Learning from integrated eCare practice and promoting deployment in European regions

D5.2 REPORT ON PILOT OPERATION

WP5 Pilot site preparation and operation

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D5.2 v1.0 BeyondSilos Report on Pilot Operation

Statement of originality

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

Executive summary

Based on outcomes of the service definition phase (WP1 & WP2), architecture specification (WP3) and prototype testing (WP4), the service to be piloted (WP5) was planned and rolled out into the field by Month 13, in terms of both technology and organisation.

The trials consist of seven sites in six different countries across Europe that have deployed the BeyondSilos service delivery model as defined in the previous WPs.

The starting point for every site has been different, even though the scenario proposed within the BeyondSilos project has meant an improvement challenge for each of them. Each particular site scenario was formalised and consolidated in WP2 through the service process modelling.

WP5 has collected all the knowledge gained by the different pilot sites within the preparatory activities and the operational phase through the RAIL tool (imported from the SmartCare project and also used within the CareWell project). Such information was collected according to seven different domains, covering user recruitment, professional enrolment, organisational changes, technical issues, help desk, training and ethical / legal aspects.

This report consolidates the input gathered by the seven sites participating in the BeyondSilos project, and is a knowledge repository for future implementers of integrated care services.

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1   Introduction

1.1   Purpose of this document

This document reports on the knowledge gained through the implementation of integrated care services in each site within the BeyondSilos project. The goal was to provide not only a description of the activities carried out by each site, but also to explain the problems and issues encountered, and how they were faced, to identify some lessons learnt and to point out the main risks present in this kind of activity.

The experiences refer to the two phases of the pilots: the preparatory activities, and operation. They have been classified in seven domains:

- User recruitment.
- Professionals enrolment.
- Organisational changes.
- Technical issues.
- Helpdesk.
- Training.
- Ethical-legal aspects.

The information was collected by using the RAIL tool, which has been imported from the SmartCare project; it is also being used in the CareWell project. The tool has been customised to BeyondSilos, and is further explained in section 2.2.

The main aim of this document is to gather all the knowledge gained by the six sites taking part in the BeyondSilos project as part of their deployment and implementation of integrated care services. The different framework conditions (such as the financing system, services deployed, cultural context, etc.) and the different starting points for each site, ensures a good coverage of the different realities across Europe. Ideally, this will help following regions and implementers in their particular deployment processes.

1.2   Structure of this document

Chapter 2 explains the background and the methodological rationale for the knowledge collection process. Further explanation on the RAIL tool is included for the reader to better understand the overall approach.

Chapter 3, an analysis of each of the different sites reporting is performed. This starts with a generic analysis for the overall reporting period according to the different domains of the RAIL tool, and then reports the status for each of the BeyondSilos sites.

Chapters 4 to 10 report on each of the RAIL domains. Each domain starts with an introductory section, explaining the relevance of the domain in a deployment and implementation process of integrated care services. After that, the knowledge collected is presented for each site.

Chapter 11 presents the conclusions after analysing all the knowledge reported by the different sites. It also includes the limitations of the overall process, and some recommendations for future implementers willing to follow a similar process.

1.3   Glossary

BS	BeyondSilos
BSA	Badalona Serveis Assistencials
BSO	Business Service Organisation
CIF	Informed Consent Form
ECR	Electronic Care Record
GDS	Geriatric Depression Scale
GP	General Practitioner
HC	Healthcare
HCP	Healthcare Provider
HSCNI	Health and Social Care Northern Ireland
ICT	Information and Communications Technology
IT	Information Technology
LHA	Local Health Authority
LTP	Long-term Pathway
MAC	Media Access Control address
MoU	Memorandum of Understanding
SC	Social Care
SCP	Social Care Provider
SCS	Shared Care Summary
SPO	Peripheral Oxygen Saturation
STP	Short-term Pathway

2   Background and rationale

2.1   Rationale

Based on outcomes of the service definition phase (WP1 & WP2), architecture specification (WP3) and prototype testing (WP4), the service to be piloted (WP5) was planned and rolled out into the field by Month 13, in terms of both technology and organisation.

The pilot partners consist of seven sites in six different countries across Europe that deployed the BeyondSilos service delivery model as defined in the previous WPs. The total number involved within this service provision is around 900 end-users.

The starting point for every site has been different, even though the scenario proposed within the BeyondSilos project has meant an improvement challenge for each of them. Each particular site scenario was formalised and consolidated in WP2 through the service process modelling.

WP5 has collected all the knowledge gained by the different sites both in the preparatory activities and the operational phase through the RAIL tool (see section 2.2 below). Such information was collected according to seven different domains, covering user recruitment, professional enrolment, organisational changes, technical issues, help desk, training and ethical / legal aspects.

The different starting points of the BeyondSilos sites have made them go through a different learning process. Because of that, not every pilot site has reported in each of the domains, but only where and when they thought they had something to share.

2.2   The RAIL tool

RAIL is a web tool (an online repository) that has been used to collect the experiences from each site in BeyondSilos. It has been set up to collect experiences across the SmartCare, BeyondSilos and CareWell regions. In the early stages of the project, RAIL was presented to the BeyondSilos Consortium, as a tool developed in the context of the SmartCare project by the region of Aragón. Within the BeyondSilos project, the validity of the tool was assessed, and after some modifications within the Help Desk domain, the Consortium agreed to use it to share their experiences with the other partners; it thus became a useful instrument to foster internal communication.

The RAIL tool for BeyondSilos is accessible through the following link:
https://sites.google.com/site/beyondsilos/home

RAIL organises the information in seven operational domains (user recruitment, professional enrolment, organisational challenges, technical issues, helpdesk, training, and ethical & legal aspect). It classifies the experiences according to the type of information provided (activities performed, problems/issues faced and solutions, lessons learnt, risks, and issue tracker) and to the phase (preparatory activities or operational). The information is organised through a database of excel spreadsheets, which facilitates reporting the inputs inserted, as well as consulting the experiences of other partners.

It must be underlined that RAIL serves not only to collect the experiences, but also to share them among partners. Access is restricted to Consortium partners, who can enter the portal whenever they want. Reading the activities that the other sites have performed, and especially the problems faced and the solutions found, the lessons learnt and some identified risks, can be very useful for the implementation of the trials. Sharing information between partners can help to avoid repeating in the same mistakes, it

provides tools to solve issues that might arise, and it gives valuable insights to improve each site's performance.

2.3 Methodological approach

The RAIL tool served as the primary source of input to construct this report. As mentioned above, it was the tool used by the different sites to gather their different experiences within both the preparatory and operational phases of the BeyondSilos project.

WP5 analysed all the information reported, and further worked on it; some reclassification and reshaping of the input provided was done. In some cases, some of the inputs provided were merged into a single experience, because the main ideas around them were essentially the same. Because of that, the number of reported activities within the RAIL tool and this report may differ.

After this process, the sites were given the chance to further comment and improve the current experiences.

3   Analysis of the sites

The following analysis shows the work done in each site, analysing the different domains, phases and kinds of information. All in all, the different sites have contributed to share 91 experiences.

3.1   Introduction

In general, BSA is the partner with a highest participation (22), followed by Valencia (21) Sofia (13), Campania and Kinzigtal (11).
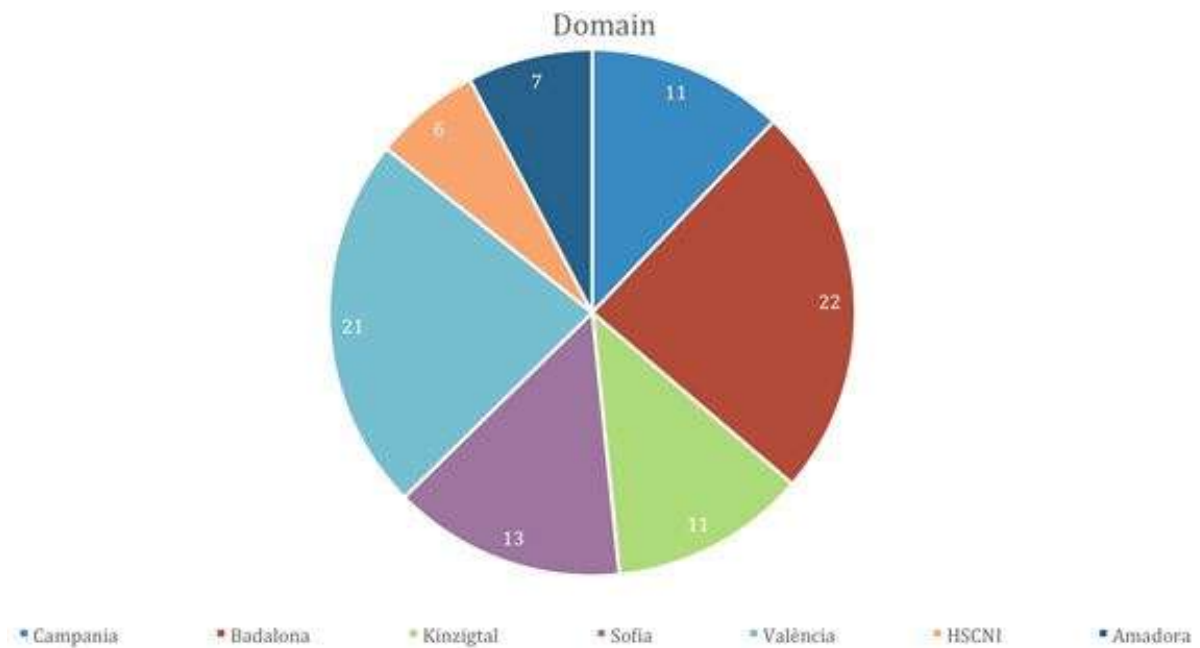
Figure 1: Distribution by site

The distribution by domain is shown in the following chart. Most of the reporting has been done due to technical issues.
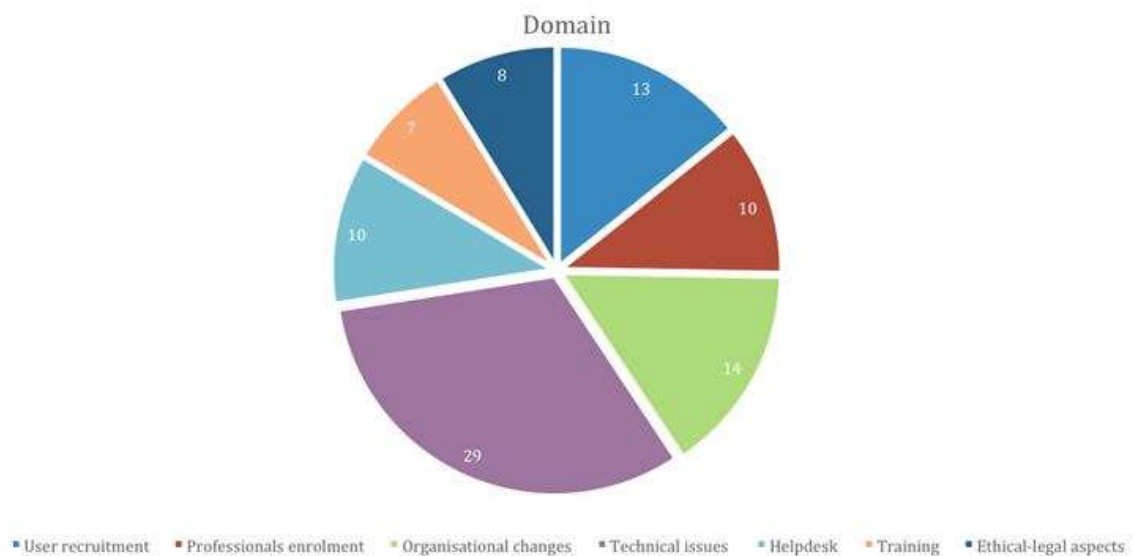
Figure 2: Distribution by domain

3.2   Status in BSA

BSA has shared 22 experiences. Most of them during the operational phase (15).

Figure 3: Badalona: Experiences by Phase

By domain, the experiences about technical issues and helpdesk (5 each) are the largest domains, followed by user recruitment and training (4 each), ethical-legal aspects (2); professional enrolment and organisational changes (1 each).

Figure 4: Badalona: Experiences by Domain

3.3   Status in Amadora

Amadora reported one experience within each of the domains of the RAIL tool. All of the reporting by Amadora applies to both preparatory and operational phases.

