

D1.2 Pilot-level Pathways and Integration Infrastructure

WP1 Requirements and use case definition

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1. Introduction

1.1 Purpose of this document

This report represents the second and last deliverable generated within the first work package (WP1) of the SmartCare workplan. As discussed in the previous report (D1.1), the general promise held by ICT to enable tailoring of care delivery processes around peoples' needs rather than according to organisational and sectoral "silos" is anything else but a self-fulfilling prophecy. Yet evidence suggests that many such initiatives - despite successful piloting - have failed to grow beyond trial projects. What is needed is 'simultaneous' innovation where care practices change to keep pace with new capabilities provided by ICT.¹

At the same time, evidence shows that the local context needs to receive sufficient attention if integrated care services are to be successfully mainstreamed under day-to-day conditions. The SmartCare deployment regions are not an exception in this respect. National and local care service schemes that have been put in place prior to SmartCare vary considerable across the individual regions, in terms of both general scope and specific features. In fact, the health and social care sectors across the SmartCare regions are serviced by many and varying organisations. Frequently, these work towards different care models and with the help of different ICT infrastructures.

This report present the outcomes of an iterative process of planning how the two generic SmartCare pathways are to be implemented in different regional context from an organisational perspective, and of analysing which implementation requirements deserve particular attention in a given regional implementation context. Interim results of this process were described in a previous report (D1.1); the current document presents a consolidated version of these.

The outcomes presented in this report have informed subsequent work on the definition of formalised services process models within WP2 and more detailed, technical specification of the SmartCare digital support infrastructure within WP3.

1.2 Structure of document

For each of the SmartCare deployment regions a high-level view is provided of how the SmartCare digital support infrastructure is being implemented under prevailing regional framework conditions. This is augmented by a verbal description of how the SmartCare pilot service will be delivered by the different organisations in a given region. Further, it summarises how key regional implementation requirements will be met, and what lessons have been learned so far.

To enable a sufficiently detailed understanding of the different regional framework conditions under which the SmartCare pilot service is being implemented, a description of the service landscape as it existed prior to SmartCare in each of the deployment regions is annexed to the main report. The annexes also provide further information in relation to particular implementation requirements identified in each of the deployment regions. They also provide further information on the potential impact of the SmartCare pilot service on different regional stake holders, as anticipated by the pilot site teams.

¹ See e.g. Goodwin, N. (2012) Nick Goodwin on International Congress on Telehealth and Telecare, http://www.kingsfund.org.uk/multimedia/Goodwin_telehealth12.html

1.3 Glossary & List of Acronyms

| Acronym | Translation |
|---------|--|
| AAL | Ambient Assisted Living |
| AHP | Allied Healthcare Professions |
| BNP | Brain Natriuretic Peptide |
| BP | Blood Pressure |
| CBT | Cognitive Behavioural Therapy |
| CHF | Congestive Heart Failure |
| COPD | Chronic Obstructive Pulmonary Disease |
| CPR | Central Persons Register (Danish Social Security Number) |
| CR | Care Recipient |
| CVA | Cerebrovascular Accident |
| DM | Diabetes mellitus |
| DoW | Description of Work |
| DSL | Digital Subscriber Line |
| ECG | Electrocardiography |
| EHR | Electronic Health Record |
| EPR | Electronic Patient Record |
| GP | General Practitioner |
| GPS | Global Positioning System |
| HCP | Healthcare Professional |
| HFN | Heart Failure Nurse |
| HSCP | Health and Social Care Provider |
| ICP | Integrated Care Pathway |
| ICT | Information and Communication Technologies |
| I/FC | Informal/Formal Carer |
| KPI | Key Performance Indicator |
| LTC | Long Term Care |
| M | Month |
| MI | Myocardial Infarction |
| NGO | Non-Governmental Organization |
| PDA | Personal Digital Assistant |
| SCP | Social Care Provider |
| SMS | Short Message Service |
| TBC | To be confirmed |
| TSCP | Third Sector Care Provider |
| VPN | Virtual Private Network |

2. Pilot site #1 - Aragon

2.1 Contextualised implementation of the SmartCare integration infrastructure

The schema below (Figure 1) graphically summarises how the SmartCare pilot service infrastructure will be implemented in Aragon (for contextual details see Annex 1).

SmartCare service user’s profile is older people over 65 who live in the Barbastro Healthcare Area, having particular home care needs, being at risk of exclusion due to general age related decline and, from a clinical point of view, who suffer from a chronic disease (COPD, Diabetes, or Heart problems -Myocardial infarction MI, as well as those who had a cerebrovascular accident (CVA)) and who are clinically stabilised. From a social care point of view, older people can be enrolled into the pilot service if they are fragile or socially / physically excluded due to illness or disability of any condition with home care needs, and have signed the consent form to participate in the SmartCare programme.

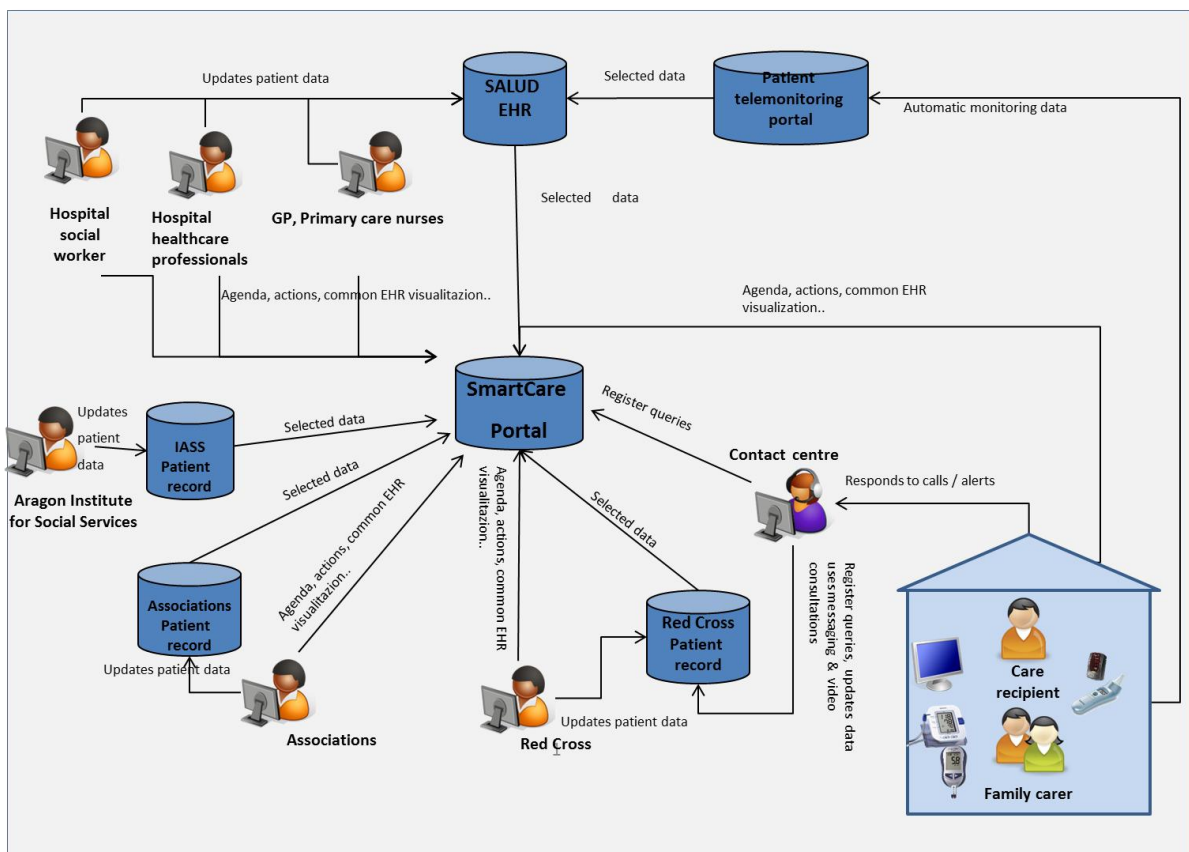


Figure 1: SmartCare service infrastructure implementation in Aragon

The SmartCare portal is a website that holds information related to the service user. This information is that of a minimum set of clinic and social information, clinical and social assessments, monitoring of vital signs data and procedures, agenda, recommendations, etc. It also contains care information that will support the organisation of service providers when performing the caring tasks. That is the care plan and agenda, and a history of actions. The SmartCare portal is composed of information coming from the different service providers' legacy systems, databases and records, and information generated from the normal development of the SmartCare programme.

Relatives and/or informal carers access information about the joint care agenda, as far as permitted by the care recipient.

Staff working for the various organisations that provide social services access information related to the monitoring of vital signs and a minimum set of client-related clinical information. They help in taking vital sign measurements, health education programmes, controlling and monitoring clinical treatments, filling out forms to detect clinical alerts. Also, they access information related to social care received and/or requested by the care recipient and the joint care agenda and history.

Staff of the SALUD healthcare provider organisation have full access to health related information of the cared-for person, coming from the SALUD electronic health record (EHR), access to vital sign measurements and full health agenda. The regional public organisation providing health services (SALUD) include all primary care doctors and nurses, all specialised health care services and staff, including emergency and mental health units in all the healthcare areas of the SALUD (the Aragon region is divided into eight sub-healthcare areas, one of them is Barbastro). That is over 17.000 healthcare professionals in the total territory of the region. Any SALUD healthcare professional has access to the health-related information of any Aragonese patient. Special remark is that the EHR is centralised in Aragon for the SALUD organisation (with records for the whole population) and that private healthcare service providers are almost non-existent in Aragon. In addition to this health related information, healthcare professionals can have full access to the SmartCare portal and the telemonitoring portal that holds telemonitoring information.

Community pharmacists access user related prescription lists. Their role shifts from mere medication management to the provision of professional services to the SmartCare end user.

Local associations that provide support to care recipients, or have a technological desk available, help the end user in taking vital signs measurements, but have no access to any data concerning the SmartCare end user. Technological desks are counters with a set of biomedical devices and a point of connection with the telemonitoring portal and the SALUD EHR that permits any patient to have their vital signs taken and whose information is integrated into the SALUD records, after a valid patient identification.

2.2 Contextualised implementation of the SmartCare pathways

2.2.1 Entry points

The entry point to the integrated-care pathway is when a patient has been suggested to be included on the SmartCare programme, either upon a visit to primary care, or during a stay at Barbastro's hospital. There are two ways to identify potential participants. First is during a hospitalisation of a patient. If any healthcare professional supposes that the patient is at social risk of any type, then he notifies the social worker working at the hospital. This social worker evaluates if the patient is at real risk. The second channel would be when a patient visits a doctor at primary care. If the GP suspects a patient to be at risk, then he refers the patient to the SmartCare Evaluation Committee who will evaluate if the user is a potential participant in the programme.

2.2.2 Assessment of the service user's needs for integrated care

The HCP, either GP or specialist, defines the medical attention that the patient may need in relation to any medical home care, the frequency of the needs, his inclusion in a telemonitoring programme, the clinical parameters to monitor, and other assistance services such as adherence to treatment, etc. This decision is made on the patient information collected from the hospital records and the EHR. The SCP, either the local SCP

or the hospital social worker, defines the social attention that the patient may need in relation to any home care. In order to identify these needs, the SCP has an interview with the patient, and relies on the notes taken by the HCP that identified the risk, recorded in the SALUD information systems when the risk was identified.

