steering group or short training meetings. Due to the high number of professionals participating in the Osona improvement project (60), and the lack of a face-to-face meeting in the period when the follow up TCI was to be collected, it was administered online. All professionals and managers received an individual email invitation and personalized survey-link, followed by two reminders during end February-early March 2018 (months 16-17). Response rate was 56.6%.

*Sabadell:* Baseline data was collected from recruited managers and professionals in approx. Month 1 of the improvement project. Responses were collected on paper in a face-to-face meeting; those not attending the meeting delivered the questionnaire via email to AQuAS researchers in the following weeks. The follow up TCI was administered on paper to professionals and managers attending face-to-face meetings taking place in Month 17 of the improvement project (focus group and manager interviews), whereas administered online to the remaining team members.

## Focus group with professionals
*Osona:* The focus group was held on 8th March 2018 in the room usually used for Osona SG meetings, at the Hospital Santa Creu de Vic. One AQuAS researcher conducted the session, whereas the other presented an overview of the improvement project objectives, observed, and took notes. The duration of the session was approximately two hours. The session followed the Focus group outline agreed at Consortium level. Eleven out of the fifty one professionals of SUSTAIN project participated in the focus group discussion; four nurses, three social workers and three general practitioners and one specialist. Since Osona group is large, invitation was sent out to some selected professionals from both the steering and executing boards, obtaining a representation of all disciplines (medicine, nursing, social work) and all institutions involved (primary health care centres, intermediate and acute hospitals, local social services).

*Sabadell:* The focus group was held on 8th February 2018 in the room usually used for Sabadell SG meetings (at PHCC Concòrdia). One AQuAS researcher conducted the session, whereas the other presented an overview of the improvement project objectives, observed, and took notes. The duration of the session was approximately two hours. The session followed the Focus group outline agreed at Consortium level. Four out of the eleven professionals of SUSTAIN project participated in the focus group discussion

(FGD); one nurse, one social worker and two general practitioners (GPs). Since Sabadell was a small group, an invitation was sent out to all Sabadell professionals (excluding the two managers, who were to be interviewed separately). It is worth noting that one of the three PHCCs participating was not represented at the focus group discussion (two professionals could not attend due to incompatible agendas, one due to illness); this might limit the representativeness of the results obtained.

### Qualitative interviews with managers

*Osona:* One manager interview was conducted by a single AQuAS researcher in March 2018 (M17 of the implementation plan), at a place of convenience for the manager. The interview followed the manager interview outline agreed at Consortium level. Contacts were made with a second manager, but an interview was not possible due to agenda incompatibilities.

*Sabadell:* Interviews were conducted by a single AQuAS researcher with the two recruited Sabadell managers in February 2018 (M17 of the implementation plan). Interviews followed the manager interview outline agreed at Consortium level, and where done in a place of convenience for each manager.

### Steering group notes and field notes

*Both sites:* Face-to-face meetings were held in Vic and Sabadell approximately every two months during the pilot and iteration 1 of the improvement project. 1-2 AQuAS researchers conducted these meetings and sent notes back to the Steering Groups summarising meeting content, decisions and action points. In addition, AQuAS wrote reflective notes after each meeting, to serve as field notes to be included in the analysis. During Iteration 2 only one face-to-face meeting took place (in Sabadell), as in the winter months a flu epidemic left health professionals with little time to devote to the SUSTAIN project. Since the improvement projects had already been designed and small adjustments discussed in the feedback session on iteration 1 findings, the recruitment, assessment and care planning for iteration 2 was given priority. Issues such as reminding of the implementation calendar or organizing data collection were dealt with over email. Therefore, e-mail exchange between SG components where decisions were made over iteration 2 have also been included in the analysis.

### Approach for pre-post comparison of user experience survey results (applied to P3CEQ and PCHC)

The small sample size of survey data meant caution was required when looking into possible differences in scores between the baseline and follow up measures. Differences could be due to missing data in one or the other measure, different participants responding at each time point, a few participants providing very different scores between one moment and the other, etc. For this reason, a first corrective measure was to create a subset that only included the –pre and –post results of users who replied both at baseline and follow up, as to eliminate the effect of changes in the composition of the group.

Another corrective measure was to avoid any comparison between users in the two different iterations but rather base the analysis on global results, since they could be due to differences in the characteristics of the individuals included in each iteration. The third decision was to not base conclusions only on the change in the total P3CEQ score or the PCHC Part B score, but focus the analysis on the change observed in the amount of users who provided positive replies at baseline and at follow up in each of the different questionnaire items. This enabled seeing if, for instance, a similar total score was due to the fact that some items increasing whereas a similar amount decreased, or rather that most of the items obtained similar scores in both measures. The P3CEQ four-point scale items were recoded so that the options "more often than not" and "always" were considered as positive, whereas "not at all" and "to some extent" were considered as negative responses. The PCHC five-point scale items were recoded so that the options "with great ease" and "with ease" were considered as positive, "not difficult, not easy" was considered as a neutral position, and "not, or with great difficulty" and "with difficulty" were recoded as negative. The analysis identified which number (and proportion) of all respondents in the dataset provided positive answers at baseline for each item, and compared this with the number of respondents who provide positive answer options at follow up. This enabled identifying the specific aspects where changes of the response of several users were observed, regardless of how many had not replied (for instance because they did not understand the question or considered it wasn't relevant). For instance, if at baseline only half of respondents had reported positive perceptions concerning being involved in decisions on their care, but at follow up this had increased to the vast majority, it was considered a sign of a potential positive change. These signs of change were triangulated with thematic statements proceeding from open responses and in-depth interviews, as well as care plan data findings and the perception of professionals, in order to seek evidence that contradicted or refuted them. If such refuting data was not found, the signs of change were then brought into the explanatory model as they provide some insight on possible changes of user experience in the frame of the improvement project. Finally, researchers acknowledge that these observed changes cannot be attributed directly to the improvement project, since multiple factors could also explain changes in user perception.

# SUSTAIN

Sustainable tailored integrated
care for older people in Europe