Amadora: Experiences by Domain

- User recruitment
- Professionals enrolment
- Organisational changes
- Technical issues
- Helpdesk
- Training
- Ethical-legal aspects

Figure 5: Amadora: Experiences by Domain

3.4   Status in Campania

Campania shared 11 experiences, all except one during the operational phase.

Campania: Experiences by Phase

- Preparatory
- Operation
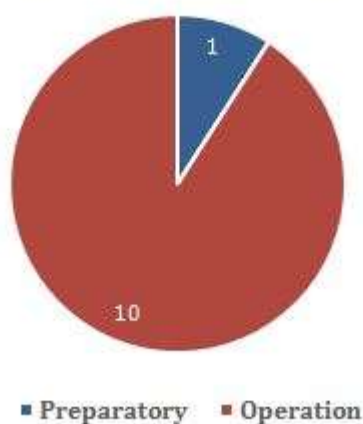
Figure 6: Campania: Experiences by Phase

By domain, technical issues is the most represented, with four experiences. The domains professional enrolment, organisational changes, and ethical-legal aspects have two experiences each, and user recruitment one.

Campania: Experiences by Domain

- User recruitment
- Technical issues
- Ethical-legal aspects
- Professionals enrolment
- Helpdesk
- Organisational changes
- Training
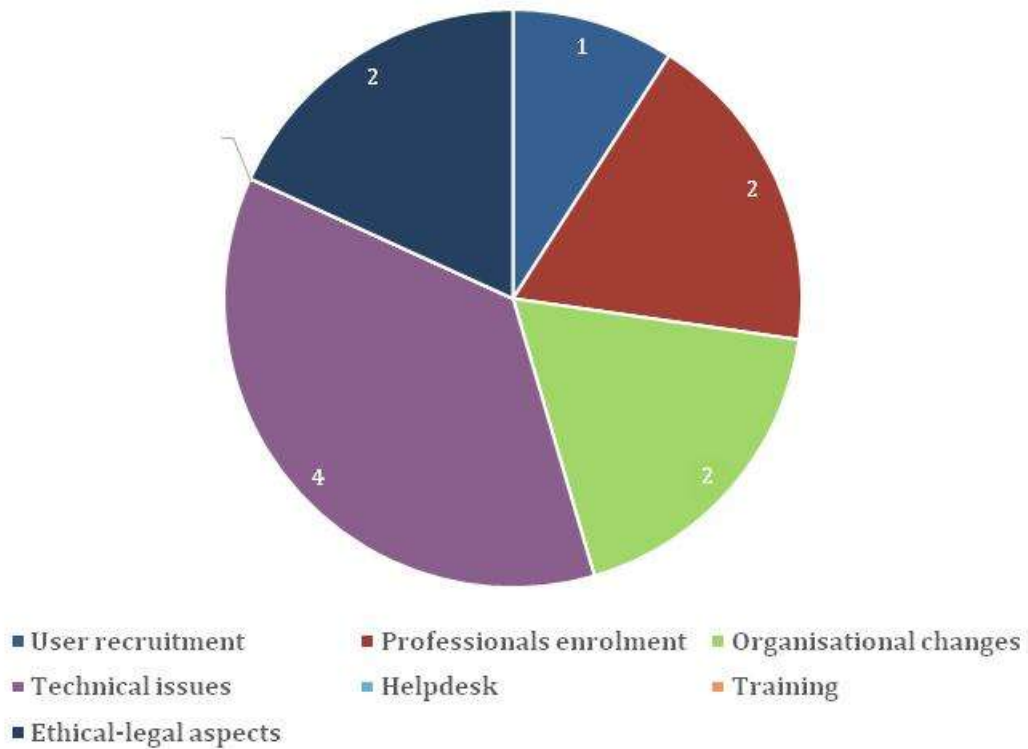
Figure 7: Campania: Experiences by Domain

3.5 Status in HSCNI

HSCNI shared six experiences, all of them referring to the operational phase. The experiences refer to professional enrolment, organisational changes and technical issues, with two experiences in each domain.

HSCNI: Experiences by Domain

- Professionals enrolment
- Organisational changes
- Technical issues
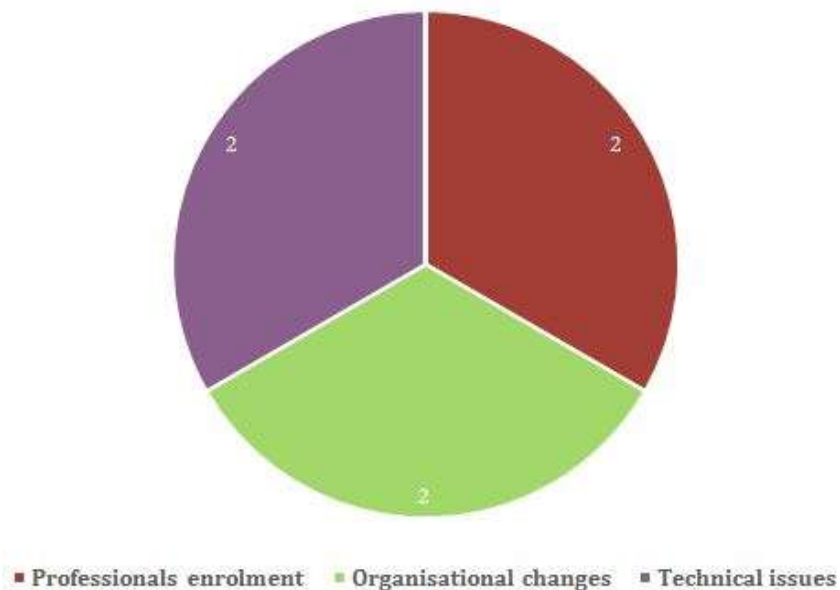
Figure 8: HSCNI: Experiences by Domain

3.6   Status in Kinzigtal

Kinzigtal registered 11 experiences in RAIL, 10 in the operational phase and only one for preparatory activities. Organisational changes and technical issues are the more represented domains, with four experiences each. Two experiences refer to user recruitment and one to the helpdesk.
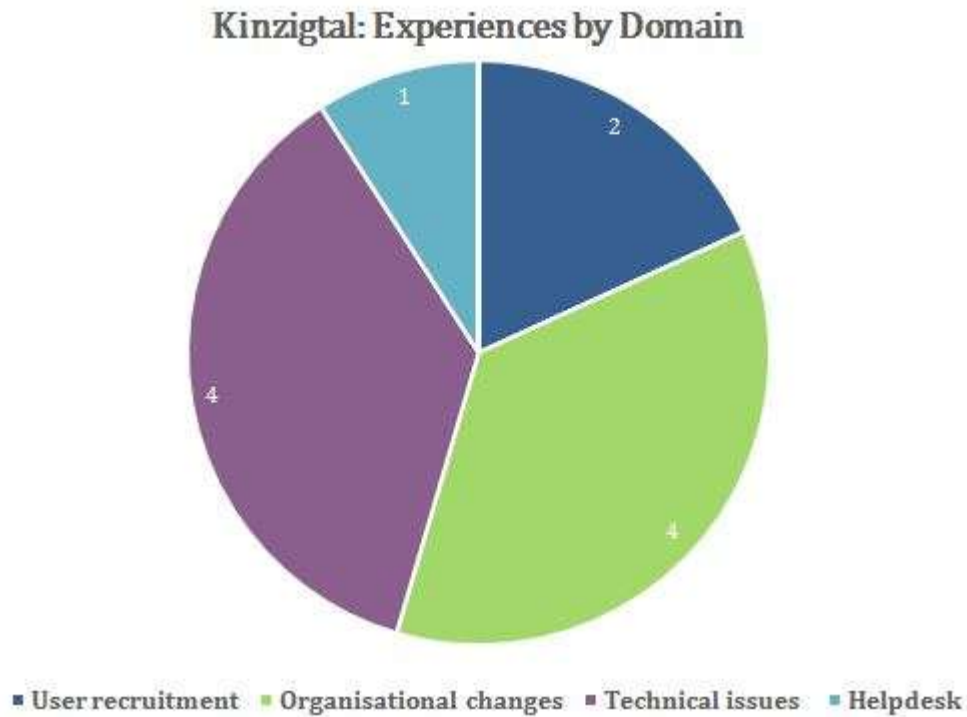
Figure 9: Kinzigtal: Experiences by Domain

3.7   Status in Valencia

Valencia shared a total of 21 experiences, 4 during the preparatory phase and 17 during operation.

Almost half of the experiences (10) are registered in the technical issues' domain. Much fewer (4), concern professionals enrolment, 3 user recruitment, and 2 organisational changes. Finally, training and ethical-legal aspects have one experience each.

Valencia: Experiences by Domain

- User recruitment
- Professionals enrolment
- Organisational changes
- Technical issues
- Training
- Ethical-legal aspects
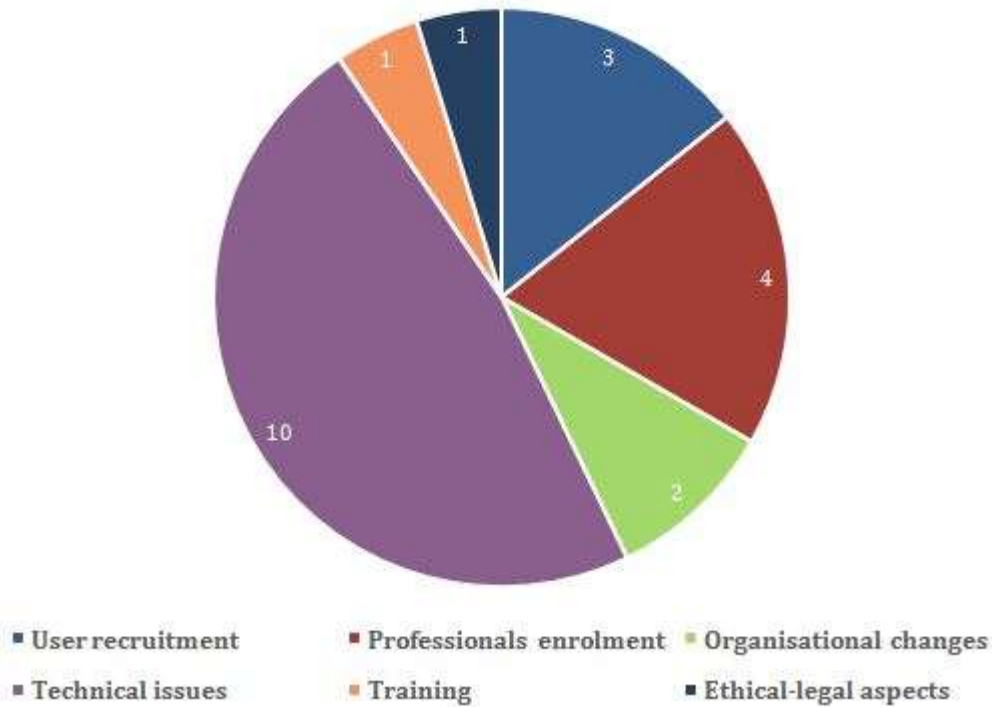
Figure 10: Valencia: Experiences by Domain

3.8   Status in Sofia

Sofia registered four experiences in the preparatory phase and nine during operation. These experiences are distributed among all domains except professional enrolment. Technical issues and helpdesk have 3 experiences; user recruitment, organisational changes, and ethical-legal aspects 2; and training 1.