2.2.3 Enrolment into the SmartCare service

A key element of the SmartCare programme is the SmartCare Evaluation Committee. The SmartCare Evaluation Committee is formed of a representative of every care provider, plus technical staff. The Evaluation Committee acts as the SmartCare project manager, and will be responsible to manage and coordinate the actions within the SmartCare programme. The procedure for enrolment into the SmartCare programme is as follows:

- Patients identified by primary care. The patient visits the GP at primary care. If the doctor believes the patient to be at risk, and could be participant in the SmartCare pilot, then he refers the patient to the SmartCare Evaluation Committee, and asks for information from the social worker of the local SCP who will evaluate if there is a real risk, and if the patient is in need of social care. The SmartCare Evaluation Committee will check if the user fulfils the SmartCare inclusion criteria; if that is the case, the patient will be included in the programme.
- Patient identified at the hospital. During a patient's stay at the hospital, any HCP may believe the patient to be at risk. In that case, the HCP records the suspicion in the SALUD information system, and notifies the social worker working at the hospital who evaluates if the patient is at real risk. If he/she is, he refers the patient to the SmartCare Evaluation Committee. The Evaluation Committee will evaluate if the user fulfils the SmartCare inclusion criteria, and will decide, together with the healthcare specialist in charge of the discharge, on the inclusion of the patient onto the programme.

The criteria from a medical point of view to select patients to be included in the SmartCare programme would be:

- Aged +65.
- Chronic disabled disease (COPD, DM, Myocardial infarction history (MI) + heart failure, cerebrovascular accident (CVA) history).
- Stabilised (for long-term cases).
- Terminal neoplastic or neoplastic illness.
- Dementia and / or psychic handicap.
- Hip fracture.
- Situation of temporary dependence at discharge time.
- Loss of autonomy due to age without pathology.
- Health problems of appearance during hospitalization requiring continuity of care.

The criteria from a social point of view to select patients to be included on the SmartCare programme would be:

- +75 living alone.
- Living with partner, siblings or elder relatives.
- Living with dependent people at home.
- Lack of support at home:
 - Lack of resources at home;

- Main carer at hospital;
- Communication problems with immigrants;
- Other problematic due to immigrant condition;
- Lack of relatives during hospital admission or during the first two days at home.
- Minor at risk:
 - Alcoholism;
 - Drug dependency;
 - Abuse or suspected abuse.

When a patient has been identified as a potential participant, he/she is informed of the programme by either the GP and local SCP worker, or the specialist and the hospital social worker. The patient has to give written signed consent to participate in the SmartCare pilot.

2.2.4 Initial integrated home care plan

Next, an initial plan will be defined to provide home support through SmartCare. First of all, and if the user is to be included in the telemonitoring programme, the process of taking vital signs will be defined. The patient will either be provided with biomedical devices and technology, or be referred to a technology counter owned by a TSCP or I/FC, or be included on the SCP agenda for home visits. This decision will be taken according to several criteria such as the patient's clinical profile, having an active social role or living in a dependency situation. A coordinated agenda will be defined between the patient, the HCP, the SCP, the TSCP and/or I/FC that will be agents in providing care to the patient, along with a schedule of actions and personnel responsible for the tasks. The patient will also be provided with a contact point to be able to communicate with his/her carers when needed. Patients will use this Integrated-Care Coordination point of contact (Contact Centre) to request care needs. The IC home care plan will coordinate the agents working in the territory and cities involved on the project, these being: Servicio Aragonés de la Salud (hospital, emergencies, and primary care centres), several councils of the Cruz Roja Española on the area, the regional and local SCP in the cities, a community pharmacy located in Barbastro, several Patients Associations, and the patients relatives.

2.2.5 Permanent coordination of integrated care delivery/revision of the initial care plan

When a user is included in the SmartCare programme, he/she will be provided with a set of services that may not be used at the same time or for the whole duration of the pilot. Therefore, there will be an essential continuous revision of the services provided and requested by the patients and the coordination plan. In order to ease this task, a web platform will hold all the information and attention provided to the patients. This platform will register the coordinated action plan, the IC agenda and schedule, and the agents responsible for providing the care, the services provided, and new services requests. This platform will be able to identify needs, assign responsibilities, coordinate carers and register actions; the information related to the care provided will be registered on this platform. This web portal will also share a minimum data set of clinical and social patient information. Moreover, the HSCP will be supported by the SALUD IS that holds all patient data, the EHR, clinical activity and monitoring portal. The SCP will also be supported by the patient's data records. The contact centre will be able to access a common set of the patient's data provided by the HCP and SCP.

The SmartCare Evaluation Committee will receive all notifications, and will evaluate if the user still fulfils the inclusion criteria. In so, the Committee, together with the SCP and HCP, will decide on the provision of the services to fulfil the demand, on cancellation if

there is no longer need of a service, modify the care plan if needed, and/or review the tasks and responsibilities assigned.

During the pilot, the user may change his needs for several reasons: enhancement or deterioration of their health; to be no longer in a risk situation; in need of more services; etc. Therefore, it is important that the patient has a procedure to communicate with the pilot to review his requirements. The entry point may be the GP at the primary care centre, or notification by the TSCP or SCP or I/CP or patient to the Contact Centre available by telephone that will be redirected to the Committee. The Contact Centre will be formed of SCP and HCP agents.

The telemonitoring programme will need a very close coordination of actors, as there may be plenty of changes to the schedule and initial plan due to changes in the clinical status and evolution of the CR. Telemonitoring of users with the aid of social associations and volunteers is a clear example of integrated care that responds to a planned social/health care intervention, and that will need constant review.

2.2.6 On-site provision of formal social care

According to the clinical profile of the patients, mainly for patients with social needs and/or in a clear situation of dependency or included in the telemonitoring programme, it may be necessary to provide services at the patient's home. These tasks can be performed by the SCP, for example, taking the vital signs parameters in defined cases, home care or home support tasks such as cleaning or helping to get up from bed.

From a social point of view, among all the services that a user may be provided in accordance with the existing social care system, those included on the SmartCare programme will be those of:

- Home help services (home tasks, home care support, home care private support).
- Accompaniment (administrative purposes, to/in hospital, at home, administrative tasks).
- Activities (leisure time, pedometers, rehabilitation programmes, health educational programmes, active living, active ageing, etc.).
- Follow-up agenda (reminders, advising).
- Product loan (loan of crutch / articulated bed / wheel chairs, orthopaedic support management).
- Shifting, transport (day centres, specialised care centres, leisure time and cultural activities, rehabilitation centres, etc.).
- Telecare.
- Occupational workshops / employment centres.
- Installation of products to reduce energy consumption.

2.2.7 On-site provision of formal healthcare

According to the clinical profile of the patients, mainly for patients with social needs and/or in clear situation of dependency, or included on the telemonitoring programme, it may be necessary to provide services at the patient's homes. Some of the medical tasks to be performed at home for patients with reduced mobility include care of wounds, participation in educational programmes on health issues through different communication channels, pain management, and adherence to treatment programmes or, in certain special cases, GP/nurse visits. From a medical point of view, the services that a user may be provided with in accordance with the existing healthcare system can be those of:

- Health services (primary care, specialised care, mental health, day hospitalisation, chronic hospitalisation, major surgery, etc.).
- Remote telemonitoring programmes.
- Education programmes on health issues.
- Adherence to treatment programmes.
- Pain management.
- Health transport, emergency transfers.
- Wound care.
- Form filling to detect alert signs.

2.2.8 On-site provision of informal care

Informal carers can perform telemonitoring tasks such as those of taking vital sign measurements, or those in the contractual relationship with the patient, such as cleaning, cooking and the like.

2.2.9 Remote provision of health / social care to the home (telecare, telemonitoring)

One of the main goals of this pilot is not only to provide integrated care to patients, but also the coordination of actors to avoid duplication of the activities provided. Other goals are tracking the patient's wellbeing, and to promote the empowerment of users in the management of their own health, making them co-responsible to maintain and keep good practices on health issues. Therefore, some of the services can be provided on a remote basis. Some examples are self-telemonitoring of vital signs by the patient or IC at home, and the provision of these measurements to the HCP, a reminder of events (such as HCP visits or others) thanks to the shared agenda, calls made by the SCP to know about the CR health status, or alarm calls thanks to push-button devices or geo-positioning devices provided to users.

A telemonitoring service is being piloted and is under evaluation in Aragon. Since 2009, there is a telemonitoring pilot implemented thanks to the European project Dreaming². This service is oriented to autonomous patients, who collect their own vital signs with biomedical devices at home, and send the measurement via DSL to a monitoring portal. This portal creates alarms that are checked by HCPs, and react to the user's needs by mobilizing resources properly.

A second telemonitoring project is ongoing, oriented to dependent users and with the collaboration of the Red Cross. Several Red Cross teams visit patients at home, and collect their vital signs, provide the information to the HCP, and respond to medical needs. In SmartCare, these two models will be extended to cover a larger population, more targeted people, and making technology available to a wider number of users (involving other care agents and bringing technology to other places that older citizens frequent) This is possible thanks to the unique identification of Aragon's population through the health card.

2.2.10 Integrated documentation of home care provided / self-care measures

The central point will be the platform that will hold the information on the services that a user can benefit from, the designation of tasks among agents for better coordination, and the history of actions performed. This platform will provide all the information that is required to provide integrated care (see section 2.2.5 above).

² <http://www.dreaming-project.org>

2.2.11 Control / reassessment of the home care recipient

Telemonitoring services need a follow-up of the measurements taken, usually in the form of tracking the alerts and alarms. This control will be performed by the HCP; according to the seriousness of the alert, the HCP will evaluate the need to provide special care, new services, or emergency services, i.e. ambulance transport.

Furthermore, the HCP will review periodically, through the documentation, the conditions of the CR that are benefiting from the telemonitoring service to check whether changes and/or revisions are to be made to the service provided or care plan. Similarly, the SCP will also review periodically the documentation to check the use of the services by the CR, and identify if they are really used or there are deficiencies that require a reorganisation of the attention provided. If that is the case, the SmartCare Committee will be notified, and act as needed/

2.2.12 Temporary admission / re-admission to an institutional setting (e.g. hospital, day care centre)

According to the changes in the condition of the patient (either social or worsening of the clinical status) there may be an admission to a hospital or social institution. These cases will be evaluated by the SmartCare Committee, as it may imply the temporary suspension or disenrollment of the patient from the SmartCare project.

2.2.13 Exit point

The end point of this pathway would be when the patient is no longer in need of medical or social attention or excluded from the medical programmes, the patient revokes consent, or his participation on the programme is closed, the patient is exitus, or the pilot causes concerns or bothers patients or relatives.

2.3 How key regional implementation requirements are met

The following table summarises in what way key implementation requirements identified in the Aragonese context (for details see Annex 1) are going to be met.

Table 1: Summary of how key implementation requirements are met in Aragon

| Type of requirement | Summary of response by the project |
|---------------------------------------|--|
| End user requirements | The identification of users is critical to ensure the security of patients. Patients can access their summarised EHR through their digital certificate on their National Identification Card. Moreover, users are differently identified on the SALUD organisation (by the Healthcare Card) and on the social providers (by NIF number or name). Therefore, a user identification mapping will have to be constructed so as to properly identify users on the Information Systems. |
| Organisational and staff requirements | The organisation workflows will be deeply studied so as to minimise the impact on current procedures. Nevertheless, changes to the procedures will happen, due to the need to coordinate with other agents; therefore training programmes will be defined. Web portals will be implemented so as to ease the access to information and care plans. |

| Type of requirement | Summary of response by the project |
|---|--|
| Legal / regulatory / contractual requirements | The basket of services, the roles of each actor, and the responsibilities for each service provider will be well defined before the start of the SmartCare programme. Consent forms will be defined, and will have to be approved by the Ethical Committees of the Region to meet the regulatory and data protections laws. Patients will have to sign the consent form for their inclusion in the programme. |
| Technology / functionality related requirements | To ensure the security of patients and by the regional legislation, health data will be stored on the SALUD network. Secure connections will be required. The web portal will have different views depending on the users and roles. |
| Other requirements | Tenders and public procurements will have to be followed to subcontract activities, developments, or for the acquisition of technology. |

The following table summarises the approach taken in the deployment region towards anticipated negative impacts potentially emerging from the SmartCare service when compared with current care practices in the deployment region (for details see Annex 1).