Sofia: Experiences by Domain

- User recruitment
- Organisational changes
- Technical issues
- Helpdesk
- Training
- Ethical-legal aspects
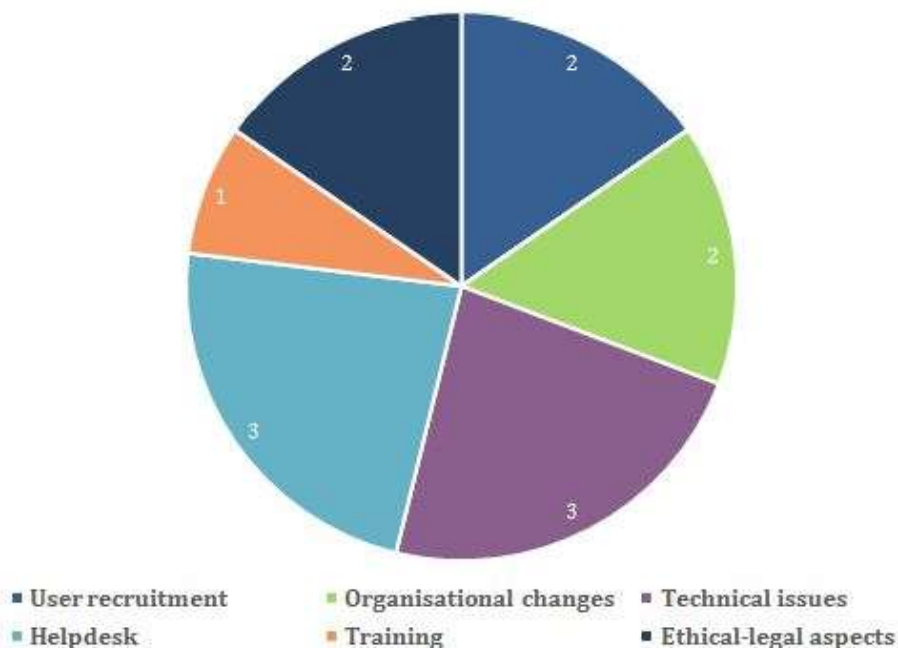
Figure 11: Sofia: Experiences by Domain

4 Operational experiences in user recruitment

4.1 Introduction

User recruitment is one of the key preparatory activities for each project that involves end-users. It is paramount to find a pool of users that is big enough to generate relevant insights into the functioning of the tested devices; and it is clear that without users, the project cannot succeed.

The identification of potential users precedes recruitment. This implies setting up inclusion criteria that citizens should meet in order to be considered potential participants. The different sites in BeyondSilos analysed carefully the characteristics of their target population in order to know which patients could benefit more from the intervention; based on this, they established the criteria. Once potential users were identified, organisations had to carry out the task of convincing them to participate in the project. In addition, it was necessary to ensure that users were motivated enough to keep their participation constant until the study was over, and that they would be willing to provide feedback and to maintain frequent communication with the coordination team in order to solve any problem that might occur, or to clarify doubts.

Sites have used different strategies and channels to reach and motivate end-users. Some examples of this were to place on health professionals the responsibility of making the first contact and explaining the project in detail to users, to reach participants through their GP, to highlight to the users the usefulness of their participation, to involve other organisations to extend the pool of potential participants, or to give more detailed information during the explanation session while ensuring that the informal caregivers participated in it.

The following sections give more details on the actions carried out by each organisation, as well as on the problems they encountered, solutions, lessons learnt, and main risks identified.

4.2 BSA

Activities performed

- The BeyondSilos evaluation framework defined eight months as the minimum time to follow up the patients included in the study. Differently to other pilot sites, BSA decided to deploy the users in two iterations of eight months, thus being able to gain insights between the first and the second wave of users, while avoiding seasonal bias in the recruitment (mainly for the ones in the short-term pathway).

- The recruitment of users to participate in the project was a big challenge in BSA. However, a timely analysis of the first issues encountered helped to avoid further problems, and to develop specific strategies that facilitated the process thanks to the learning process between the two waves of recruitment.

Problems/issues faced and solutions

- BSA is an integrated health and social care organisation with entirely public capital that manages the Hospital Municipal de Badalona, the Homecare Integrated service, the Socio Health Centre El Carme, and seven Primary Care Centres. With 10 centres and more than a thousand professionals providing services, BSA provides care to a total population of almost 420,000 inhabitants in a very populated suburban area of Barcelona.

- For this reason, BSA had to deal with geographical dispersion. During the pilot, the helpdesk was in charge of installing the devices at the user's home, in order to ensure that everything worked correctly. However, these installations took longer than expected, because parking in some areas

of Badalona is not easy. On the other hand, in the "first wave", care recipients helped by collecting the devices from BSA premises. This proved useful, but it entailed the risk of losing some devices (which fortunately did not happen).

Lessons learnt

- BSA had approval from the Local Investigation Ethical Committee in conformity with existing local clinical guidelines and local legislation and, as it is usual, they approved the informed consent form for the project. However, in this case, BSA also added an assignment agreement for the care recipients, making them responsible for taking care of the devices handed to them, which was also approved. This type of contractual relationship served the purpose of making users feel responsible and take care of the devices. As a result, after the "first wave" with 50 users (10 STP, 40 LTP), no device was lost or damaged.

- It is very important that there exists confidence between professionals and users, to meet the project goals and be aligned with the mission of our organisation. In order to achieve this, the professionals were in charge of making the first contact and explaining the project in detail. Moreover, whenever the helpdesk contacted a user, they always identified themselves. In addition, before the helpdesk visited an elderly person's home, the professionals called him/her. During the project, BSA realised that taking care of these details helped the development of the study and made the work easier.

- Communication is an essential factor in the success of the project. It is very important to give clear and detailed information to informal caregivers and older people on the project's goals, the services and products offered, and the study's development.

Risks

- The main risk is to have several drop outs in the recruitment's waves. In fact, there were some drop outs in BSA in both waves. Most were due to a change of mind by the informal caregiver side. They had accepted to participate in BeyondSilos, but when the helpdesk went to install the devices, they had changed their mind. This was sometimes due to the fact that the extra effort that this would bring was too high. Another caregiver was annoyed because she was not there when the formal caregiver explained the services.

Phase

- Operational phase.

4.3   Amadora

Activities performed

- Target group in Amdora, in terms of end users, is composed by 100% of the clients of Misericordia of Amadora Home Care Support services, which means 150 persons enrolled. This means that the comparator group was the same as intervention group.

- In Amadora, complementary activities were delivered in order to enrol the end users, such as: focus groups; awareness group sessions; and home visits to explain the process.

Problems/issues faced and solutions

- Main issues faced were related to the "normal" resistance to change; and to the introduction of ICT tools such as the equipments and devices for telemonitoring. There were three strategies defined and implemented to overcome these issues:
  - diversity of the motivational engagement activities: focus groups; awareness sessions; home visits;
  - the implementation and delivery of the Informed Consent; and

- the "quality of time" spent with the end users and relatives during the home visits to explain the project.

- Amadora did not face complex problems regarding enrolment, due to the fact that BeyondSilos solution represented an upgrade to the Home Care Support Service for all the clients of Misericordia.

Lessons learnt

- Misericodia of Amadora benefits from a very confident relationship with the clients, so that most of the time clients are available for the new challenges. However, and given that BeyondSilos introduced a totally new service (before the project there was no integration of care at home due to the lack of conditions to provide healthcare services), some issues needed to be overcome for recruitment that triggered the following lessons learnt:
  - the importance of having diverse awareness and motivation activities of engagement;
  - the importance of involving clients in the definition of the processes through focus groups;
  - the importance of having a structured document that states all the actions to be taken and that encompasses the security of the clients;
  - the importance of training for the introduction of ICT Tools; and
  - the importance of involving and training the professionals that visit the patients at home, in order for the clients to be sure that they are secure and aware of the project.

Risks

- Misericordia of Amadora enrolled in the project 100% of the Home Care Support services. According to this, the risk of dropouts was high. Additionally, and given the fact that the project is about a completely new service and based on ICT Tools, the level of demotivation to participate was also high.

Issue tracker

- In Amadora, a risk mitigation chart was introduced that covered all phases, status, and the mitigation actions to be taken and when. For recruitment, the more important actions taken were related to delivering more training to professionals and end users, and also individual "meetings" with end users and relatives.

Phase

- Both preparatory and operational phase.

4.4 Campania

Activities performed

- In Campania, user recruitment was performed through the usual care path.

Problems/issues faced and solutions

- A problem arose during the recruitment process, in particular during the administration of the questionnaires. This task was hampered because several patients were not sufficiently motivated to respond.

- A strategy had to be developed in order to motivate patients to respond to the questionnaires and to enrol in the project. This consisted of trying to reinforce the user's perception of the usefulness of his/her participation in a project that had the aim to generate knowledge to better manage his/her needs, as well as those of other people suffering from similar conditions. Sometimes, this perception of being useful helped to improve participants' self-image.

Lessons learnt

- It is essential to ensure that potential participants are properly motivated to enrol in the study. A good option is to emphasise that by participating they can help to improve the management of their health conditions and those of other people.

Risks

- If potential participants do not have a clear motivation to enrol, they might refuse to do so, which can endanger the success of the project.

Phase

- Operational phase.

4.5   HSCNI

Activities performed

- User recruitment activities had the goal to enrol 420 patients in the intervention group and 420 patients in control group for the evaluation of the impact of SCS.

Problems/issues faced and solutions

- Only 166 patients in total were eventually enrolled into the evaluation process, and only 86 of these were subsequently included at the end of the evaluation period.

Lessons learnt

- The shortfall of patients is a direct result of the low number of GP practices that initially were involved, and the drop-out of practices by the end date of the evaluation. Thus, it is key to involve as many GP practices as possible in order to reach more users that could potentially participate in the study.

Risks

- Users' recruitment can be negatively affected by a low enrolment of health professionals.

Phase

- Operational phase.

4.6   Kinzigtal

Activities performed

- As part of the preparatory activities, Gesundes Kinzigtal planned and started user recruitment. Later, the German Red Cross was also involved in the process.

Problems/issues faced and solutions

- The main problem related to the user recruitment during the preparatory activities was that Gesundes Kinzigtal faced the risk of not reaching the planned recruitment numbers for evaluation.

- The implemented solution was to subcontract a second social care provider, namely the German Red Cross, which was given the responsibility of recruiting the control group. Thanks to this, the risk of not reaching the numbers was reduced, although not eliminated.

Lessons learnt

- Achieving the planned recruitment numbers can be often challenging, and can compromise the development of the project. It would be convenient to consider in advance the possibility of involving other organisations that could extend the pool of potential participants. This is especially important if, as in this case, the organisation in charge of the pilots has a small number of clients.

Risks

- The main risk is to fail to reach the planned recruitment numbers for evaluation by the end of the recruitment deadline. In this case, the organisation identified the risk in the preparatory activities, and performed corrective actions to reduce it. However, some risk still persisted. This risk was probably greater in this situation because the nursing service was quite a new branch of the social care institution which was established just one year before. As a consequence, its total number of clients was quite small.

Phase

- Both preparatory phase and operational phase.

4.7 Valencia

Activities performed

- Recruitment activities were performed. First, there was a phone contact through which some patients accepted to participate in the programme. Afterwards, nurses visited their home in order to explain patient participation in more detail and to sign the CIF.

Problems/issues faced and solutions

- Some patients accepted to participate during the phone contact, but later refused when the nurse visited their home. These patients showed some doubts during the nurse explanations, and indicated that they did not want to participate because the ICT tools were too complicated for them. The approach to address this problem was to provide better information about the intervention, and also to involve the informal carer during the explanation.

- Some users had problems to correctly complete the GDS. Several patients (most of them controls) did not understand well the questions, or did not want to answer. In order to address this, nurses helped users to fill in the questionnaire.

- Users were recruited after confirming that they met the inclusion criteria. The next step was to install the devices at their homes. However, when the organisation in charge of installation (ATENZIA) arrived at some of the users' homes, they realised that they did not have a landline phone, and thus, they could not do the installation. As a result, these patients had to be excluded from the eligible sample.

Lessons learnt

- Most patients over 65 years are not ready to deal with ICT tools without help from their relatives or caregivers. Therefore, this support is crucial for the success of the project. It is also key to involve them during the explanation of the project to the participant.

- Some technical requirements (e.g. having a landline phone) should be considered when recruiting users.

Risks

- An important risk is that some patients are not comfortable with ICT tools and tele-assistance devices. They often feel overwhelmed, and complain that there are too many devices to handle.

Phase

- Both preparatory phase and operational phase.

4.8   Sofia

Activities performed

- Sofia performed user recruitment through several sources, such as referrals from social care services, and referrals from medical professionals. The process revealed that the target group could be better reached via GPs.

Problems/issues faced and solutions

- One of the main problems identified was that older people were not motivated enough to go through lengthy interviews; this was especially relevant for those in the control group. Since they could not try out BeyondSilos devices, they had fewer incentives to keep participating.

- One solution was to involve the person's GPs in the recruitment process, in order to increase patients' motivation and willingness to participate. However, sometimes it was also difficult to motivate GPs.

Lessons learnt

- It is key to assess which are the most suitable strategies to motivate the elderly to participate in the study, as well as the best channel to reach them.

- A convenient way to reach the elderly is via their GP, because the patients usually know and trust them. If the older person does not know the person that introduces the project to him/her, this might decrease the likelihood that he/she decides to get involved.

Risks

- It might be difficult to find people who are motivated enough to enrol in the project. This concerns patients but also health professionals.

- Due to the fact that they cannot try the devices, and that they can perceive their participation as less essential, the control group might have a lower motivation.

Phase

- Both preparatory phase and operational phase.

5   Operational experiences in professionals' enrolment

5.1   Introduction

As with the users' recruitment, the enrolment of professionals in the project represents a challenge. It is not easy to find motivated professionals who are willing to participate. In fact, there exist several difficulties related to health and social professionals' participation. Some examples identified by partners are the complicated task to find professionals with enough motivation to participate (for example due to a perceived extra burden), the risk that they drop-out in the middle of the project, and the challenge of dealing with changes of personnel.

As mentioned before, the participation of users in BeyondSilos was indispensable to carry out the project. However, the enrolment of professionals was also crucial to guarantee its success. They are key players in the provision of health and social care. Moreover, they develop an important role in reaching patients, promoting trust in the project, and following-up users' participation to ensure their satisfaction and avoid drop-outs.

For these reasons, it was deemed necessary to examine the experiences in the different sites regarding professionals' enrolment, including the activities performed, problems encountered and corresponding solutions, lessons learnt and risks.

5.2   BSA

Activities performed

- The enrolment of social and health care professionals in the project was considered a challenge for BSA. At the start of the project, some professionals were identified and enrolled in BeyondSilos. Later, some of them had to be replaced by others. The coordinating team supplied these newly recruited professionals with detailed information on the project and training.

Problems/issues faced and solutions

- Some issues arose during the preparatory activities because BSA had to undertake some organisational changes that concerned the professional team. As a result, some of the professionals who were recruited during the "first wave" moved to other areas, and they could not continue with the project. In order to minimise the negative impacts that this could have on BeyondSilos, knowledge of the pilots was transferred to other professionals; the coordinating team worked closely with them in order to ensure the success of the process, and to make their tasks easier.

- Another issue, spotted during the preparatory activities, was that although BSA had experience in similar programmes, some professionals showed a resistance to participate. They thought that it would imply a high work burden for them. In addition, some professionals did not have much confidence in the project, because at the beginning there were some technical incidents. Thanks to the training they received, and their own experience with BeyondSilos, they realised that the solution could be very useful to improve the care provided to patients. For example, in BeyondSilos, users are more controlled because of the alarms and the weekly report. In addition, some professionals believe that with BeyondSilos they could detect early health deterioration in the end users. On the other hand, when technical incidents were solved, their concerns regarding the devices and the portal were reduced. In fact, the professionals valued the project positively because most of their patients, who were assisted when they had any technical problem, told them that they were happy because they received a lot of support from BSA.

Lesson learnt

- It is essential to guarantee proper communication between the coordinating team and those professionals engaged in the project. This is especially important when new professionals join at a later stage.

Risks

- As with user recruitment, one of the main risks is that professionals drop-out from the project. Linked to this, there is the risk that if new professionals enrol in later stages, they miss important information about the pilots.

Phase

- Preparatory phase.

5.3   Amadora

Activities performed

- In Amadora, the active involvement of the relevant professionals was crucial, even more because there was no previous integration of services at home, which means that there was no collaborative work.

- Bearing this in mind, the main activities delivered were the following:
  - Awareness and Kick Off: In order to involve all the relevant health and social workers from Misericordia of Amadora, it was very important to have all the institutions on board. In line with this, the Coordination Team of BeyondSilos organised a launch session to all the Directors and Coordinators of the organisation to introduce and explain the project, and to explain how important it was to count on their collaboration, namely those working in health and social departments; and how important the process could be for the change management process and collaborative work between silos within the organisation.
  - Focus groups: Sessions with social and health workers in order to obtain contributions for the project; but mainly to promote cooperation and motivate them to participate in the project.
  - Training: Initial and continuous joint sessions, for health and social care professionals, about: integrated care; collaborative work; biomedical approach; ICT tools.
  - Regular operational meetings: fortnightly meetings in the first four months of the trial, and on a monthly basis thereafter, promoted and facilitated by the Coordination Team, with participation from the health and social care workers, in order to define roles & tasks, and to monitor the progress of the project.
  - Participation in the change management study developed by the University of Twente: This participation was crucial due to the fact that professionals from the health and social care departments of Misericordia of Amadora could perceive the real importance of collaborative work to boost change management in the organisation.

Problems/issues faced and solutions

- In Amadora, the main issues faced regarded the introduction of collaborative work between social and health care workers, in the Home Care Services delivery, and the engagement of GPs from the public Health Care Centre.

- Collaborative work: strategies to overcome this issue were focused on:
  - the identification of the main relevant actor from both silos;
  - the active involvement of them in the process definition and workflow;
  - highlighting the contributions from both departments for a real integration of services and for the success of the project;

- the clear definition of roles and tasks; and
- the implementation of regular operational meetings.

- Engagement of GPs from public Health Care Centre: It was quite difficult to engage the GPs, but the Portuguese consortium was able to achieve this after the trial started thanks to the following strategies:
  - persistence in the attempts to enrol them, leveraged on periodic meetings with the Coordinator of the public health care centre; and
  - periodic "live demonstrations" of the project, and its progress and added value.

Lesson learnt

- The importance of having a previous and structured plan for professionals' engagement.
- The importance of involving them in the co definition of the process and workflow.
- The importance of a clear communication process, covering a clear definition of roles and tasks.
- The importance of having regular operational meetings.
- The importance of reporting continuously the progress of the project and its added value.

Risks

- During the engagement of professionals, some risks were identified and addressed:
  - potential "conflicts" between health and social care professionals roles and tasks;
  - demotivation of professionals due to overloading them with tasks; and
  - lack of engagement of GPs from the public Health Care Centre.

Issue tracker

- A risk mitigation chart was introduced that covered all phases, status, and the mitigation actions to be taken and when. Regarding the engagement of professionals, the quick identification of the potential risks quickly triggered the mitigation actions introduced and described above under *Problems/issues faced and solutions* and *Lessons learnt.*

Phase

- Preparatory phase.

5.4   Campania

Activities performed

- Some actions were performed to facilitate the work of the professionals enrolled in the project, with the aim to avoid participation being seen as an extra burden, and to ensure that they remained motivated during the whole project. For example, the monitoring devices were placed in the patient's home before the visit of the nurses. Thanks to this, the nurses did not have to carry the devices from the medical centre to the private homes.

- During the local project implementation phase, the project coordination team in Campania tried to involve the Local Health Authority (LHA) of Naples 1. To this end, they produced a Memorandum of Understanding that was signed by the rector of the University of Salerno and the director of the LHA of Naples 1. The effector of the MoU was identified by the LHA Napoli 1 in its geriatric services. They had many meetings with the director of the geriatric services, and prepared a local protocol targeted at its medical personnel. The local protocol included the enrolment by the geriatric services of 25 patients and 25 controls.

- Each patient had a doctor assigned who took care of him/her. When the doctor asked for reports of measurements, a report was provided in a short time.

Problems/issues faced and solutions

- Despite the actions performed to involve the LHA Naples 1, the medical personnel of the geriatric services there were not willing to participate in the project. The Campania coordinating team in BeyondSilos therefore decided to potentiate and reinforce the activity at the Salerno site. Salerno became the only active site and all the expected cases were enrolled there.

Lesson learnt

- It is important to make the work of the professionals in the project as easy as possible. This is essential to promote their participation and ensure that they are fully engaged with the project.

- It is convenient to consider alternative options regarding the institutions from where to recruit health professionals. This would help to deal with situations in which a specific institution refuses to participate.

Risks

- Health professionals can have a low motivation and might refuse to participate. This can be an obstacle for the correct development of the pilots.

Phase

- Operational phase.

5.5   HSCNI

Activities performed

- The goal of these activities was to engage 30 GP practices for the evaluation of the BeyondSilos study.

- GPs were reimbursed for the time they spent gathering data from care recipients for the evaluation, and also for the cost of locum cover to free them up to do this data collection.

Problems/issues faced and solutions

- The site failed to engage 30 GP practices as planned. Even GPs who were very enthusiastic to participate subsequently withdrew from the pilot process because of pressures of work in their practice. Even with the availability of funding, many practices found it impossible to engage locum staff to cover those who needed time to collect patient data.

Lesson learnt

- The enrolment of health professionals is key because it also effects the recruitment of users.

- Time constraints and GPs' heavy workload should be considered, since they can negatively affect the enrolment of health professionals.

Risks

- The main risk faced was not having enough GPs participating. Getting commitment from GP practices to participate in the evaluation process and collect data has been very difficult. Of 18 practices that had attended workshops and had given input to design the SCS, only eight practices agreed to collect the data at enrolment. Of these, the first one started to enrol patients in late June 2016, and the last one in mid-October. The evaluation period ended on 23rd November 2016 with only four GP practices submitting end data.

Phase

- Operational phase.

5.6   Kinzigtal

Activities performed

- The goal of the activities related to the enrolment of professionals was to introduce the BeyondSilos project to GPs and to obtain their consent to participate.

Problems/issues faced and solutions

- One of the GPs from Kinzigtal who participated in the BeyondSilos project decided to move back to Hungary and to sell her practice. That meant that some of the enrolled patients would lose their GP, and would not be provided with the new service. In order to address this, it was necessary to find a replacement. The search for potential candidates started as early as possible, and enough time was assigned to the negotiation phase on practice price and the implementation phase of the new GP. This is especially important if the physician comes from a foreign country. In the present case, the GP was Hungarian.

Lesson learnt

- If some GPs that participate in the project drop out, it is necessary to find an adequate successor as quickly as possible to avoid losing a large number of participants, which could complicate the evaluation tasks. It is necessary to have enough time to carry out the replacement process in an optimal way.

Risks

- GPs might drop out during the pilots. It might be difficult to find an adequate replacement.
- It might be difficult to find GPs willing to participate in the project.

Phase

- Operational phase.

5.7   Valencia

Activities performed

- One of the tasks of the nurses was to engage in an "open conversation" with patients in order to provide them with all the information they needed. For example, nurses explained clearly the meaning of the different sections of the questionnaires that users had to fill in. This had the aim to ensure that patients responded to the questionnaire in the most reliable way possible.

Problems/issues faced and solutions

- While the pilots were running, one of the case management nurses was moved to another health department. There was no immediate substitute for her, and her patients had to be assigned to another case management nurses. This process of reassignment was slow, and had several bureaucratic barriers.
- Some of the nurses that were contacted did not want to participate in the project. They had some patients assigned, but they did not collaborate to facilitate contacts with them. Therefore, this negatively affected users' recruitment.

Lesson learnt

- The organisation should be prepared to act in case there are personnel changes in the middle of the project. The adaptation should be quick and smooth to ensure that the project is not greatly affected.

- If health professionals are not motivated, they might not perform the tasks that are planned for them. Therefore, it is paramount to ensure that the professionals engaged with the project have high levels of motivation.

Risks

- Health professionals might drop out from the project (either voluntarily or because they move to other departments).

- Health professionals might refuse to participate.

Phase

- Operational phase.

5.8   Sofia

Activities performed

- The recruitment of healthcare professional has been a real challenge.

- The social workers were more eager to participate, but were resistant to using ICT.

- Many of the GPs and practices approached refused to investigate the project. Some were offered payment but still declined.

- Specialist doctors were recruited with an interest in the new approaches.

Problems/issues faced and solutions

- It is difficult to recruit GPs. We found participants through personal contacts and peer-to-peer relations.

Lesson learnt

- Health professionals need to be intrinsically motivated. They need to be eager to change routines and adopt new ICT.

Risks

- Health professionals might drop out from the project.

- GPs might refuse to participate.

Phase

- Preparation phase.

6 Organisational changes

6.1 Introduction

This domain refers to organisational aspects that were relevant during the deployment of BeyondSilos. Organisational elements or dysfunctions might, in some cases, increase the difficulty of running the trials. On the other hand, the institutions might apply some organisational changes in order to adapt to the needs of the project and to ensure that it is a success.

In addition, organisations sometimes need to undertake changes that are not directly linked to the project, but that can affect its performance. For example, one change mentioned by various sites in the previous section is the reorganisation of staff. This implied that new professionals willing to participate in the project had to be found and trained.