Table 2: Summary of how anticipated negative impacts of the SmartCare service are addressed in Aragon

| Stake holder concerned | Summary of approach taken towards anticipated negative impacts |
|-------------------------|---|
| Care recipient | The care recipient can exit the SmartCare programme at anytime and without explanations if the programme disturbs him/her in any way. |
| Informal / family carer | Training programmes will be performed and driven so family carers feel comfortable in assuming new roles and tasks. Nevertheless, the informal carer can exit the SmartCare programme at anytime and without explanations if the programme disturbs him/her in any way. |
| Formal social carer | Training programmes will be performed and driven so formal social carers feel comfortable in assuming new roles and tasks. The responsibilities of each actor will be well defined in advance of the start of the SmartCare programme. |
| Formal health carer | Training programmes will be performed and driven so healthcare professionals feel comfortable in assuming new roles and tasks. Specialised training programmes can be performed. The responsibilities of each actor will be well defined in advance of the start of the SmartCare programme. Intervention protocols will be defined so as to avoid workloads. |
| Third sector carer | Training programmes will be performed and driven so carers feel comfortable in assuming new roles and tasks. The responsibilities of each actor will be well defined in advance of the start of the SmartCare programme. |

2.4 Main lessons learned in the deployment region

The main lessons learned during the pilot service and infrastructure definition phase of the overall project are briefly summarised below. For a description of workshops conducted see also Annex 1

- Enrolment of actors from the beginning of the service description is key for the future success of the services, staff participation and collaboration (care receivers, SCP agents, healthcare professionals, associations, etc.).
- Clear definition of the basket of services that each service provider will provide.

- Clear definition of each role and their responsibilities so as to avoid professional intrusion or taking inappropriate decisions.
- Identification of the competences to be transfer among agents and that can be assumed.
- Empowerment of actors, care receivers and relatives is essential for a successful assumption of new competences.
- New platforms have to be integrated with the already existing information systems if continuity of the developments is expected.
- Identification of patients is key for a transparent, secure, error-less data transfer.
- The assessment of innovation on integrated care programmes has to be extended and from several points of views so as to evaluate the continuity of these services without compromising the sustainability of the public welfare systems.

3. Pilot site #2 - Friuli Venetia Giulia

3.1 Contextualised implementation of the SmartCare integration infrastructure

The schema below (Figure 2) summarises how the SmartCare pilot service infrastructure will be implemented in Friuli Venetia-Giulia (for contextual details see Annex 1). Care recipients are aged 50 and above, and suffer from a chronic disease (heart failure NYHA II-IV, COPD, diabetes). They have a high probability of complications and/or destabilisation. Multiple co-morbidities are the rule in this population. Persons with cognitive impairment (MMSE<24), dementia and/or severe mental disorder (e.g. major depression) are not enrolled in the service. The care recipient accesses the SmartCare integration infrastructure to look up and enter care related data in a personal record. Information accessible to the care recipient also includes diagnosis, instrumental and laboratory data, and measurements taken by professional caregivers as well as narrative data (e.g. on lifestyle and social issues, activities, goals, emotional self-monitoring, symptoms and contact persons).

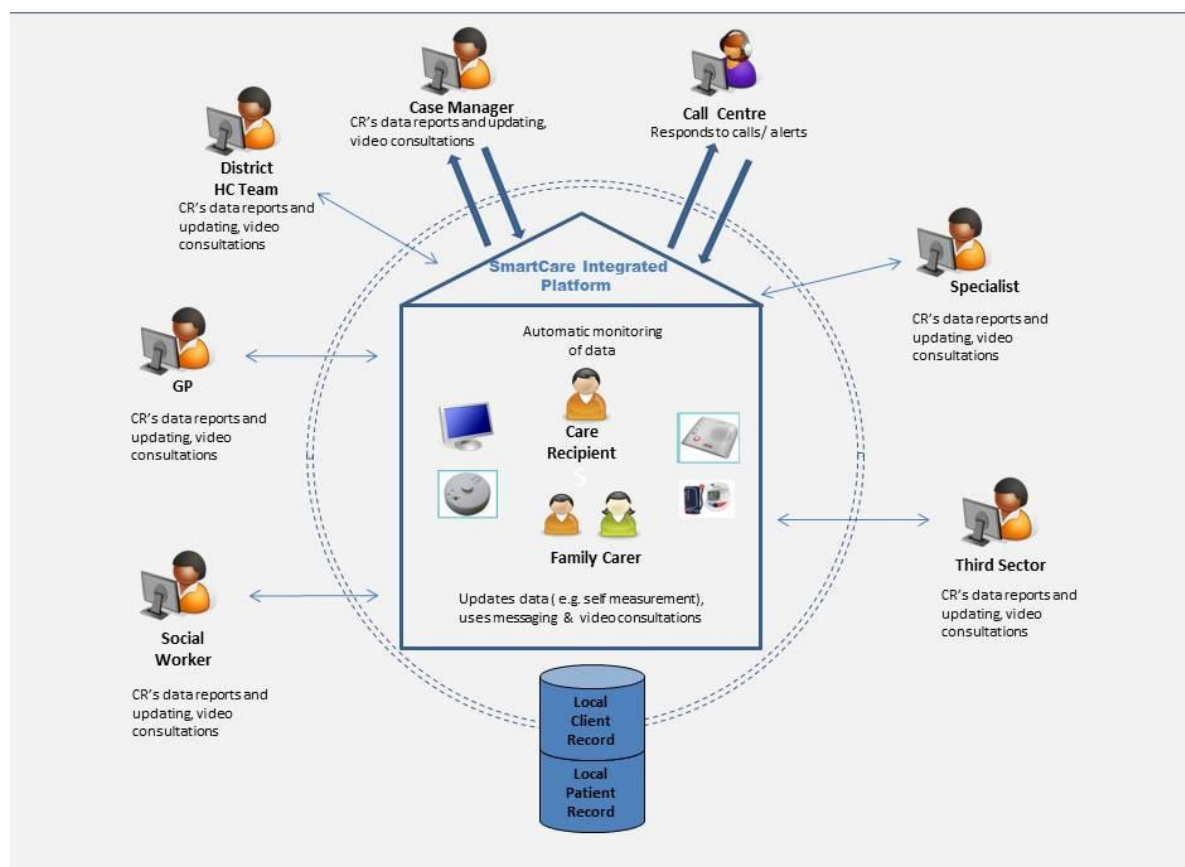


Figure 2: SmartCare service infrastructure implementation in Friuli-Venezia Giulia

Upon consent from the care recipient, relatives and/or friends have access to the electronic data through the SmartCare integration infrastructure. In principle, they perform all tasks for the care recipient on permission of the person they care for.

A social care worker employed by the municipality provides home-based social care such as cleaning, food delivery, bathing, shopping, etc., as well as help in the procedures needed to obtain financial support from the municipality / state. Through the SmartCare integration infrastructure, they access selected information about the care recipient's

disease and self-care capabilities which are provided by other care providers such as hospital staff and GPs. They can also leave notes in the care recipient's personal record, set up goals together with the patient, and fill out questionnaires (which may be filled out as self reports or on behalf of the CR).

Members of a multi-disciplinary healthcare team (specialists, GPs, nurses, psychologists, physical therapists, etc.) share data from their individual systems, and use the SmartCare integration infrastructure to support their workflow across existing unit boundaries. They also view data from all other care providers. Information shared include lab results, measurements, notes, symptoms, diagnoses, goals set with the patient, activities, questionnaires, reports and self-care indicators provided by patients.

Trained staff and/or volunteers of a non-profit organisation, a citizen association (“active citizenship”) and a social cooperative provide support to patients as far as needed. This includes participation in multi-disciplinary meetings or entering (with CR's consent) data relevant to care recipient's well-being (e.g. home support, social support, emotional changes in well-being, etc.) into his/her personal record through the SmartCare integration infrastructure.

Video conferencing will be made available in selected case, to CRs who live in remote areas.

3.2 Contextualised implementation of the SmartCare pathways

3.2.1 Entry points

The district nurse (eventually with social worker) at the hospital or at PUA carries out a pre-assessment on the basis of the information available. At this time, patients are asked to sign a pre-enrolment consent form.

3.2.2 Randomisation to intervention or usual care groups

A multidisciplinary team is led by a Case Coordinator chosen to meet prevailing needs and to define and share care planning. Randomisation to intervention or usual care groups is carried out through an external call centre. In the intervention group, an order is sent to a dedicated external service to set up home devices for the monitoring of vital parameters (BP, HR, weight, SO₂, glucose level, etc.) as well as environmental data and videoconferencing (only for selected cases). CR randomised to usual care will be followed according to care planning and usual procedures.

3.2.3 Assessment of the service user's needs for integrated care

The District Nurse is in charge of completing the assessment by contacting all parties involved in the multi-disciplinary team approach. Subsequently, and according to specific needs, a Case Coordinator is appointed from among the members of the multidisciplinary team. He/she acts as the reference person for the home care integrated plan.

3.2.4 Enrolment into the SmartCare service

During a first meeting, provided the patient is deemed eligible for enrolment in the SmartCare pilot service, the Case Coordinator asks for the patient's consent to enter and share patient's data with other relevant actors through the SmartCare integration infrastructure. She/he also provides the patient and caregiver (if available) with basic information on the SmartCare platform and the possibility to access it directly from home. The Case Coordinator also evaluates the patient's ability to perform home monitoring.

The Case Coordinator then asks for patient's final consent for enrolment in the SmartCare service. At this time, in CRs randomised to the intervention group, the required devices are installed at the CR's home, and instructions on their use are given to relatives. Should no relatives either be present or available, instructions and training will be provided to CRs by call centre personnel. Through regional Registry of Birth, the nurse collects available information (health and social) from different databases. After collecting and entering the available information, the Case Coordinator updates the personal record in the SmartCare integration infrastructure with disease information and relevant health and social care data.

3.2.5 Initial integrated home care plan

A ValGraft assessment, together with the relevant clinical data, is shared with all the participating actors who proactively start a planned and individualised integrated care plan. This plan is periodically reassessed and adjusted by the multidisciplinary team. Depending of clinical and social needs, and according to the integrated home care plan, specific targets and care priorities are set (healthcare: e.g. hemodynamic stability for heart failure etc; social care: e.g. food delivery, preparing meals, home sensors, etc.).

3.2.6 Permanent coordination of integrated care delivery / revision of the initial care plan

A multidisciplinary team is activated, led by a Case Coordinator. Data and information are continuously shared among the different parties. Goals and needs are adjusted accordingly.

3.2.7 Coordinated delivery of integrated care at point of care / revision of the initial care plan

The Case Coordinator coordinates home-care. He/she supports the GP (and/or specialists) in delivering healthcare, and keeps in touch with social workers, family and volunteers for other needs. The Case Coordinator activates different care providers in the presence of unmet or urgent needs of CR / family.