6.2 BSA

Problems/issues faced and solutions

- Some patients insisted that they wanted to keep the devices from BeyondSilos at home after the end of the project. In order to address this request, BSA is currently working to offer this kind of services at home, which could be facilitated by the fact that the organisation already offers a set of home care services. However, at the moment, it is not possible to offer devices like the ones used in BeyondSilos' project to all BSA patients.

Lessons learnt

- It is convenient to organise beforehand the post-project situation. Especially, it would be optimal to offer some kind of continuation to study participants, because many demand this.

Risks

- Participants might feel disappointed if they cannot continue using the devices after the end of the project. However, institutions might lack the capacity to offer this, or some organisational changes may be required.

Phase

- Operational phase.

6.3 Amadora

Activities performed

- Amadora region, and Misericordia of Amadora (which was the services provider organisation involved in the project), benefited from important changes in its management scheme, given that BeyondSilos introduced integrated care at home in the portfolio of the organisation services.
- Following this, it was very important to involve, complementarily, all the relevant stakeholders in the region, in order to boost the future transference of the model, and also all the relevant stakeholders within Misericordia of Amadora. The main activities delivered were the following:
  - Focus group sessions: delivered to some of the 67 organisations that are part of the Local Council for Social Action managed by the Amadora Municipality, and that gather all the relevant stakeholders of the Council, from Social Area, Health Care, Education, Security forces,etc.; focus group with directors and coordinators of Misericordia of Amadora.

- Awareness / kick-off events: Presentation of the project in a plenary session of the Local Council for Social Action; presentation of the project to all the staff of Misericordia of Amadora; presentation of the project to the medical staff of the public Health Care Centre.
- Awareness / project progress events: Presentation of project interim results in a plenary session of the Local Council for Social Action; presentation of project interim results to Misericordia staff; presentation of the project interim results to the medical staff of the public Health Care Centre.
- Involvement of Misericordia in the Change Management study led by University of Twente.
- Operational meetings with health and social care staff of Misericordia: definition of processes, workflow, roles and tasks.
- Study visit to BSA: The Coordination Team of BeyondSilos, along with the Misericordia Board, identified the need for a study visit to one of the most developed organisation in terms of integrated care in the project, i.e. BSA. This initiative was very well welcomed by BSA staff, and constituted a very important milestone in the definition of an integrated care pathway for Misericordia of Amadora.

Problems/issues faced and solutions

- In Amadora and in Misericordia of Amadora, the main problems identified were related to the introduction of a new service, and with the introduction of ICT tools such as the telemonitoring devices / equipment, and the online platform to store the information.
- Solutions identified were a strong awareness process for what was coming, not only in Misericordia of Amadora, but also in the Council; a "negotiation" process with the Board of Misericordia of Amadora in order to release "quality time" for the professionals to participate in all the awareness and training sessions, and for the dematerialisation of the information and new storage in the online platform; delivering initial and ongoing training sessions for the professionals; a close monitoring and supervision process, in order to have the professionals motivated, and aligned with the specific roles and tasks.

Lessons learnt

- Whenever a new service is being introduced, and especially when it implies collaborative work, it is very import to:
  - "seat" the relevant actors at the same table on a regular basis;
  - involve the Board of the organisation in the change management process;
  - prepare and deliver training sessions;
  - monitor and supervise the processes through regular meetings; and
  - give professionals the necessary time to get used to the new service.

Risks

- For Amadora and Misericordia of Amadora, the main risks were related to :
  - the lack of previous experience in the delivery of integrated care at home;
  - the lack of collaborative work between social and health care departments of the organisation;
  - the lack of expertise in use of telemonitoring tools and online record systems and databases.

Issue tracker

- A risk mitigation chart was introduced that covered all the phases, and the status and mitigation actions to be taken, and when. New and/or old issues used to "appear" in the regular operational meetings through the "voice" of the professionals involved, and through the daily reports of the Home Care Support staff.

Phase

- Both preparatory and operational phase.

6.4   Campania

Problems/issues faced and solutions

- The coordinating team identified that patients were using more glucometer strips than recommended by the project. The first answer was to give more strips to meet patients' demand. However, this was a relevant economic issue, because the budget for each patient was becoming higher than expected. Therefore, the final solution was to tell patients that they should use this device only with the medical team of BeyondSilos. This small organisational change avoided budgetary problems.

- Campania staff distributed the questionnaires among pilot participants.

Lessons learnt

- Expenses need to be closely monitored to ensure that they are in line with the planned budget.

- During the preparatory activities, some patients had difficulties filling in the questionnaire. This was due to the cultural level of the caregiver or because some questions generated discomfort (e.g. questions about income or the ownership of the house). In these cases, parts of the questionnaire were left blank.

- Some devices that were at the storage place of the subcontractor, Magaldi Life, disappeared. The subcontractor provided more devices.

Risks

- If patients use the devices more than planned, the organisation can incur budgetary problems.

Phase

- Both preparatory phase and operational phase.

6.5   HSCNI

Activities performed

- The Shared Care Summary (SCS) was developed in NIECR.

Problems/issues faced and solutions

- In order to ensure that SCS was properly developed, and to avoid future problems with it, different actions were undertaken which concerned several stakeholders. GPs were involved from the beginning in the design of the SCS to ensure that it included fields that they considered useful. In addition, a dedicated Project Manager and Clinical PAs were appointed in BSO to drive the design and build of SCS. The ability to deliver and complete the SCS was positively impacted by eNISAT and RTNI, and it guaranteed the provision of data and the availability of Key Information Summary.

Lessons learnt

- Getting clinician buy-in to use SCS was easier when they could be reassured that large areas of information would be auto-populated. There was much resistance to the idea of GPs having to input information, and concern about who would take responsibility for ensuring the SCS was kept up-to-date.

Risks

- The main risks identified were a failure to reach agreement on the content of the SCS, and a failure to build SCS into ECR.

Phase

- Operational phase.

6.6   Kinzigtal

Activities performed

- Related to the organisational domain, Kinzigtal tried to arrange meetings with social care providers on a regular basis in defined dates in order to promote communication among the personnel involved in the project. However, this was sometimes difficult.

- Mismatch between high expectations of evaluation results and high workload to fill out questionnaires.

Problems/issues faced and solutions

- The project management encountered difficulties getting in touch with the responsible staff such as GPs or nurses in order to obtain information or discuss urgent issues. Most of the health professionals did not respond to e-mails, or they even lacked an e-mail address. It was also difficult to reach them by phone because they were working with patients either in their practice or outside it. This caused a delay in the completing tasks with a clear deadline, such as collecting evaluation data. To address this, Kinzigtal tried to organise face-to-face meetings, but these were not successful. Many of the social care provider staff could not attend the meetings because they had unexpected appointments, or they had an extra workload due to some sick leave.

- During the preparatory activities, some patients had difficulties filling in the questionnaire. This was due to the cultural level of the caregiver or because some questions generated discomfort (e.g. questions about income or the ownership of the house). In these cases, parts of the questionnaire were left blank.

- Most of the data collected for medical data, assessment scores or number of contacts were not extracted electronically but manually from printed patient records. This causes a huge workload, especially for social care provider. Finally, in many cases some data field were left blank.

- In the end, this means that evaluation results might not be as valuable as project partner were expecting at start of BeyondSilos.

Lessons learnt

- During the preparation phase, it is necessary to agree how communication will take place (by phone, face-to-face meetings, etc.). Appointments should take place on a regular basis with a previously agreed date (for example, on the last Monday of each month).

- At start of the project, it must be clarified which objectives should be reached with evaluation framework. There needs to be clear communication about which tasks are necessary to reach the objectives of the evaluation.

Risks

- A lack of proper communication between the project management and the other people in charge of the different tasks might cause delays in the plan, and might prevent the organisation from detecting problems in time.

- Underestimation of workload when defining objectives for evaluation.

Phase

- Operational phase.

6.7   Valencia

Activities performed

- During the preparatory activities, Valencia signed an agreement with a social provider (ATENZIA), which was involved in the organisation of the pilot.

Lessons learnt

- When organisational changes occur, representatives of all kinds of stakeholders need to be involved in order to minimise risks during implementation.

Phase

- Preparatory phase.

6.8   Sofia

Activities performed

- During the preparatory activities, Sofia separated the activities of BS into three domains: health, social and ICT. For each of the domains they set up framework agreements with subcontractors.

Problems/issues faced and solutions

- Some GPs indicated that they lacked enough time to enter medication in the system and track medication reminders. In order to address this issue, training on the functioning of the medication reminders was provided to nurses, who were then able to perform this task.

Lessons learnt

- Time constraints should be considered when planning the organisation of the pilots and assigning tasks to each player.
- If during the pilots it becomes evident that some of the staff cannot fulfil the previously assigned tasks due to heavy workload, the option of transferring some tasks to other employees should be considered.

Risks

- Time restrictions can be a barrier for the success of the project, and might require organisational changes.

Phase

- Both preparatory phase and operational phase.

7 Technical issues

7.1 Introduction

The domain on technical issues has been the one with the most shared experiences. This might be because an significant proportion of the elderly population is not familiar with ICT, and hence might encounter problems when using the technology involved in BeyondSilos. Another explanation might be that technical problems are usually more evident, and prevent the proper functioning of the devices, and thus it is more likely that they will be reported quickly.

This domain includes issues related to the technological infrastructure, software development, software testing, deployment and implantation of developments. Some recurrent issues were that devices did not work properly, that links were lost between devices and web portals, that data was not received as expected, problems with the battery due to being in use for too long, and the fact that part of the elderly and health professionals struggled to use the devices.

7.2 BSA

Activities performed

- During the preparatory activities, BSA had to undertake some actions to ensure that the relationship between users and devices was as easy as possible, and to avoid losing credibility and confidence on the data collection process. SIM cards were introduced in the tablets to be used in the study, but this implied that mobile phone operators could phone users and send them notifications (SMS, emails, etc.). This could annoy users, add an extra burden, and decrease the confidence in the project (BSA is a public health system, hence it could seem strange to receive calls from private companies in the devices provided by the organisation). In order to prevent these potential problems, BSA blocked all tablets to avoid the reception of these calls and notifications. This action was especially important for this project, in which most users lacked experience and knowledge on IT.

Problems/issues faced and solutions

- Regarding the telemonitoring solution deployed at the patient's home, when somebody tried to delete a wrong measurement from the Tablet-PC (for example, because someone else other than the assisted person used the device), this not only deleted the result, but also the link between the telemonitoring solution and the back-end portal. If when trying to restore the link, this was done with the SIM card attached, the link was established between the MAC address of the SIM card and the back-end portal resulting in a wrong link. The technology provider was informed about this issue. The provisional solution was to restore the link without the SIM card inside, and creating the link with the back-end portal through a WiFi connection. This was not always easy because there was normally no WiFi available at the patient's home, and the connection had to be done through a mobile phone in hotspot mode.

- BSA detected that some tablets were not working properly about 15 days after the beginning of the trial. These tablets burned out due to battery issues, and it was a problem for some patients who could not turn them on. This was a technical incident, but it was very important because it happened at the very beginning of the trial, when the deployment of the BeyondSilos service process model was starting, and when it was essential for users not to lose confidence. The issue was examined, and it was concluded that these tablets could not work well if they were switched-on 24 hours per day, over eight months, with the screen lit while plugged in. Within these conditions, a tablet works correctly for 10 to 15 days, but after this time it does not. In order to deal with this problem, some instructions and recommendations were issued. These specified the steps to take when the problem arises. If the tablet was not cold, it had to be unplugged from the

electricity for approximately 10 minutes. Then, the tablet had to be reset by using four buttons during approximately 10 seconds. Finally, the tablet could be switched on and it would work correctly again. However, to avoid this situation, it was recommended to turn on the tablet only when it had to be used to take measurements (with the different devices). Afterwards, it should be turned off. In addition, it was recommended to connect the charger when the battery capacity was at 20%. These recommendations were explained to end users and caregivers face-to-face, by telephone and through the different documents provided (User's Guide, fast reference manual, etc.).

- Some problems were detected between the BSA web portal and the different devices. BSA found out that the portal had not received data from some tablets. Some actions were undertaken to address this issue. First, BSA phoned the users to investigate what had happened. In these calls, some patients recognised that they had not used the devices. As a response, BSA personnel encouraged them to start using the solutions. On the other hand, some tablets appeared to have configuration problems related to the MAC address. Finally, there were problems with the 3G coverage at user's homes. The helpdesk called users to solve this, and when necessary BSA personnel visited users' homes. Fortunately, all users had WiFi, and thus it was possible to configure the tablets with WiFi; they then began to send all stored data.