3.2.8 On-site provision of formal social care

Social care actors update the CR's personal record in the Smart Care platform with details of care delivered. They will also highlight, if necessary, specific needs arising from interactions with CRs and their caregivers. Depending on social needs and according to the integrated home care plan, dedicated targets and care priorities are set (i.e. food delivery, preparing meals, home sensors, etc.).

3.2.9 On-site provision of formal healthcare

Healthcare actors update the CR's personal record in the Smart Care platform with details of care delivered. Depending on clinical needs and according to the integrated home care plan, dedicated targets and care priorities are set (e.g. hemodynamic stability for heart failure, etc.).

3.2.10 On-site provision of informal care

Family members and/or friends, upon patient's request, are able to access the system and share information on the CR. This allows them to feel more secure and less isolated, provides them with better tools to monitor and contribute to the patient's maintenance of health and QoL, and allows them to be more directly involved in the provision of services.



3.2.11 Remote provision of health / social care to the home (telecare, telemonitoring)

For all FVG region, remote home health and social care services are provided by an external company with a 24/7 Call Centre. Smart Care services provide full support to cooperative delivery of care, integrated with self-care and across organisational silos, including essential coordination tools such as shared data access, care pathway design and execution, as well as real time communication support to care teams and multi-organisation access to home platforms.

3.2.12 Integrated documentation of home care provided / self-care measures

Any intervention made by the various parties are documented in the SmartCare system and are made available to other parties. Depending on the home care plan (targets, criticisms, needs, intensity of monitoring) the Case Coordinator plans periodic meetings with district team. Daily update from the CR and home monitoring (clinical and environmental) are provided, as well as periodic updates from the care team according to care priorities, CR needs, roles of actors.

3.2.13 Control / reassessment of the home care recipient

Integration of data into care planning and management processes is updated at three months (short term pathway) or six months (long term pathway) to decide whether to end the home care plan or prolong it. Sharing and analysis of clinical, scheduling, monitoring information will continue.

3.2.14 Temporary admission / re-admission to an institutional setting

An Integrated Care Record allows sharing of updated clinical information of in-hospital and out-of-hospital care. Updated information provided in emergency situations by a Call Centre is available through a pre-defined printed version. Exit of patient from Smart Care platform is evaluated at the time of readmission according to specific parameters.

3.2.15 Exit point

At the end of the programme, the Case Coordinator together with district team, on the basis of global review of persistent CR needs and results obtained with ICT program, decides about exit from SmartCare pathway.

3.3 How key regional implementation requirements are met

The following table summarises how key implementation requirements identified in the Italian context (for details see Annex 2) are going to be met.

Table 3: Summary of how key implementation requirements are met in FVG

| Type of requirement | Summary of response by the project |
|-----------------------|---|
| End user requirements | Communication, education, monitoring and platform accessibility requirements will be met by focusing on training, easy-to-use and efficient devices, together with adequate follow-up provided by all stakeholders. Glitches in data access procedures will have to be dealt with in a speedy manner. Regional coordinators will supervise the timely, efficient and effective flow of information and communication. |

| Type of requirement | Summary of response by the project |
|---|--|
| Organisational and staff requirements | In order to make experimentation and adoption of ICT-supported integrated care successful, focus will be on ensuring adequate training, and enhancing time-saving communication skills among all stakeholders involved. Remote monitoring should activate proper alarms with satisfactory sensitivity and specificity. Streamlining the health and social care processes will ensure sustainability of service, ideally improving quality and intensity of home monitoring. |
| Legal / regulatory / contractual requirements | Final drafting of requirements is expected to be completed by 30 th April 2014. |
| Technology / functionality related requirements | The public procurement was issued in November 2013, and will be closed at the end of March 2014. Main goals to be met are platform's ability to integrate web-based care records, allow for timely and effective integration of clinical and non-clinical information from formal and informal care providers and care recipients. The platform also requires sufficient flexibility and ease-of-use. The technical system will appropriately manage a large amount of real time data for effective monitoring and intervention. |
| Other requirements | Protocols for platform shut-down in case of CR's inability or unavailability to participate in the programme, or death, will be drafted upon receipt of platform's technical specifications following procurement. The rules for accessibility to health and social information by SmartCare stakeholders and CR / family carer will be defined and shared upon implementation of the electronic record. |

The following table summarises the approach taken in the deployment region towards negative anticipated impacts potentially emerging from the SmartCare service when compared with current care practices (for details see Annex 2).

Table 4: Summary of how anticipated negative impacts of the SmartCare service are addressed in FVG

| Stake holder concerned | Summary of approach taken towards anticipated negative impacts |
|-------------------------|---|
| Care recipient | During dissemination meetings, awareness has been brought to formal carers about the importance of clear, effective communication. Easy-to-use manuals will be made available to CRs; training will be carried out and followed-up to make sure the information has been clearly conveyed. Volunteers may also be involved in providing training reinforcement. This would help strengthen social connections, possibly through the involvement of younger volunteers (possibly college students) . Privacy issues will also be discussed with CR. |
| Informal / family carer | During dissemination meetings, awareness has been brought to informal / family carers about the importance of clear, effective communication. Easy-to-use manuals will be made available to informal / family carers; training will be carried out and followed-up to make sure the information has been clearly conveyed. Volunteers may also be involved in providing training reinforcement so as to provide support and enhance sense of connectedness. Privacy issues will also be discussed with family carers. |
| Formal social carer | During dissemination meetings, social carers' concerns have been highlighted and discussed. Effective training will be carried out, and no one will be left behind. They all agreed on the importance of clear, effective communication. Easy-to-use manuals will be made available to social carers; training will be carried out, and follow-up provided to make sure the information has been clearly conveyed. Every effort will be made to prevent glitches in communication and provide continuous self-motivation, while keeping workload manageable through avoidance of unnecessary duplication of information and management of a large amount of possibly non relevant data. |

| Stake holder concerned | Summary of approach taken towards anticipated negative impacts |
|------------------------|--|
| Formal health carer | During dissemination meetings, formal health carers' concerns have been highlighted and discussed. Effective training will be carried out, and no one will be left behind. They all agreed on the importance of clear, effective communication. Easy-to-use manuals will be made available to health carers, training will be carried out, and follow-up provided to make sure the information has been clearly conveyed. Every effort will be made to prevent glitches in communication and provide continuous self-motivation, while keeping workload manageable through avoidance of unnecessary duplication of information and management of a large amount of possibly non relevant data. |
| Third sector carer | Effective training will be carried out and follow-up provided to make sure the information has been clearly conveyed. Easy-to-use manuals will also be made available. Degree of involvement in CR's assistance will be chosen by each volunteer according to his/her computer literacy level and self-confidence. |

3.4 Main lessons learned in the deployment region

The main lessons learned during the pilot service and infrastructure definition phase of the overall project are briefly summarised (for a description of workshops conducted see also Annex 2).

Despite some initial perplexities arising from the complexity and large-scale definition of the project, all stakeholders have later shown great interest in the opportunities provided by SmartCare. Integration of services together with communication and person-centred approach have been welcomed, and identified as fundamental needs both for individuals and groups. The ability to make the platform easily available to all, and the ensuing social / healthcare interaction and integration of information have been identified as core issues. It is of paramount importance to avoid fragmentation of communication and service, and to establish a strong network of people supported by the SmartCare platform which will serve as a driver for better care and stronger and healthier communities.

4. Pilot site #3 - Scotland

4.1 Contextualised implementation of the SmartCare integration infrastructure

Reshaping care for older people is a Scottish government initiative aimed at improving services for older people by shifting care away from acute services and towards, rehabilitation, anticipatory care and prevention, in particular falls prevention. Falls services across Scotland have been mapped and benchmarked against key criteria. The criteria were based on evidence based practice. The purpose of the work was to establish how well integrated the best practice knowledge was across generic health and social care teams and other key agencies. The findings of the national Up and About report were that "Scotland still had much to do to provide older people with equitable, high quality services for falls and fractures".

In the local areas / regions of Lanarkshire, Ayrshire, Renfrewshire and East Renfrewshire, there is clear recognition that participating in SmartCare will build on local successes and support the significant improvements which have taken place since the report was published. Further information on the work in progress in Scotland can be found at www.fallscommunity.scot.nhs.uk.

Key achievements so far have been:

- Higher awareness across key agencies of the impact of falls on individuals and their family.
- Increased collaboration across agencies to develop the falls service and work towards common aims set out in national guidance.
- Improve data collection indicating number of fallers and nature of outcome.

As part of the continuous improvement programme, the local areas are participating in the SmartCare project with the intention of improving integrated working and coordination of all services by linking up existing systems where possible. The diagram below (Figure 3) summarises how the SmartCare pilot service infrastructure will be implemented in the Scotland (for contextual details see Annex 3). The existing living it up (LiU) platform (livingitup.org.uk) already developed by SCTT in Scotland will be used to host the SmartCare products being developing to support falls. LiU is currently available in five health board areas in Scotland, and will be extended to a further three regions in South West Scotland to host the SmartCare tools. LiU currently provides a range of digital services for people with long term conditions. We will use this platform to host the falls tools we are developing to promote integration and coordination for people requiring falls services.

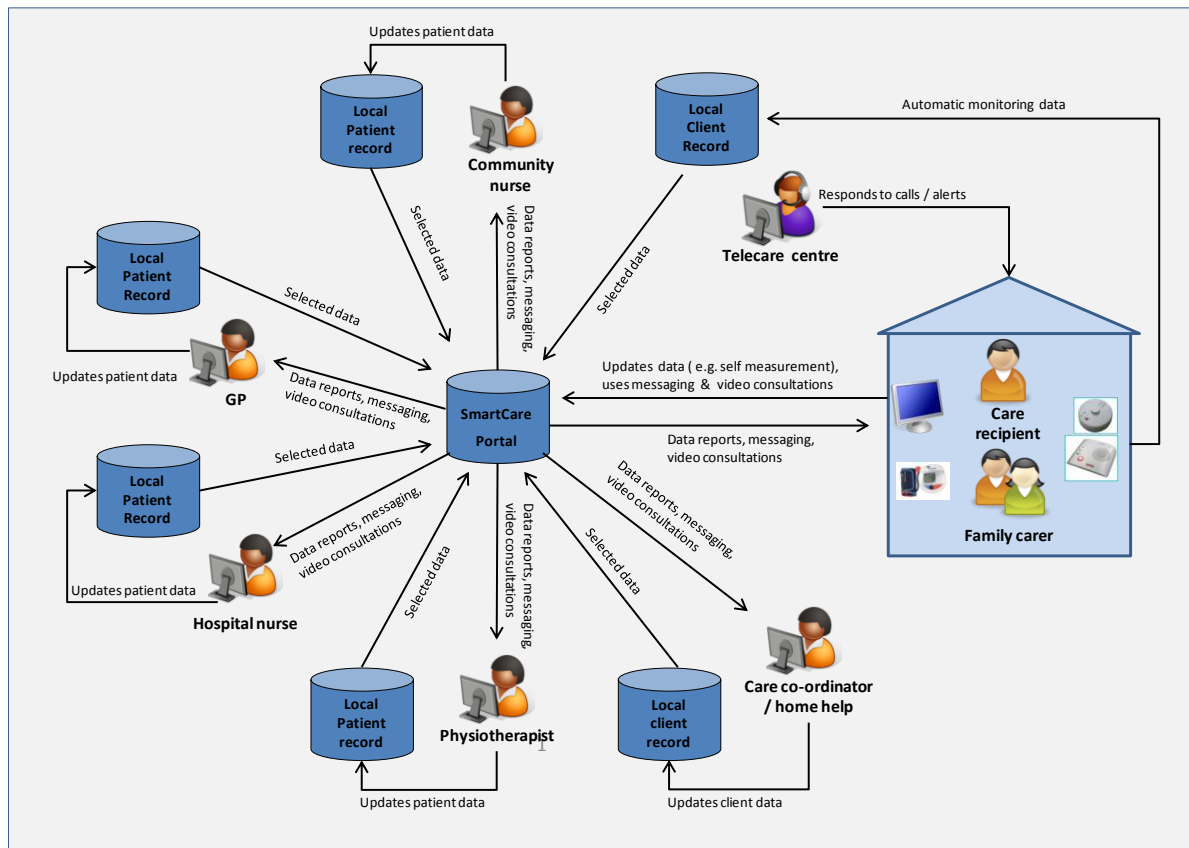


Figure 3: SmartCare service infrastructure implementation in South West Scotland

The SmartCare falls service has a person centred approach at each stage in the care pathway, promoting integration of information and the coordination of care. This will start with prevention services, supporting people to stay independent and away from formal services. It will also support very vulnerable people with high care needs who are receiving support from a range of different agencies. The person who has experienced the fall and their carer will determine who their personal information including health and social care information will be shared with.

The SmartCare service model is designed along with service users and their carers. They have been involved in various workshops which have helped to determine their requirements to recover from a fall and remain as independent as possible through sharing information and improving coordination of services. In addition, staff across various organisations will have the facility through SmartCare to have access to more comprehensive information on the person they are supporting, including the care and risk management plans as well as data from telecare, telehealth and response services. Self referral and cross organisational referral for services will be facilitated through the SmartCare integration infrastructure. Various social care professions access the SmartCare system as part of a multi-professional team, including social workers, intermediate care, AHP staff in the community and hospital, home care providers and telecare response staff. This comprehensive personal information will be used to improve outcomes in an emergency situation where the person has fallen again. This could include NHS24, specialist and multidisciplinary teams, falls leads, GPs, allied health professionals, community nursing (other community health services), and Scottish Ambulance Service. SmartCare will facilitate improved sharing of information across social care response services and the ambulance service, preventing hospital admissions and preventing inappropriate use of ambulance services.

Third sector and independent sector providers will access the SmartCare integration infrastructure to agree interventions and review outcomes or discharge plans in

partnership with the statutory services. They will participate in the person's recovery plan, and provide support to SmartCare users including input to care plan reviews.

Family members, neighbours and friends of the service user who provide care and support will access information on care coordination with the consent of the cared-for person. They will also access self-management and self-care information. The informal carers may also be responders or key holders of a telecare recipient.

4.2 Contextualised implementation of the SmartCare pathways

4.2.1 Entry points and enrolment into SmartCare

To identify potential service users, the entry point for SmartCare will be integrated into mainstream assessment and referrals processes across health and social care and other key agencies. The person who has fallen or is at risk of falling is experiencing changes in their lives depending on their current level of frailty. This will range from someone who has lost confidence to go outdoors after a fall, to someone who has had a serious physical injury after a fall such as a fractured hip, which will require a hospital admission.

SmartCare offers support to the person and their care at whatever stage of recover they are at, and supports them to prevent future falls. The person can self refer to the SmartCare service, or will be supported to register by staff supporting them to recover, in particular, AHP staff who will be using SmartCare tools to promote recovery. The agencies in the local areas that will use SmartCare will include:

- Intermediate care.
- Pharmacy.
- Podiatry.
- Rehabilitation teams.
- Telecare/community alarm services.
- Social Work.
- Housing.
- Third sector.
- Independents sector.

People or their carers can access the SmartCare products themselves via the LiU website. They will use their own smart devices, or where necessary access will be facilitated.

Coaching services to support older people and disabled people to use smart devices are established in the local areas. Third sector providers will work alongside people who are keen to use the service, but not confident using technology. They will also facilitate access to smart devices if the service user does not have one at home.

Awareness raising and training will be enabled via electronic means. Self referral will be encouraged via community groups - exercise classes, lunch clubs, elderly forums, citizen panels. The SmartCare service will be promoted within local community plans with are currently integrated across agencies. An existing telehealth learning portal is in place in partnership with NHS National Education Scotland and the Scottish Social Services Council which will help support professional activity in this area.

Date collection:

- Establishes a baseline of number of fallers in each area to inform 'before and after' considerations. This will require information to be collated consistently from similar data producing areas, e.g. telecare monitoring centre information.

- Has developed a common minimum data set for people who fall or who are at significant risk of falling. This is used to identify the target population within local systems and supports the development of a comprehensive register of fallers.

Using this minimum data set, health and care professionals identify the target population via a range of means:

- Reactively when they present either at GP surgery, hospital or via the emergency services with a fall or an injury due to a fall ('Trigger' care bundle implementation).
- Opportunistically by health and social care practitioners, e.g. osteoporosis clinics, home care visit, during implementation of a care package, mainstream assessment processes.
- Proactively via existing databases, e.g. Scottish Patients at Risk of Readmission or Admission (SPARRA) database can usefully identify some high risk fallers, along with information from telecare / community alarm databases (e.g. 3,000 fallers identified in Lanarkshire), social care and health databases.

SmartCare supports the implementation of a simple, common referral process at a local level which links all access points to a single point of contact for Falls Prevention & Management. This includes people who wish to self-refer or their carers, voluntary sector, Scottish Ambulance Service, fire service, A&E. In summary, the process follows a number of general principles as follows:

- Process for referral by health or social care worker: Referral form completed. New referral routed through Single Point of Access. If already known, pass to existing case / care manager. If not known, pass to identified local contact for completion of mini screening process.
- Process for self referral: Self referrals or carers referrals are encouraged to the Single Point of Access via a range of means, e.g. local information and advertising. Self referrals can be made by telephone or by completion of referral form available on local websites. If already known, the service user is passed to existing case / care manager. If not known, pass to identified local contact point for completion of mini screening process.

4.2.2 Assessment of the service user's needs for integrated care

It is accepted that the integration of information and coordination of support benefits everyone regardless of the stage they are at in the falls care pathway. Open inclusion criteria have been agreed which will facilitate high engagement in the service and encourage self management. Inclusion criteria are as follows:

- Age 50+ (banding into 50-64, 65-74, 75-84, 85+) and living in the identified Clyde Valley and Ayrshire area.
- People with history of falls (defined as: evidence of at least one fall in the past year, SPARRA risk score).
- People at significant risk of falling (defined as: concern expressed by user / patient / carer, via mainstream assessment processes in health and care).
- Carer of someone with a history of falls or at significant risk of falling.
- People who have access to smart devices at home, through their carer or local community access.
- Self identification of a falls risk e.g. poor vision.

Initial Screening

A broad range of agencies are now involved in screening for falls. The health or social care worker undertakes a mini screening to identify the key contributory risk factors to their falling. (Note: SmartCare investigates the potential for the mini screening to be undertaken electronically, remotely and by non-professionals). SmartCare has developed a common approach to mini screening to provide consistent, good quality initial assessment across the seven local partnership areas. The mini screening will identify if there is a need to:

- Refer on for a full multifactorial assessment (Level 2 - URGENT or Non-URGENT).
- Notify senior colleague/onward referral for other reason.
- Recommend common sense precautions, provide information and advice.

As part of this initial introduction to SmartCare, CR and I/FC are introduced to a range of Information and self management resources which:

- Enable access to ‘trusted’ information and advice: e.g. National Falls Training Pack for Care Homes. This will be provided via the Living it Up portal as referred to above, which will be able to record contacts achieved via the SmartCare project.
- Develop single point of information to support falls prevention and self management. Also to be used for dissemination of training, awareness raising of referral routes.
- Data hub which could be fed into and accessed by all services. One single repository that enables other systems to feed information in. Could include a data base of simple technology, equipment, share experiences and services available to healthcare providers to use as part of patient care, e.g. telehealthcare, befriending services etc. It is anticipated that this will be provided via the Living it Up portal.
- Promote access to healthy activity: Get up and Go, Invigor8 (700 people participating in exercise classes) partnerships with leisure services (50 week courses), Seniors Together Group, Active Lanarkshire, making life easier website. It is anticipated that this will be provided via the Living it Up portal.

Care recipients and their carers have opportunities to engage in health promotion and lifelong learning around health improvement, and minimising falls and fracture risk, e.g. build information on Slips and Trips, South Ayrshire pack for sheltered housing. They also have opportunities to access appropriate services and organisations, e.g. local falls and telecare services, which aim to support the maintenance of health and wellbeing, a safe home environment, and a safer community environment. Information, advice, peer support groups and access to appropriate services are enabled as part of SmartCare, and are provided within the Living it Up portal (which will link to a range of resources and information sources) and other appropriate formats.

Multifactorial Assessment

People who require more tailored and specific interventions or investigations, and who are likely to be requiring services from both health and social care. The mini-screening identifies if the need for the multifactorial assessment is:

- URGENT; or
- NON-URGENT.

The multifactorial assessment is used to identify specific risk factors for falling; this includes a comprehensive falls history (data from telecare and other ICT systems), medication review, fracture risk assessment, assessment of gait and balance, assessment

of their home environment, postural hypotension, vision, cognition, and feet / footwear ('Assessment' care bundle implementation). Where appropriate, and with the consent of the care recipient, communication and exchange of relevant data takes place between secondary and primary care, social work, and informal carer and is initially paper based, facilitated by telephone / email contacts.

The multifactorial assessment is completed and stored (note: further clarification will be required on access, storage, consent to share), and will be used to guide tailored interventions for the care recipient.

Following the multifactorial assessment, the individual and/or their carer is provided with detailed information about the SmartCare project, via leaflets / discussions with healthcare professionals and voluntary sector providers. Style and language of information to increase potential uptake and minimise concerns will be carefully reviewed. Benefits of the SmartCare project are explained, discussed and agreed with the individual and his/her carers, and any decision to decline involvement will be respected. Where they wish to participate, the CR is enrolled into Level 2 of the SmartCare pilot service, along with their informal carer if agreed.

At this point, where appropriate an assessor or co-ordinator / case manager is appointed from either health or social care to coordinate the elements of any care package. This helps support coordinated management, including specialist assessment (Stage 4 of the *Up and About* pathway). A summary of relevant care recipient information and the multifactorial assessment is provided as background to the project with the prior consent of the CR.

4.2.3 Initial integrated home care plan

Although there are examples of good practice, there are no electronic integrated care plans at present for people who fall or who are at significant risk of falling. Once the multifactorial assessment is completed, and the CR has agreed to be enrolled into the SmartCare project, they are then put forward for an individualised, multifactorial programme, i.e. the integrated care plan or personal plan ('Intervention' care bundle implementation).

This is integrated where appropriate with other mainstream care planning processes, and aims to identify and then minimise an individual's risk factors for falling and sustaining a fracture. The Personal Plan considers the role of any informal / family carers (I/FC) and is aimed at:

- minimising the identified risks for falling and/or sustaining a fracture;
- promoting independence via a self management and self care programme; and
- improving physical and psychological function.

This Plan could include strength and balance exercises, telecare / community alarm service provision, telehealth home monitoring, interventions to mitigate home hazards and promote the safe performance of daily activities, self management coaching, information, peer groups, and support via the Living it Up portal.