- A doctor reported that a tablet installed in a patient's home was giving system errors, and some services, such as Start TouchWiz, had stopped working. It was impossible to restart or turn off the tablet, as similar errors were constantly displayed on the screen. A BSA technician went to the patient's home. First, he restarted manually the tablet with the button ON / OFF, and the two buttons of volume up / down (the three buttons at the same time). As a result, the tablet turned off and when it turned on again, it worked correctly.

- During the first wave, some professionals detected a persistent problem with the oximeters that affected some specific patients, although not daily. In these cases, the oximeter did not send correctly the measurements by Bluetooth to the tablet. The tablet could receive three kinds of different measurements: SPO% = 0 (this occurred when the oximeter was put on the finger but had sent data to the tablet before starting the measurement); SPO% = 4x (this occurred when the oximeter registered a correct measurement, after first giving the error measurement of SPO% = 0; the value of SPO% = 4x represented the average of 0 and 9x); and SPO% = 9x (the correct measurement that should have been sent at the beginning). In order to solve the problem, BSA helpdesk team contacted the services provider, who concluded that there might be a problem with the finger of the patient. It could be that the finger was cold, wet or too wrinkled, which could lead to wrong measurements. In order to address these issues, the helpdesk explained to patients that they should persist until the oximeter sent the measurement correctly. For this, the patient had to remove the device from the finger, ensure that the finger was not cold or wet, and try to take the measurement again until an optimal measurement was obtained (above 90% of SPO). Sometimes several tries (around 4 or 5) were required, which could have entailed a loss confidence of the professionals, even if the problem was solved. For this reason, BSA did not set any alert about the SPO%.

- Some tablets had to be replaced because Bluetooth was not working. In other cases, it was not working because users or their relatives had changed some items in the tablet, and had disconnected the Bluetooth option. To solve this, BSA had to retrain some users and their families. In this "new training", the focus was on the fact that only BSA users were allowed to use the tablets. In fact, they signed this in the informed consent.

Lesson learnt

- Before starting the deployment, it is necessary to check if there is sufficient 3G coverage or WiFi available at user's homes.

Risks

- Several technical issues might interrupt the development of the trial. If these interruptions are too long or frequent, they could seriously damage the outcomes of the project.

- If technical issues occur often, users might decide to drop-out.

- It can take some time to detect a technical problem; for example, users might not realise that there is a problem, or they might not be aware of the importance of communicating it. This implies that data collection might be interrupted for a long period.

Phase

- Both preparatory phase and operational phase.

7.3 Amadora

Activities performed

- In Amadora pilot site, some activities were delivered in both the preparatory and deployment phase, in order to reduce technical constraints and/or problems, such as:

- Preparatory phase: Training health and social professionals and informal carers on how to use the equipment / devices and the online platform; regular reporting to Portugal Telecom (ICT provider) about new needs in terms of functionalities of the online platform (installed on laptops, smartphones and TV).

- Deployment phase: creation and implementation of three channels to report problems: online folder with a Reporting Errors template; technical reports on the operational meetings; face-to-face daily reports to the Coordination Team. Another activity was the fortnightly online meetings with Portugal Telecom (in the first four months) and monthly meetings thereafter.

Problems/issues faced and solutions

- During the pilot phase, Misericordia of Amadora faced several challenges on technical issues, such as:

- Late delivery of the ICT solutions: Amadora had to delay the start of the trial due to the acquisition of Portugal Telecom by another group, which delayed all the processes of delivering and testing the equipment / devices of teleassistance and telemonitoring, and, also the online platform.

- Lack of / missing the necessary information blocks in the online platform: the constant redesign and upgrade was a progressive process, in order to cover the complete social and health status of the end users, and in addition, not only current data but also historic data. There was also a need to include "open text fields", so that the staff involved in service delivery could communicate and provide feedback regarding the inputs inserted in the platform.

- Access / permissions to edit data on the online platform: the match between the role of the professionals in the project and the necessary permissions to edit the platform data was quite a slow and confused process with Portugal Telecom.

- Difficulty to connect the telemonitoring devices with smartphones: During the first three months of the trial, there were several constraints regarding Bluetooth interoperability between the telemonitoring devices and smartphones; this meant the need to replacement some smartphones, and also some telemonitoring devices.

- Teleassistance installation: there was a constraint regarding the high number of end users without either a fixed telephone line or a contract with Portugal Telecom. This made it necessary to put in place mobile teleassistance equipment, which delayed entry into the trial.

Lesson learnt

- Based on the several challenges faced during the implementation process, the Coordination Team highlighted the following lessons learnt: the importance of a good and robust analysis of all the steps needed for installation and use of the equipment / devices; the importance of having a good communication process and understanding between ICT professionals and health and social care professionals; the importance of a good testing process before deploying the solutions; the importance of structuring and delivering initial and continuous training sessions in the use of ICT.

Risks

- Demotivation of professionals and end users.
- Missing end users data.
- Errors in the manual insertion of data due to technological failure.

Issue tracker

- A risk mitigation chart was introduced that covered all the phases, status and the mitigation actions to be taken and when. It was also very important to introduce regular online meetings with the ICT Department of Portugal Telecom in order to overcome the problems, and also have constant contact, by phone, with the ICT developers.

Phase

- Both preparatory and operational phase.

7.4 Campania

Activities performed

- Campania carefully oversaw the development of the ICT solutions in order to identify technical issues and provide a timely solution to them.

Problems/issues faced and solutions

- Batteries at the user's home had a very short life because the devices for telemonitoring were often on standby. In particular, the batteries of the blood pressure meter did not last very long, resulting in the need to change batteries too often. After a while, patients were instructed to remove the batteries from the device at the end of the measurement, and keep them out until the next measurement.

- The audio confirmation of the parameter value that the mobile phone emits generated anxiety in patients when values deviate from the norm. To avoid this, staff were instructed to turn down the mobile phone volume, and to repeat the measurement in case of an anomaly.

- The oximeter needed a long time to get the measurement. In order to speed the process, users were recommended to rub their hand before staff performed the measurement. However, the problem was not always solved.

- The weight scale presented difficulties because many patients were not able to maintain their balance for long enough without help.

Lesson learnt

- Technological devices should have an optimal functioning and they should be user-friendly for the elderly. In this in mind, it is convenient to check that the devices do not run out of battery too quickly, and that the measurements can be performed easily.

Risks

- Devices can run out of battery quickly, especially if they are always left on, or on standby.

- Devices can have problems taking measurements, or they can give wrong values.

Phase

- Operational phase.

7.5   HSCNI

Activities performed

- The RTNI system had to be integrated with the NIECR system. Similarly, the eNISAT had to be integrated with the NIECR system. The three systems previously existed, and were already used in a live environment.

Problems/issues faced and solutions

- In order to deal with technical aspects in an optimal manner, meetings took place from early on in the project between the RTNI contractor (TF3) and the HSC Business Services Organisation (BSO), which oversaw the operation of and changes to the NIECR system. The challenge was to provide detailed specifications for the information to be integrated, and to engage with the NIECR contractor (Orion). Likewise, meetings took place between NIECR team and eNISAT team in BSO to scope integration and identify technical issues.

Lesson learnt

- It is never too early to get all parties around the table to start looking at the specifications for the work to be done. When working within an already live system, pilot projects will inevitably have to play second fiddle to issues that impact on the operation of the live service. Delivery is facilitated by direct supplier engagement.

Risks

- RTNI integration with the NIECR, and eNISAT integration with the NIECR, are the original two main outcomes of the BeyondSilos project in Northern Ireland. There was a risk that if the integration did not happen successfully, this would have had a major impact on the Region delivering its part of the project. NIECR was upgraded during a crucial phase of the project resulting on a freeze on all new developments; this led to significant delays in the project work.

Phase

- Operational phase.

7.6   Kinzigtal

Activities performed

- The social care staff communicated any technical problems / difficulty that they had to the IT department, which investigated the possible causes of these and provided solutions.

Problems/issues faced and solutions

- Kinzigtal faced technical problems after handing out tablets to the social care institution. It was not possible to enter data in the electronic patient record system. In fact, data was entered via the tablets, but it did not appear in the GPs' electronic patient system. The IT department was not able to identify the error that was causing this, but it was solved by deleting the accounts and creating

new ones. Maybe the errors were caused by the existence of several updates and/or because some components of the old accounts were corrupted.

- Sometimes, the system could not find the master dataset in the electronic patient record platform, and the access was denied. This was caused by mistakes in entering patients' master data (such as a wrong street name) which occurred several times. In order to minimise the likelihood of errors like this, the social care institution made sure to have a copy of the patient's master data sheet before registering him/her in the system, in order to cross check that the data was the same.

- During the operation of BeyondSilos, the social care staff realised that it was very difficult to push buttons and enter the data into the tablet by working with a digital keyboard on the device. It took a lot of time, and the staff found this stressful. These problems were reduced by using a Bluetooth mouse and navigating through the system by clicking on buttons. However, they still had some difficulties in entering data with the internal keyboard.

- Social care staff explained that sometimes when they tried to enter the interface software DocAccess via their tablets, in order to connect with the central electronic patient record, an error message appeared: "link could not be found". This error occurred with three tablets; it might have been caused by a Windows update of the operation system that started automatically. This update deleted the specific link for accessing the electronic patient record. After updating the DocAccess software, the link appeared again. However, the technical staff were required to monitor whether this error appeared again.

- Some tablets of social care staff were infected by a virus as a consequence of downloading unprotected apps and software. This problem was addressed by advising the staff not to use the tablets for entertainment. In addition, devices were checked on a regularly basis for updates and virus protection.

Lesson learnt

- New technologies or devices should only be used for their intended purpose.
- Creating new accounts and deleting the old ones might help to solve technical issues.
- Devices should be user-friendly, so that they can be easily used by social care staff.

Risks

- Small mistakes, such as errors in the patients' personal data, can cause technical problems. Software updates might also generate issues.
- Staff might have difficulties in using the technological devices. Technical problems can create obstacles to the tasks of social care personnel.

Phase

- Operational phase.

7.7   Valencia

Activities performed

- The staff responsible for BeyondSilos in Valencia detected some technical problems. TSB addressed some of them, in other cases it was necessay to purchase new devices.

Problems/issues faced and solutions

- During the operation, several PC tablets were not working. For example, one tablet did not upload the patient's data. Another one had a faulty SIM card that did not synchronise with the PC tablet. Similarly, the tablet system of one of the patients shut down.

- One of the blood pressure devices did not work properly; it was sending wrong measurements. It was necessary to purchase new devices to replace those that were not working (PC tablets, blood pressure devices).

- Some errors were reported in relation to the Nomhad platform. Nurses could not save the patients data in the platform. TSB changed the access route to the platform for those nurses whose computers did not save the patients' data.

- The software was stuck when patients pressed the enter button three times (with or without entering the PIN number). To solve this, TSB had to refresh the tablet software in order to change the enter screen. There was a login password failure with another tablet, and it was impossible to send data. The password had to be rebooted.

- There was an issue of incompatibility of the social teleassistance devices with Vodafone. Patients were required to buy a voice box to use this service. The solution was to offer patients to continue only with the tablet service if they agreed.

Lesson learnt

- Some budget should be allocated for potential new purchases of equipment in case some devices need to be replaced.

- Check before-hand that the technological devices are compatible with the telecommunications company.

Risks

- Some technological devices might be faulty.

- Problems might arise regarding the collection and upload of data.

- Errors with the passwords might cause technical issues.

Phase

- Operational phase.

7.8   Sofia

Activities performed

- Technical support was provided to address any technical issue that might arise and to help elderly use the ICT devices.

Problems/issues faced and solutions

- Elderly people found it difficult to use a standard Android smartphone. To address this, the technical team installed an interface with large icons, in Bulgarian.

- Data from blood pressure measurements was lacking for several new users. This was solved by updating the smartphone firmware.

Lesson learnt

- It is essential to solve technical problems in order to allow the continuation of the trial, and to avoid drop-outs by users.

Risks

- The complexity of the technical solutions demands an ongoing technical support. Recurrent technical problems can frustrate users and might be a reason to leave the service.

Phase

- Both preparatory phase and operational phase.

8   Helpdesk

8.1   Introduction

This section shows the experiences shared in relation to the helpdesk. The sites set up their support structures as planned, and started to provide functional and technical support to the service users, as well as to health professionals. This support was key to engaging users in the project, and to promoting the image of technology as a tool to empower older people, rather than as a barrier. Issues encountered within the helpdesk have been reported through the RAIL tool in order to allow for further exchange of experiences amongst sites and projects. Some of these issues were difficulties in reaching the helpdesk (due to an unsuitable timetable or outdated contact details), the fact that sometimes users failed to communicate technical issues or other incidents, and weekly reports that were not received as expected.

8.2   BSA

Activities performed

- Helpdesk services were implemented in BSA in order to support end users during the trial, and to address any issues that could arise. For example, the helpdesk detected that some users had Bluetooth disconnections.

- BSA technical team configured a set of parameters in the portal web for each patient that participated in the trial. Examples of these parameters are the alerts and the report that were sent to professionals on a weekly basis (Wednesdays at 12:00). Once the patient ended the study, the configuration of the alerts and reports for that patient were erased, in order to avoid false alerts or reports without content.

- BSA considered that the regular attention by telephone and/or email, besides face-to-face attention, was very important for the participants. Because of that, participants could phone from Monday to Friday, from 08:00 to 17:00 hours.

Problems/issues faced and solutions

- BSA received a report without content from a patient who was not enrolled anymore in the pilot. To solve this, the helpdesk team first confirmed that the user had been deleted correctly. Since after one week the problem persisted, the helpdesk contacted the recruiter professional in charge of the patient and also explained the problem to the service provider. However, BSA continued receiving the weekly report from this patient. Finally, the service provider explained that they had had a problem with their database, and the issue was solved.

- A professional notified the helpdesk that they were not receiving any weekly report from patients. As a response, the management team began to check the parameters in the web portal looking for a wrong setup. However, everything seemed to be correct. Since the following week the reports were not received, BSA contacted the service provider, explaining the problem and providing all the information that they had. Six days later, the provider informed BSA that it was due to a configuration change in their firewall, and they solved the problem. The following day, all weekly reports were received correctly.

- Sometimes users did not communicate technical or other incidents. For example, BSA had an internal process to replace the battery of devices, but sometimes users did not inform that the battery had expired. Then, BSA personnel had to call them to investigate what had happened. The reasons for not communicating this problem was sometimes that they did not know that the tablet did not work due to the battery, but also that they did not want to disturb BSA employees. The solution was to strengthen the communication channels.

Lesson learnt

- It is important that the helpdesk regularly checks that everything is working fine, and that it is able to promptly contact the service provider if a problem is detected.

- It is essential to explain to users the meaning and goal of the study, and to emphasise the importance of using the communication channels when any technical issue arises, so that the study can resume as quickly as possible.

Risks

- If the helpdesk had not contacted the service provider on time, several weekly reports might have been lost.

- If users do not communicate problems, it might take some time to detect them.

Phase

- Operational phase.

8.3   Amadora

Activities performed

- Portugal Telecom, the ICT provider, also acted as Help Desk assistant to all the members of the Coordination Team and health and social care professionals. The department of ICT development of Portugal Telecom is based in Aveiro, in the north of Portugal. Because of this, the Coordination Team arranged regular online meetings with the ICT Team, on a fortnightly basis in the first four months of the trial, and on a monthly basis thereafter. These meeting had the aim of "feeding" the platform with new inputs and functionalities, producing new versions of the ICT solution; and also to identify errors / constraints and solve them.

- In addition, all the health and social care professionals had direct access to the ICT developers, through email and mobile phone.

- One of the tasks of the operational staff of the Coordination Team was to identify and collect errors and constraints, and report them to the ICT Team, in order to solve them.

Problems/issues faced and solutions

- Apart from the important delay to the start of the trial due to the commercial acquisition of Portugal Telecom by other group, the ICT Team was available all the time, and was very quick to correct errors, and to update the platform with new versions that included new functionalities.

- The main issue was the barrier of the jargon that sometimes existed between ICT "language" and the "language" of the health and social care professionals.

Lesson learnt

- The few issues faced cannot be isolated from important preparatory actions that were put in place. Preparatory meetings were held with Portugal Telecom, along with a study visit to Aveiro and another meeting in Amadora. These helped to better know not only the professionals, but the persons behind the professionals, and were crucial to creating a confident relationship, and to define what was expected from each side.

- Regarding the specific issue of a common "language", this was controlled by the intensive meetings and outstanding commitment from each side.

Risks

- Loss of critical data from the patients

- Demotivation of professionals

- Lack of capacity to promote a secure environment for the end users.

Issue tracker

- A risk mitigation chart was introduced that covered all the phases, status and the mitigation actions to be taken and when. For this topic, the main issue was the "jargon" barrier between ICT professionals and health and social care professionals, which was overcome by regular and intensive contacts.

Phase

- Both preparatory and Operational phase.

8.4 Campania

Activities performed

- The Help Desk in Campania was originally thought of as a service for users to establish contact with the nurses in order to confirm or change appointments, or to report issues with the devices.

Problems/issues faced and solutions

- The users also called for health related problems, such as fever, cough, astenia, increased blood pressure and other acute health issues. This was not among the competence of the call centre, since emergency calls in Italy have to be handled by GPs or emergency service (1-80 number). The nurses answering the phone realised that they needed a protocol / codebook to respond to such issues, even if they had to forward these calls to the appropriate professional.

Lesson learnt

- The availability of a call centre increases the expectations of the users.

Risks

- The call centre can be considered as an emergency number to call, although this is not its role.

Phase

- Operational phase.

8.5 HSCNI

Not applicable for HSCNI.

8.6 Kinzigtal

Activities performed

- Health professionals in Kinzigtal were given the contact details of the helpdesk (name, email and phone number) so that they could easily reach it if any issue arose. These details also appeared in the manuals for using BeyondSilos services.

Problems/issues faced and solutions

- The company in charge of the helpdesk services moved to another location. There were also personnel changes within the helpdesk.

- When health professionals tried to contact the helpdesk, they could not reach it, because the contact details were not up to date.

Lesson learnt

- Guidebooks and manuals should contain the latest information available, and updates should be sent to users on time.

Risks

- If users cannot reach the helpdesk, they can feel frustrated.

Phase

- Operational phase.

8.7   Valencia

Not applicable for Valencia.

8.8   Sofia

Activities performed

- A Call Centre service was established to provide support to users. Users could call the helpdesk to ask for information, report technical problems, etc. Later on, the protocol changed, and it was decided that the Call Centre would call users if they had not received any communication from them for three days. This turned out to be more convenient for care recipients, and made the follow-up of the trial easier.

Problems/issues faced and solutions

- Several patients phoned the Call Centre outside working hours, and thus could not access the support that they were expecting. In order to facilitate users' access to the helpdesk, the Call Centre service was extended to 12 hours: from 08:00 to 20:00.

- The initial protocol stated that users should phone the Call Centre on a daily basis, and when needed. Some users did not like this obligation. Therefore, the responsibility for initiating the calls was shifted to the Call Centre personnel.

Lesson learnt

- The helpdesk should have a proactive attitude and call users to check that everything is working fine, rather than just waiting to receive calls from them.

Risks

- Users might fail to call the helpdesk promptly when they encounter a problem. Therefore, the helpdesk might have difficulties in detecting and addressing issues.

Phase

- Operational phase.

9   Training

9.1   Introduction

This section presents the work done in each site in the training domain. The goal of the training was to provide information and to teach skills to the participants in BeyondSilos (elderly, relatives, health professionals, etc.) in order to enable them to carry out the assigned tasks successfully. Training programmes were tailored to the needs and characteristics of each site and type of user. The provision of training was essential and challenging, because most recipients had low ICT skills. Therefore, they were not able to use the devices without support, and sometimes it took longer for them to learn the skills. This especially concerned the elderly, but also caregivers and health professionals. Apart from teaching skills, another goal of the training was to emphasise the importance of following the treatment, with the aim to avoid drop-outs, or that users stopped treatment for a long period, for instance during holidays. In general, training was not limited to an initial session; support was provided throughout the project.

9.2   BSA

Activities performed

- BSA provided dedicated training to the target populations; this training depended on the target group addressed. Although some end-users and their caregivers had sufficient ICT competences to use different devices without problems, most did not have these competences, so the training was very important to avoid problems related to the lack of ICT skills.

- Training was also provided to professionals, and helped them feel more confident about the benefits of the project, and increased their willingness to participate.

Problems/issues faced and solutions

- During the preparatory activities, it was identified that many end-users had low ICT skills, which made it more difficult for them to follow the training. The approach was to train the end users by different channels, and to have a contingency plan to avoid problems or to solve them as soon as possible. During the process, users learnt or improved their ICT skills, reducing their lack of expertise in the use of technology. The training started with an oral explanation to inform both the end-user and caregiver about everything. After that, there was a training session in their homes, because this setting was considered very important to create an atmosphere of confidence. The doctor and/or nurse who took care of the patient in the homecare setting were the first people to training them, which also increased patients' confidence and familiarity with the project. After this, participants had different channels to ask for or to order anything linked to the project (training, resources…).

- Often caregivers had enough ICT competences to use the technology and support end-users on this. However, in some cases BSA detected that caregivers also lacked the required ICT skills. Therefore, it was very important to also provide training to them. Caregivers and end-users were trained through different channels to better address their needs.

- During operation, some problems were detected with some Long Term Pathway users related to holiday periods. For example, in summer some people left for a long time, during which they did not use the devices and did not follow the treatment. In addition, most of them did not say anything about it. To avoid this, their referring health professional insisted on the importance of following the treatment. Moreover, this was detected in the platform, and staff were able to see the information. When the user returned from his/her holidays, BSA personnel insisted on following the treatment, stressing its importance for improving and/or maintaining the patient's health status. Later on, before the Easter break, BSA professionals talked with their patients about

the importance of following the treatment. This action was considered key to achieve the parallel goal that users take responsibility for their own health.

Lesson learnt

- The support from caregivers is very important, thus it is necessary to involve them in all the training activities. Similarly, it is key to involve the doctor and/or nurse that usually take care of the patient.
- Some users interrupted the treatment during summer holidays. To avoid this, it is a good idea to talk with patients before the holiday periods, in order to stress the importance of following the treatment.
- It is useful to adapt the training to the needs of the different types of end-users and caregivers.

Risks

- If not enough training is provided, end-users might not be able to use the devices properly, especially those with low ICT skills.
- Treatment can be interrupted during holiday periods.

Phase

- Both preparatory phase and operational phase.

9.3   Amadora

Activities performed

- Training was a very critical topic in Amadora pilot site, even more because BeyondSilos represented a new service for both the region and Misericordia of Amadora. During the preparatory phase, the Coordination Team defined target groups, contents to be delivered, and the frequency of the sessions.
- Two days of initial training took place in the Misericordia of Amadora Auditorium, delivered to health and social care professionals, and informal carers. The contents focused on providing social and health care and ICT usage, following these topics: role and status of the carer; communication; satisfaction of daily life activities from an environmental and personal perspective; biomedical approach; telemonitoring and online platform; teleassistance.
- Regarding the training for end users, this was a more individual and specific format, delivered at home, and focused on the ICT Tools.
- Regular training took place on a quarterly basis to health / social professionals and informal carers; the contents were based on refreshing the initial training, and on specific contents requested by the end users, professionals and informal carers, namely ICT usage.

Problems/issues faced and solutions

- The main issues were related to the obvious difficulty of providing all the guidance on ICT tools during training sessions. That is why the Coordination Team reinforced the ICT theme in all the ongoing training sessions.
- On a train-the-trainers format, the Operational Team and some key staff were trained to provide daily support to all the professionals involved and to the end users.

Lesson learnt

- The importance of structure and plan continuous training.

- The importance of having training sessions attended by different categories of stakeholders, such as health and social care professionals, and informal carers.
- The importance of providing training to the end users in their comfort zone, i.e. their houses.

Risks

- If training was not an important topic, the following risks could acquire a much bigger dimension:
  - lack of capacity of end users to adapt to technology;
  - slowness in the process of adaptation of professionals to ICT Tools;
  - demotivation of professionals and end users.

Issue tracker

- A risk mitigation chart was introduced that covered all the phases, status and the mitigation actions to be taken and when. All the professionals and informal carers involved reported, on a daily basis, all the training needs. All these needs were also collected during the operational meetings. The Coordination Team collected the needs and embedded them in the process delivery.

Phase

- Both preparatory and operational phase.