Prior consent from the CR and I/FC is obtained to enable the Personal Plan to be shared as necessary, and appropriate elements are anticipated to be integrated with the CR's Key Information Summary (KIS) and any individualised Anticipatory Care Plan (ACP). (KIS is an electronic record which is currently being rolled out across Scotland; it captures important information on an individual's care needs and situation.)

SmartCare identifies opportunities and mechanisms to support better communication and share relevant data more effectively (e.g. care diaries such as Ayrshire system for Children Services, falls summary Anticipatory Care Plan, Key Information Summary). The Scottish Ambulance Service has identified that when they attend a fall they would benefit from a system that provides reassurance that the person is not left unmonitored when the person is not transported to hospital. Referrals / links to local social / leisure services are also considered at this stage.

Self Directed Support legislation has been introduced in Scotland³. In summary, the Act gives people options for how their social care is delivered, empowering people to decide how much ongoing control and responsibility they want over their own support and arrangements. A diary which will integrate information across agencies and assist with the coordination of care will be very useful for the people who decide to take up this option and be more in control of their care. The option is also open to carers who have needs to support them to care.

Coordination of integrated care delivery of the initial care plan

Input from the key stakeholders including the service user will inform the delivery and review of the Care Plan for SmartCare service users. At every stage, accurate and relevant data will be collected and shared where appropriate to support direct care and provide information for service and resource evaluation, planning and improvement ('Monitoring' care bundle implementation).

This will identify any hospital admissions / readmissions or significant care incidents. The best mechanisms for this have yet to be agreed across the partnerships, along with the timescales for the review / reassessment of the CR. The care diaries mechanism may be one means of doing this, e.g. East Renfrewshire's IT Manager and Carenet Manager developing a mandatory field for fallers which will support data integration.

Local health and social care stakeholders have already agreed that at all points where local pathways might connect with the high level pathway, the best service can only be achieved with adequate communication and data sharing between the teams, and between health and social care organisations. This view is also likely to be shared by informal carers.

4.2.4 On-site provision of formal social care

The Care Plan (care diary) will provide detailed information about the on-site social care provision. This will include mainstream social care services such as home care and telecare which are identified and commissioned via the care planning process. Provision of support from other agencies such as housing, third sector and independent sector will also be recorded in the Care Plan (care diary).

4.2.5 On-site provision of formal healthcare

The Care Plan (care diary) will provide detailed information on the on-site healthcare provision. It will improve coordination across local health services, including CNs, local pharmacy, intermediate care services and community rehabilitation. It could also include the local nursing home if the service user uses the facility for periodic respite.

³ www.selfdirectedsupport.org.uk

4.2.6 On-site provision of informal care

The Care Plan (care diary) will provide detailed information about the on-site informal care provision. The majority of the support provided to frail older people is provided by family and friends. In addition, services such as hairdressers, low level podiatry, complimentary therapies, social clubs and meals at home services are perceived by the service user as important, sometimes more, as statutory services. SmartCare will incorporate these informal supports into the Care Plan and raise the awareness of the significance of informal support.

4.2.7 Remote provision of health / social care to the home (telecare, telemonitoring)

Improved access will be provided for smart devices, familiar technology to support early identification of fallers, self management and co ordination of care, and enable effective and timely responses to those who fall. The technologies and their associated data will be investigated to identify how best they can improve care co-ordination, communication and service planning, e.g. NHS24 can investigate the extent to which home health monitoring information should be included within the Key Information Summary.

4.2.8 Integrated documentation of home care provided / self-care measures

SmartCare will provide a great opportunity to improve the awareness of the local falls service. The pilot service will support improved access to home based technologies which can provide early identification of fallers, support self management and care, and enable effective and timely responses to those who fall.

The technologies and their associated data will be investigated to identify how best they can improve care co-ordination, communication and service planning, e.g. NHS 24 will investigate the extent to which home health monitoring information can be included within the Key Information Summary. Referrals to telecare services and health telemonitoring services will be enabled. For example, Hospital discharge with a home pod may enable people to return home sooner reducing hospital admission days. Current telecare monitoring stations and response teams operate 24/7 all year round. SmartCare will improve the use of the valuable data available via the monitoring stations and improve the integration and coordination of the monitoring stations with the ambulance service and other out of hours services e.g. home care, CNs, ADOC. This will ensure the ambulance service only visit cases where real emergency medical care is required and fallers who have not injured themselves will be supported by the response teams locally. A common trigger will be identified to facilitate early installations for URGENT cases e.g. preventing hospital admission or accelerating hospital discharge.

Control /reassessment /review of the home care recipient

Today, there is a statutory requirement to formally review care packages within social care in Scotland. However, for the large number of small care packages this can be undertaken from an administrative perspective due to resource issues and pressure on assessments and care planning. In SmartCare health staff will utilise additional information from telecare and telemonitoring and link these in to inform the mainstream reassessment / review processes.

4.2.9 Temporary admission / re-admission to hospital

Today, care providers are not often aware when a service user/patient is admitted by another provider to an institutional setting for a short period of time. Improved communication and co-ordination could help to address this. SmartCare will identify a

mechanism to record known short stays in institutional settings. Admission and discharge from hospital

SmartCare will improve the quality of the information available to Emergency services at the point of contact in the person’s home when a fall has occurred. Through the person held record of care and the care diary paramedical staff will have a more holistic picture of the persons need and level of independence at home and the nature of support the person has available to them, and to effectively integrate with (and perhaps adjust) existing hospital discharge procedures. These differ between hospitals.

4.2.10 Exit point

After formal review, the care recipient will either continue in the ‘At Home Service’ with appropriate adjustments or exit from the service with a self management plan where it no longer meets care recipient needs or preferences. SmartCare will identify common outcome measures for individual and system. IoRN could be adapted for this purpose and measured at entry and exit. The Talking Points Personal Outcomes Framework is envisaged to be included. www.jitscotland.org.uk/action-areas/talking-points-user-carer.

4.3 How key regional implementation requirements are met

The following table summarises in what way key implementation requirements identified in the Scottish context (for details see Annex 3) are going to be met.

Table 5: Summary of how key implementation requirements are met in Scotland

| Type of requirement | Summary of response by the project |
|---|--|
| End user requirements | Shared record/shared diary Digital diary to record falls / near misses, compliance with programme of recovery, progress, informal and formal care supports. Information regarding local community events. Self assessment tool facilitating access to additional services. Apps for exercises to promote recovery. Co production service design. Improved outcome based on personal targets. |
| Organisational and staff requirements | Briefing/training sessions. Intuitive electronic assessment tools where the assessor is supported to achieve accuracy and consistency and collaborate with the person being assessed. |
| Legal / regulatory / contractual requirements | Data protection governance/secure electronic systems to exchange of information. EU procurement rules will apply to products to be developed. |
| Technology / functionality related requirements | Community connecting info - promote activity socialising, health and well being. Diary- coordination of formal and informal care promoting choice and control. Recovery-Rehabilitation and enablement - Tools for assessment, apps to support programme of activity - outcome focused. Person held file - integration of key information about person across several agencies. |
| Other requirements | Accessible products taking into account equality issues. Need to be in line with national agenda - integration, SDS, co-produced, outcome focused. Data security. |

The following table summarises the approach taken in the deployment region towards negative anticipated potentially emerging from the SmartCare service when compared with current care practices in the deployment region (for details see Annex 3).

Table 6: Summary of how anticipated negative impacts of the SmartCare service are addressed in Aragon

| Stake holder concerned | Summary of approach taken towards anticipated negative impacts |
|-------------------------|--|
| Care recipient | Familiarity with Smart devices and how to use them. Coaching and peer support. |
| Informal / family carer | Self management would mean a reduction in current services. |
| Formal social carer | Security of information - detailed specification at tendering stage regarding secure information requirements. |
| Formal health carer | Additional information will be required to be input into a different system - The SmartCare person file will pull through information input to existing systems preventing duplication. |
| Third sector carer | That they are sufficiently included as key partners in the process. Ensure engagement at Board level and in local groups. |

4.4 Main lessons learned in the deployment region

In the following, the main lessons learned during the pilot service and infrastructure definition phase of the overall project are briefly summarised (for a description of workshops conducted see also Annex 3).

Table 7: Lessons learned

| Issue | learning |
|----------------------------------|--|
| Sign up of local areas | Now that we are more familiar with the WP's and the content we would start preparatory work earlier and would be better prepared to collect and present information the way Europe requires. |
| Appointment of programme manager | The timing of the appointment of the programme manager was dependent on the grant being finalised. This resulted in the PM being appointed 6 months into the project. In future we would look at ways to access start-up monies and appoint the PM at the start of the project |
| Appointment of local PMs | This happened 7-8 months into the project and was determined by the local partnership areas. In future we will ensure they are identified early through adjusting recruitment approach and accountability arrangements. |
| Stakeholder engagement | This has been very positive. There are some key stakeholders still on the fringes, e.g. housing. In future we will ensure they are around the table at an earlier stage and at a senior level. |
| Geographical scope | This is wide which means the range of stakeholders is wide. This requires significant capacity and expertise to ensure they are fully engaged and informed. |

5. Pilot site #4 - Region South Denmark

5.1 Contextualised implementation of the SmartCare integration infrastructure

The SmartCare service from the Region of Southern Denmark is a combination of the existing electronic messaging system, MedCom, which ensures that the relevant information is sent electronically between the three care giver organisations according to the care pathways and joint agreements (SAM:BO). Building on top of that is the Shared Care platform, which allows all the care givers, as well as the care recipients and relatives, to have access to a complete overview and the possibility to share data at any given time during the course of treatment. The illustration below (Figure 4) shows the entire SmartCare service in the Region of Southern Denmark.

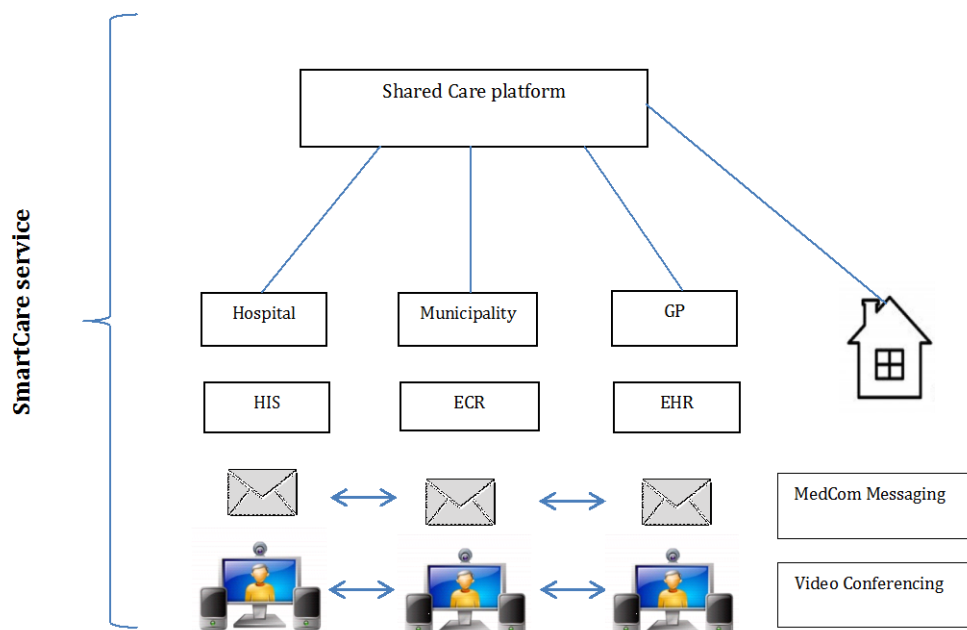


Figure 4: SmartCare service ICT infrastructure in Region of Southern Denmark

Figure 5 below graphically summarises how the Shared Care platform, a part of the SmartCare pilot service infrastructure, will be implemented in the Danish context (for contextual details see Annex I). Information can be accessed by the care providers regarding the care recipient’s disease such as diagnosis, measurements taken by professional carers, relevant data on lifestyle and social factors, filled out questionnaires, goals, notes, activities, symptoms and contact persons. The integrated care recipient can also look up relevant information and also add information to the Shared Care platform in both text, such as questionnaires and notes, and measurements from home monitoring devices. The care recipient can include relatives in the treatment and permits access to the electronic data in the Shared Care platform. In principle relatives supporting the patient can have the same access rights as the patients themselves.

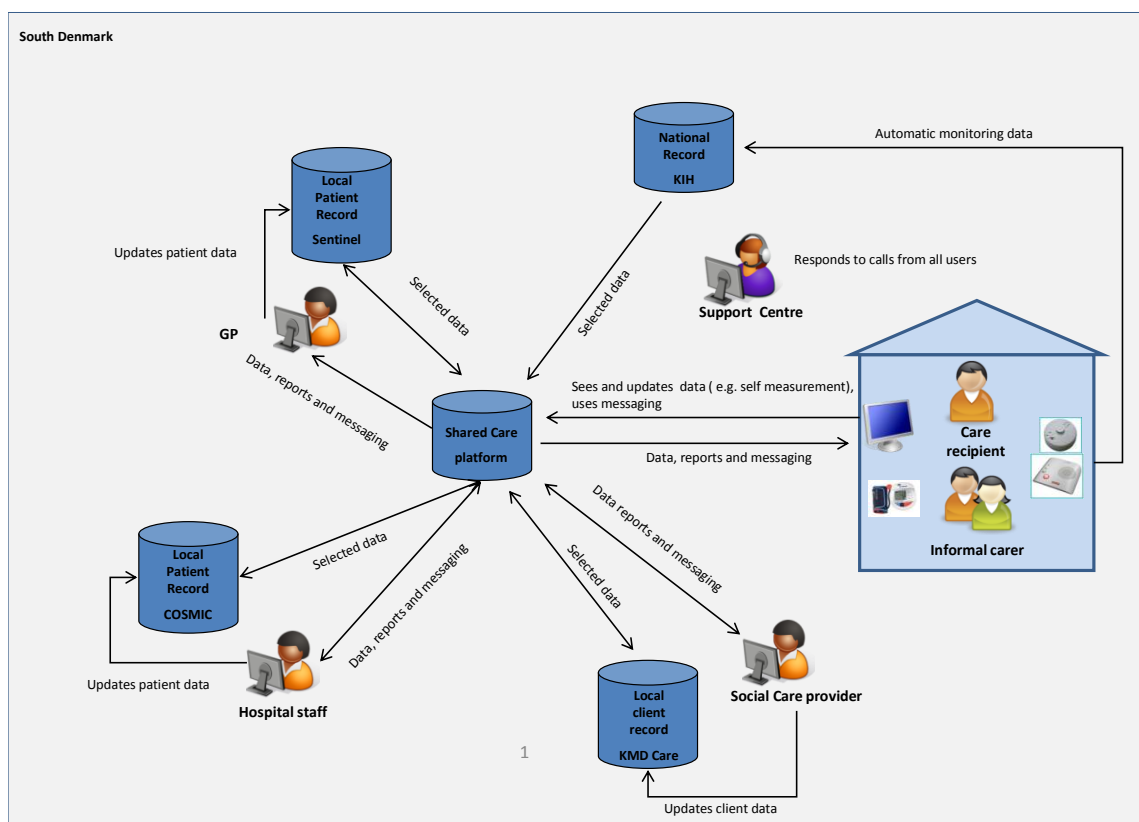


Figure 5: SmartCare service infrastructure implementation in Region of Southern Denmark

Social carers involved in service delivery to the care recipient include care coordinators, educators and physical therapists in the municipalities. They deliver different types of local support such as education in lifestyle, including diet, exercise, alcohol and smoking in rehabilitation centres in the local communities. A number of SmartCare users also receive home care services by the home care department in the municipality such as cleaning, food delivery, bathing, shopping and other daily tasks. Finally some of the patients have a care coordinator from the municipality, who helps the patient navigating in the system and helps them to implement lifestyle changes where necessary.

Health care providers who are involved in the SmartCare pilot service include hospitals and general practitioners. The hospital is in charge of acute heart problems, specialised treatment as well as discharging and following up on the patient after discharge for a period of typically a year. The general practitioner is responsible for the long term check-ups yearly and the general communication with the patient about their health.

Care professionals from the different relevant clinics in the hospitals as well as staff in the general practitioners offices and selected staff from the municipalities will be able to share data from their individual systems, use the platform to support their workflow across sectors and to view data from the different caregivers. Information shared from the hospitals and GPs could be lab-results, measurements, notes, symptoms and diagnosis as well as goals set with the patient, activities, questionnaires, reports and self-care indicators. They will also be able to see the information provided by the different actors such as patients and municipalities.

Third sector organisations provide support and counselling to the SmartCare end user if needed, such as joining them in meetings or accessing personal data of if the end user permits them to do so. They also offer group counselling, coaching, advice on diet and training as well as taking measurements in a local setting.

5.2 Contextualised implementation of the SmartCare pathways

In the following, it is described in what way the SmartCare integration infrastructure will be utilised in the Danish context for the purposes of service delivery according to the SmartCare pathways.

5.2.1 Entry points

Typically a heart failure patient's first contact with the health care system is when he or she has an acute heart problem that needs admittance into the hospital. Either that or the patient expresses their symptoms and their concerns to their general practitioner. In that case the GP sends an electronic admittance referral to the hospital. When a patient is admitted to the hospital the system sends a message to the patient's municipality informing them of the admittance. The municipality's system sends back a message containing detailed information on the patient.

In SmartCare, either the social care professionals or the GP or the hospital staff may also choose to enter the patient into the Shared Care platform at any given time. All these actors will evaluate the patient and see whether or not he or she is a candidate for sharing information in the platform between the actors. This will be relevant if the patient receives both health care and social care services. If the patient already has a heart plan, with specific goals and appointments, this will also be entered into the platform by the caregiver entering the patient into the Shared Care platform. Typically the patient will be entered into the Shared Care platform at discharge from the hospital.

5.2.2 Discharge from hospital

The patient is discharged and the hospital nurse send a discharge report to the municipality stating the patient's needs in terms of home care and a notice to the general practitioner. She also sends a rehabilitation plan to the municipality for physical rehabilitation. With SmartCare, instead of filling out the heart plan in paper the hospital nurse fills it out in the Shared Care platform. As the heart plan is available in the platform adjustments are easily made at any point in time and shared with the other involved caregivers and the patient. Seeing that the patient has access to the information and can add measurements and notes, revisions can be made more on a need-basis rather than on a plan-basis. She can also give the patient access to home monitoring and videoconference possibilities making some of the visits to and from care professionals unnecessary. This also means that she has the opportunity to discharge the patient earlier and keep contact via telemonitoring/telecare services in the patient's home.

5.2.3 Assessment of the service user's needs for integrated care

When the patient is ready to be discharged the responsible nurse fills out a discharge report in the hospitals IT-system, which she sends to the homecare department in the municipality. In this report she includes information such as:

- General information on the patient and their relatives contact information.
- Information on the cause of the admittance and the treatment delivered while in the hospital.
- The patients current need for further treatment and medicine.
- An evaluation of the patients functional level and a description of which social care elements that need to be put in place in the patients home.

A distinction between how significant the change to the patient's functional level is made. If there is a significant change the hospital is urged to host a videoconference between the

hospital professionals, the GP, the municipality and the patient. In the conference a coordinated plan for the level of care after discharge should be made and the responsibility between the caregivers is divided. If the change is not significant it is the hospital nurse who evaluates the need for home care and sends this in the abovementioned report.

So in this phase the hospital nurse decides which care services the patient needs when discharged from the hospital both health care and social care services. She also sends an electronic report to the general practitioner with relevant information on the patient's treatment. The hospital nurse also sends a plan for physical rehabilitation to the training facility at the municipality, where she describes the patient's need for training. These messages are all automatically sent to the specific IT-systems in the different sectors.

If the patient is already entered into the Shared Care platform at the time of the assessment the hospital nurse will be able to see the information when assessing the need for social care based on the history of the patient. She will also be able to see the contacts in the municipality and the GP and so will be able to contact them for further information if needed. She will also be able to take into account the possibility for the caregivers to follow the patient closely through the platform combined with the possibility for home monitoring - this might have an impact on the assessment and might make the patient more independent.

5.2.4 Enrolment into the SmartCare service

At the first meeting in the clinic the nurse will ask consent to enter the patients data and to share it with other relevant actors involved in the patient's treatment in the Shared Care platform. She will also give the patient information on the Shared Care platform and the possibilities for getting access themselves. The nurse also evaluates the patient's ability to perform home monitoring and if they are considered eligible they are given the opportunity to get home monitoring equipment. This is then ordered at the Region, where employees set up the devices at the patient's home and at the same time introduces the patient to the use of the equipment. The nurse simply enters the patients CPR (personal security number) and the Shared Care platform retrieves the basic information on the patient from the national database. After entering the basic information, she chooses the disease and follows the predefined form to enter relevant data together with the patient.

5.2.5 Initial integrated home care plan

At the point of discharge a rehabilitation plan is made by the hospital staff where the patient's needs are described. Information needed in this plan includes:

- Full name and address of the patient.
- The rehabilitation plan has to include a description of the patient's ability to function just before the event/disease that led to the current hospital treatment. The plan also includes a description of the patient's usual ability to function related to body function, activity and level of participation.
- The rehabilitation plan has to include a description of the patients' ability to function when discharged which includes the patient's current ability to function related to body function, activity and participation that can involve both the patient's resources and limitations.
- The rehabilitation plan has to include a description of the patient's need of rehabilitation at the time of discharge. The description has to include a clarification of which limitations the rehabilitation should focus on. Furthermore this description has to consider the patient's disabilities and possible limitations regarding participation in activities and the rehabilitation in general.

- The rehabilitation plan has to state if the patient needs rehabilitation in the hospital after being discharged.
- The rehabilitation plan has to state the timeframe within the municipality of residence has the first contact with the patient with a view to plan the course of rehabilitation. This also includes the patient's right to be guided regarding the possibility of choose between different rehabilitation offers. In cases where the patient needs specialised rehabilitation in the hospital after being discharged, the rehabilitation plan has to state a timeframe within the hospital has to have the first contact with the patient.
- The rehabilitation plan has to include information about how the region of residence and the municipality of residence can be contacted.

The nurse also sends a discharge report stating the patient's treatment, discharge date, functional level and need for assistance including medication and need for personal remedies to the municipality. From this report the municipality can assess the patient's need for social care.

When the SmartCare user returns to the hospital after a discharge the nurse fills out a personal heart plan in the Shared Care platform. This heart plan is a questionnaire developed in collaboration with the municipalities and is the patient's tool for setting goals and keeping track with the agreed treatment. If the patient is not yet included in the Shared Care platform the nurse enters the patient's social security number and chooses the patient's condition. This enables her to fill out the heart plan in the platform with the patient after they have given their consent. Afterwards they fill out the questionnaire together setting goals, entering measurements and scheduling check-ups after 3, 6 and 12 months.