9.4   Campania

Activities performed

- Campania organised training session to teach professionals (specialists and nurses) how to use the technological devices for users, how to use the technologies, and how to teach the users how to use them for self-management.

Problems/issues faced and solutions

- Professionals found the technology easy to use, but they underestimated the lack of ICT knowledge of patients, in particular elderly patients. Therefore the training of patients in some cases required teaching skills by the operators.

Lesson learnt

- Patients' need for technology skills is often underestimated; the digital gap is often a generational gap. It needs specific skills in pedagogical and informatics to be addressed.

Risks

- Pedagogic skills might be required for health professionals in order to involve patients in the use of the service and the technology involved.

Phase

- Preparation phase.

9.5   HSCNI

Not applicable for HSCNI.

9.6   Kinzigtal

Activities performed

- Training was only provided to professionals of the social care provider because GPs were already familiar with using ICT in terms of electronic patient record. Training of about 6 people were necessary to feel more confident about using BS service, the benefits of the project and increased their willingness to participate.

Problems/issues faced and solutions

- During the pilot activities, technical problems occurred so that it was impossible to use devices and ICT infrastructure. After this period, which lasted about two to four weeks, staff forgot how to handle the system. But staff did not report problems; they tried to manage the problem themselves by trial and error, which led to time spent in their daily work, and finally to a reduced frequency using BS service. It was an initiative of project management of Gesundes Kinzigtal to offer refresher training sessions for the social care team. In a second face-to-face meeting with IT experts, training was given to caregivers. Finally they were grateful that they again felt comfortable using BS service.

Lesson learnt

- The support from caregivers is very important, thus it is necessary to involve them in all the training activities and keep them updated. Periodically (every two months), social care staff were asked by project management of Gesundes Kinzigtal to refresh their expertise.

Risks

- If not enough training is provided, end-users might not be able to use the devices properly, especially those with low ICT skills; their fear of new technologies rises, and finally they refuse to face the challenge.

- Especially if majority of staff have low ICT skills, the risk of a negative group dynamic exists that affects the minority who are familiar with using the BS service. Over time, they also neglect to work with BS service.

Phase

- Preparation phase.

9.7   Valencia

Activities performed

- Valencia organised an initial training session to teach users how to use the technologies for self-management.

Problems/issues faced and solutions

- The initial training session proved to be insufficient to fully enable patients to use the devices in BeyondSilos. Consequently, initial training was supported with some user-friendly material that was left at patients' homes, which could be consulted by patients at any time. Remote support was also provided.

Lesson learnt

- Patients need more than an initial training session to gain the required skills to use the self-management technologies. The provision of printed material and some kind of remote support is therefore very useful.

Risks

- There is a risk in assuming that the information provided at the beginning of the project is enough. Users are probably unable to learn all the required skills in one day.

- Further training needs might arise that were not foreseen during the planning of the initial training session.

Phase

- Operational phase.

9.8   Sofia

Activities performed

- Initial training was provided to all professional and care recipients.

Problems/issues faced and solutions

- Despite receiving some training, elderly people found it difficult to operate smartphones with small icons and an English interface. In order to address this, the technical team started installing the Necta launcher with large icons and a Bulgarian interface.

Lesson learnt

- Training, as well as the software and hardware, must be tailored to the needs of each site. For example, it should be available in the users' native language.

Risks

- The initial training might not be enough for the full use of ICT components of BS.

Phase

- Operational phase.

10   Ethical-legal aspects

10.1   Introduction

This section shows the work done in each site in the last domain: ethical-legal aspects. It is mandatory that each of the BeyondSilos pilots is operated according to European data protection standards as well as related legislation / regulations enacted at each site. As the project aims at cross-sectoral service delivery, different sectoral legislative / regulative data protection frameworks may deserve attention. In addition, organisational and/or occupational codes of practice may exist at a given site which, although they may not be legally binding, must be adhered to when it comes to data protection / privacy.

As in the case of data protection, adherence to existing ethics legislation and standards needs to be ensured for each trial. On the one hand, a formal ethics approval was required to be sought according to national regulation. On the other hand, key ethical principles needed to be followed even if such a formal ethics approval was not required according to national regulation.

10.2   BSA

Activities performed

- To start the operational phase, BSA had to go through the Local Investigation Ethical Committee to get their approval. When presenting the documentation to the Ethical Committee, the study protocol and the codebook must also be delivered.

Problems/issues faced and solutions

- A problem arose during the preparatory activities. When the information had to be presented to the Ethical Committee, the codebook was not in place, even though the generic indicators to be collected were clearly specified in the study protocol. Because of this, BSA got a nonconformity from the Committee which delayed the process.

- As a solution, BSA committed to deliver the codebook to the Ethical Committee as soon as it was finalised, in order to get approval and avoid postponing the start of the operational phase, which would have led to significant delays.

Lessons learnt

- When preparing the documentation for the Local Investigation Ethical Committee, the anonymised codebook must be clearly specified and attached to the study protocol. The study protocol may already contain a list of the data to be collected, but it is also necessary to provide a more detailed specification which is made with the codebook.

Risks

- If the documentation presented to the Ethical Committee misses some important parts, the Committee might fail to give approval to perform the trial, which could result in delays.

Phase

- Preparatory phase.

10.3   Amadora

Activities performed

- Amadora submitted the necessary documentation to the Ethical Committee in order to obtain approval. Another important aspect was the signing of the Informed Consent form by the end users.

Problems/issues faced and solutions

- The main problem faced was the delay in obtaining a response from the Ethical Committee.

Lessons learnt

- Submit documents to the Ethical Committee in good time.

Risks

- The main risk faced was the delay in starting the trial. In reality, this delay was not the main cause of the delay tot he trial, which was caused by the acquisition of Portugal Telecom.

Phase

- Both preparatory phase and operational phase.

10.4   Campania

Nothing reported.

10.5   HSCNI

Not applicable for HSCNI.

10.6   Kinzigtal

Nothing reported.

10.7   Valencia

Activities performed

- Valencia submitted the required documents, such as the study protocol, to the ethical committee in order to get its approval.

Lessons learnt

- It is key to ensure that all documents submitted to the ethical committee are up-to-date and definitive, to avoid having to amend the study protocol, because this then needs to wait for at least one month before being sent again to the local ethical committee.

Risks

- The procedures related to the ethical committees might be long, which could delay the trial if these issues are not planned with sufficient time.

Phase

- Preparatory phase.

10.8   Sofia

Activities performed

- CPRH, FPI and Divaro were registered as operators of personal information due to the nature of the information collected for BeyondSilos. The registration entailed a review of the software and internal procedures by the State authority.

Problems/issues faced and solutions

- Many care recipients were conscious of providing personal data.
- The bare minimum of personal data was collected.

Lessons learnt

- It is very important to define and communicate the scope of the new services, in order to avoid wrong expectations.

Risks

- Patients might have high expectations of the new service that cannot be met.

Phase

- Both preparatory phase and operational phase.

11 Conclusions

11.1 General

This section summarises the information previously described for each specific domain.

Recruiting patients

Regarding users' recruitment, BeyondSilos' partners encountered some difficulties when trying to convince patients to participate in the project; moreover, they suffered some drop-outs during the study. Both implied that sites struggled to reach the target number of participants. Some barriers to recruitment of users were that:

- they did not see clear motivations to enrol;
- they perceived ICT tools as too complicated for them; and
- filling in questionnaires and going through lengthy interviews required too much effort.

Sometimes patients accepted to participate, but then changed their mind when personnel went to their homes to do the installation. Some end-users had to be removed from the participants' sample because they did not have a landline phone. On other occasions, it was the caregiver who refused to participate, due to not having enough information, considering that this would represent an extra burden for them, etc. Therefore, it is very important to involve caregivers during training and information sessions.

Sites realised that communication is an essential factor for the success of the project, as well as emphasising the importance of users' participation for the improvement of the management of health. In addition, they learnt that it is very useful to involve health professionals (GPs, nurses, etc.) in user recruitment, since they often represent the most efficient channel to reach patients. Another lesson learnt is that it would be convenient to consider in advance the possibility of involving other organisations that could extend the pool of potential participants, and thus help to reach target numbers of participants.

Enrolling professionals

Pilot sites also experienced some difficulties in enrolling professionals. Some of them were insufficiently motivated to participate, and perceived the project as an extra burden to their already heavy workload. In fact, some withdrew due to pressures of work in their practice. Others dropped out because they moved to another position, either voluntarily or due to a reorganisation of personnel, which is common in health institutions.

Finding motivated professionals to participate in the project, avoiding drop-outs or being able to deal with them quickly, proved essential for the functioning of the trials, not only because professionals are key players in the provision of health and social care, but also because they can reach patients better, and can motivate them to participate.

Some important actions to reach this goal are to provide information on the expected benefits of the solution, to make their work as easy as possible, to address promptly technical incidents, and to reimburse the extra time they spend on the project or engage locum staff to cover them.

Organisational changes

The main organisational change that sites experienced during BeyondSilos was, as mentioned above, personnel restructuring. This implied that new staff had to be recruited and trained. Partners realised that

this process needed to be quick and smooth, and that it was essential to transfer all the relevant information to the new staff. In addition, the coordinating team should work closely with them in the beginning. Similarly, if part of the staff cannot fulfil the previously assigned tasks due to heavy workload, tasks should be redistributed and some should be transferred to other employees.

It proved very important to ensure proper communication among all personnel and organisations involved in the pilots; for example, between the project management team and the other people in charge of the different tasks, between different departments within the organisation, or between the leading organisation and a subcontractor. Similarly, in order to minimise organisational and coordination problems, it could be useful to agree on holding regular meetings, and plan beforehand how the communication will take place.

Technical issues

Pilot sites experienced several technical issues and shared them in RAIL. Most of these problems related to devices and features that were not functioning properly (tablets, oximeters, Bluetooth, batteries, etc.), links between devices and web portals that did not work, and errors regarding the transfer of data. On the other hand, some of the issues were because the elderly and health professionals struggled to use the devices, and some stopped using them.

To address these problems, the technical staff called or visited participants to find out the possible causes, and they examined the devices. Sometimes they contacted the service provider. On most occasions, problems were solved, sometimes it was necessary to purchase new devices. In addition, further recommendations were provided to participants regarding the proper use of devices.

It must be stressed that technical issues can interrupt the development of the pilot, and endanger its outcomes, especially if data collection is interrupted for a long period or if participants become frustrated and decide to leave the service. Therefore, constant technical support is essential.

Help desks

Helpdesks played a crucial role in detecting and dealing with technical issues in a timely way, and providing continuous support to users. Unfortunately, sometimes participants failed to communicate technical issues or other incidents, maybe because they were not aware that there was a problem, or because they did not want to bother the personnel. To avoid this, it is necessary to tell participants that it is very important to use the communication channels.

In addition, the helpdesk should have a proactive attitude, and it should often check that everything is working properly. In other occasions, users did try to contact the helpdesk, but they could not reach it due to an unsuitable timetable or out-of-date contact details. This shows that it is important to offer the helpdesk services for longer hours, and to ensure that contact details are always up-to-date and available to users.

Training

Training is essential to teach participants the skills required for performing their tasks within the project. Moreover, it is especially important in situations such as the present one in which a significant proportion of the participants have low ICT skills. It must cover not only the older patients, but also caregivers and health professionals. Training also emphasised the importance of following up the treatment. In general, it was provided throughout the project, and was adapted to the needs that emerged.

Ethical & legal

Finally, ethical and legal aspects include taking account of data protection issues and the ethics legislation, and standards both at European and national / regional level. In this context, sites were usually requested to ask for formal ethics approval before beginning their operation. This can pose problems if the documentation is not complete, or is updated and needs to be resubmitted. These bureaucratic processes are usually slow, and can delay the start of the trials. Sites must be aware of this, and deal with ethical and legal aspects as early as possible.

Conclusion

Overall, the effort that sites put into sharing their experiences was useful to analyse the sites' operation in each domain, and to identify the main problems, solutions, risks, and lessons learnt that partners, as well as third-parties, should take into account in similar projects or situations. In brief, some key recommendations stemming from partners' inputs across domains are to:

- provide extensive information to users, caregivers and health professionals;
- foster constant communication between all stakeholders;
- support participants in the use of ICT tools;
- avoid technical incidents or otherwise tackle them promptly;
- be aware that health professionals will require extra time for the project, and arrange how to address this; and
- plan in advance, trying to anticipate potential problems and prepare solutions for them.