5.2.6 Permanent coordination of integrated care delivery/revision of the initial care plan

At each point of contact with a care professional the patient or the care professional has the opportunity to revise the needs of the patient and the services accordingly. As the heart plan is available in the SmartCare system adjustments are easily made at any point in time and shared with the other involved caregivers and the patient. Seeing that the patient has access to the information and can add measurements and notes, revisions can be made more on a need-basis rather than on a plan-basis. The Shared Care platform has an alarm-mechanism that allows the care professionals to be alerted when a measurement exceeds an agreed value. This means that the care professionals have an opportunity to intervene faster than in the existing system.

5.2.7 On-site provision of formal social care

When the patient returns home the social care is waiting according to the message/report sent by the hospital nurse. This could typically be a home care professional from the municipality which provides services such as cleaning, bringing food, bathing, dressing and helping the patient to bed. These services depend on the needs described by the hospital nurse. The patients are also offered an individual conversation with a coordinating social care professional if they are expected to have low self-care ability. The patients are also offered a group-based educational programme of six weeks at a local facility, regarding lifestyle factors such as diet and exercise according to their condition.

When the SmartCare user is discharged the local rehabilitation centre in the municipality contacts the patient either by telephone or personally for a follow-up meeting on the current treatment and the planned rehabilitation course (typically 6 weeks of training and education in lifestyle elements). Depending on the level of self-care ability the patient

either has a range of meetings or just the one. In the meeting the rehabilitation worker fills out a list of information in addition to the heart plan, where personal goals and expectations are elaborated. This is entered directly into the S platform. He or she may also determine which information is to be shared in the platform, such as guides for the patient, activities and notes. He or she will also look at the measurements taken at the hospital or from home.

5.2.8 On-site provision of formal healthcare

The on-site provision of health care may include physical rehabilitation, medication or treatment of wounds and check-ups at the general practitioner. All these services are assessed at the time of discharge and the patient's needs are re-evaluated before starting as an example physical rehabilitation. Here a 6 weeks long programme is made according to the individual's needs - either in groups or individually. The patient sees their local GP for annual check-ups after the first year after discharge. If there is a need for rehabilitation this can either be performed at a local training facility or at the patient's home depending on the patient's ability to transport themselves. The caregivers will find great value in seeing information from the other actors in the treatment as well as benefiting from possible home-monitoring or videoconferencing functions. For heart patients the time for adjustment of medication has shown to be cut in more than a half when using videoconferencing. Also the GP and the hospital clinic will be able to see the patient's measurements and notes before the scheduled check-ups and some of these check-ups might be able to be replaced by home-monitoring or videoconferencing. The caregivers will enter relevant information such as measurements or goal status either in the Shared Care platform or in their own IT-system, which is then shared between the two systems.

5.2.9 On-site provision of informal care

This section is very limited in the Danish system, however relatives will be able to see the information in the Shared Care platform as the same way the patient does. This allows them to support and monitor their relatives.

5.2.10 Remote provision of health / social care to the home (telecare, telemonitoring)

Today, there is not a wide-spread use of telecare and telemonitoring possibilities. There are however a number of projects, that show the relevance of these elements. In the Shared Care platform the patient is able to enter data from devices into the platform themselves or connect devices that automatically update in the platform. The measurements are stamped with the point of origin so that the care professionals are able to see where the measurements are coming from. Videoconferencing will also be made available in this service in a complimentary system, not yet defined. These possibilities may replace physical meetings in the hospital or at the GP, and will also supplement the measurements taken at the scheduled check-ups.

5.2.11 Integrated documentation of home care provided / self-care measures

In the Shared Care platform it is possible to get reports based on the entered data. There is a very flexible configuration which allows users to set up their own report templates with selected information from the platform. This is only limited by the access and rights of the individual ordering the report. In addition the entire platform is based on presenting relevant and updated information on the screen so that the caregivers or patients will not need to search for it in the system. The screen set-up can be customised to suit the individual user's needs. It is also easy to see historic data and have them presented in a visual and user-friendly way.

5.2.12 Control / reassessment of the home care recipient

The patient attends check-ups at 3, 6 and 12 months after discharge at the hospital clinic. The patient is called in for a check-up at their own general practitioner after the first year of check-ups at the hospital. Depending on the level of functionality and self-care ability the home care may be reduced and the hospital passes the responsibility of check-ups and monitoring measurements made from home to the GP. The GP may also refer the patient to additional patient educational activities in the municipality by sending them a referral. It is the GPs responsibility to be the main responsible caregiver on a long term basis including evaluating the patient's needs at a regular basis. However the municipality will also assess the patient's needs for home care services on a regular basis as they are the ones that deliver the services. In between check-ups the SmartCare end user is able to see and enter relevant information from home giving the caregivers a better insight into his / her needs. The involved caregivers are able to access the Shared Care platform to see and enter relevant information to be shared. Also the GP will be able to see the patient's measurements and notes before the scheduled check-ups and some of these check-ups might be able to be replaced by home-monitoring or videoconferencing. This also means that the care professionals are better able to evaluate the patient's needs on a regular basis rather than on the scheduled visits.

5.2.13 Temporary admission / re-admission to institutional setting

The patient is already entered into the Shared Care platform and the involved caregivers are able to see the historic data and include this in their decision making.

5.2.14 Exit point

The need for care is reassessed by the social caregivers and the GP on a regular basis and services are adjusted accordingly. The care recipient will probably remain in the Shared Care platform until they are deceased or wishes to be taken out of the system.

5.3 How key regional implementation requirements are met

The following table summarises in what way key implementation requirements identified in the Danish context (for details see Annex 4) are going to be met.

Table 8: Summary of how key implementation requirements are met in the Region South Denmark

| Type of requirement | Summary of response by the project |
|-----------------------|---|
| End user requirements | <p>The service is going to include an on-line secure access for the care recipients and their relatives to see the information recorded by the caregivers, view the goals set by them and the care professionals, view relevant guides, view lab values and measurements. They will also have an opportunity to enter relevant information such as measurements taken at home, notes for the care givers, diary notes, and questionnaires and to send messages to the care professionals.</p> <p>The interface for the care recipients will be made user friendly with illustrations of goals and current measurements and a mobile version will be made available.</p> <p>User friendly guides and an available support line will be in place for the pilot start.</p> |

| Type of requirement | Summary of response by the project |
|---|---|
| Organisational and staff requirements | The care professionals will be able to view information recorded by their collaborators and the patients themselves minimizing the time spent on searching for important information and asking the patients the same questions. The service will also support the concrete workflow of each organisation as well as integrations to the existing individual IT systems to minimize the work with entering information. The messaging system will enable the care givers in contacting relevant collaborators when necessary including receiving information from the patients, e.g. via questionnaires. User friendly guides, training and an available support line will be in place for the pilot start. |
| Legal / regulatory / contractual requirements | The consent part will be a mandatory element when entering the patient into the Shared Care platform. They will at any given point be able to withdraw their consent. Also the patients will receive a pamphlet describing what information is shared and what information is used in the evaluation of the project. They will also have to sign a written consent form to join the evaluation of SmartCare. |
| Technology / functionality related requirements | The service will be based on national and international standards and a focus will be on integrating the Shared Care platform to the existing systems to prevent redundancy. The platform will also be highly connected to existing databases and platforms to make sure, that there is a reuse of existing data. |
| Other requirements | There will be implemented a delay on the lab results to ensure that the patients receive the information in person first. There will be invested in making easily readable printed versions to those patients that will not have access to the Shared Care platform. |

The following table summarises the approach taken in the deployment region towards negative anticipated impacts potentially emerging from the SmartCare service when compared with current care practices in the deployment region (for details see Annex II).

Table 9: Summary of how anticipated negative impacts of the SmartCare service are addressed in the Region South Denmark

| Stake holder concerned | Summary of approach taken towards anticipated negative impacts |
|-------------------------|---|
| Care recipient | We will focus on providing relevant and abundant information to the care recipients when they are included in the project and entered into the Shared Care platform, including information given from the care professionals, hand outs, guides and a support function. We will also make sure to have easily readable printed versions for all patients and generally work with user friendliness in the system. |
| Informal / family carer | We will work on user friendliness with inputs from care professionals, patients and relatives as they are included in the project. Trying to minimize information and making it easy to navigate in. |
| Formal social carer | We will provide information in meetings, folders, guides and newsletters. We will also make sure to offer relevant training at start-up and involve the users in continuous development and improvement of the service. |
| Formal health carer | We will provide information in meetings, folders, guides and newsletters. We will also make sure to offer relevant training at start-up and involve the users in continuous development and improvement of the service. |
| Third sector carer | We will provide relevant representatives with information on the service in meetings and in written material, such as folders. Again we will generally work on the user friendliness of the service. |

5.4 Main lessons learned in the deployment region

In the following, the main lessons learned during the pilot service and infrastructure definition phase of the overall project are briefly summarised (for a description of workshops conducted see also Annex 4).

- We have learned that it takes time to define and develop integrations to the different systems. This is also caused by many external providers.
- It is important to start early and make time for discussions between the actors of what they need.
- If it is possible the providers are more willing to cooperate if they can get paid for the time they use testing a new system.
- We might have underestimated how different the needs of the different actors are. It was mainly the hospital specialists who were consulted in the beginning. When the social care providers were involved in the project they had very different needs. This is why many of the workshops were held. It was meant as a possibility for the different actors to express their wishes for their individual use of the platform.
- Social care providers and health care providers have different needs. Health care providers focus more on the hardcore medical data and values connected with their field of expertise.
- The social care providers focus more on the rehabilitation aspects and they might only need to view some of the medical values. They focus on lifestyle changes, questionnaires and goals for the patient's progress. This is what the workshops have taught us and it is important to address the different needs of the different actors early in the process.
- The project manager in RSD is supposed to be able to configure the user interface but so far it has not been working properly. This makes RSD more dependent on our provider of the IT solution.
- It is currently possible to configure the interface BUT it is difficult for us at the Health Innovation of Southern Denmark. This is why we are more dependent on our provider as described above since they have to do the configuration. However in the future the support team at the Health Innovation Centre of Southern Denmark should do the configuration.
- We have realised that it takes time to develop common language and definitions between the different care givers in the project.
- We have spent a lot of time describing and trying to understand how the system and collaboration actually works in real life, how it should work according to joint agreements and how it could be improved in the SmartCare service.
- The Danish health care system is different than some of the other deployment sites' systems. So we have spent a lot of time describing how the Danish system works and that the Danish SmartCare service is not only the Shared Care platform. So the Danish SmartCare service is the existing system with MedCom messages and then the Shared Care platform is added to that to improve the integrated care across sectors.

6. Pilot site #5 - South Karelia

6.1 Contextualised implementation of the SmartCare integration infrastructure

The schema below (Figure 6) graphically summarises how the SmartCare pilot service infrastructure will be implemented in the regional deployment context in South Karelia (for contextual details see Annex 5).

In this deployment region the SmartCare pilot service addresses older people who suffer from long terms conditions and who are aged 65 and above. The care recipient accesses the SmartCare integration infrastructure to consult different care providers remotely with help of a video connection. Beyond this, various home safety sensors collate data in the care recipient’s home. Sensor data are submitted to a dedicated telecare service platform, which again feeds selected data into the SmartCare integration infrastructure.

Upon consent by the cared for person, relatives who support the care recipients at home can view home safety data through the SmartCare system. They can also participate in video sessions, provided the care recipients give his/her permission.

South Karelia

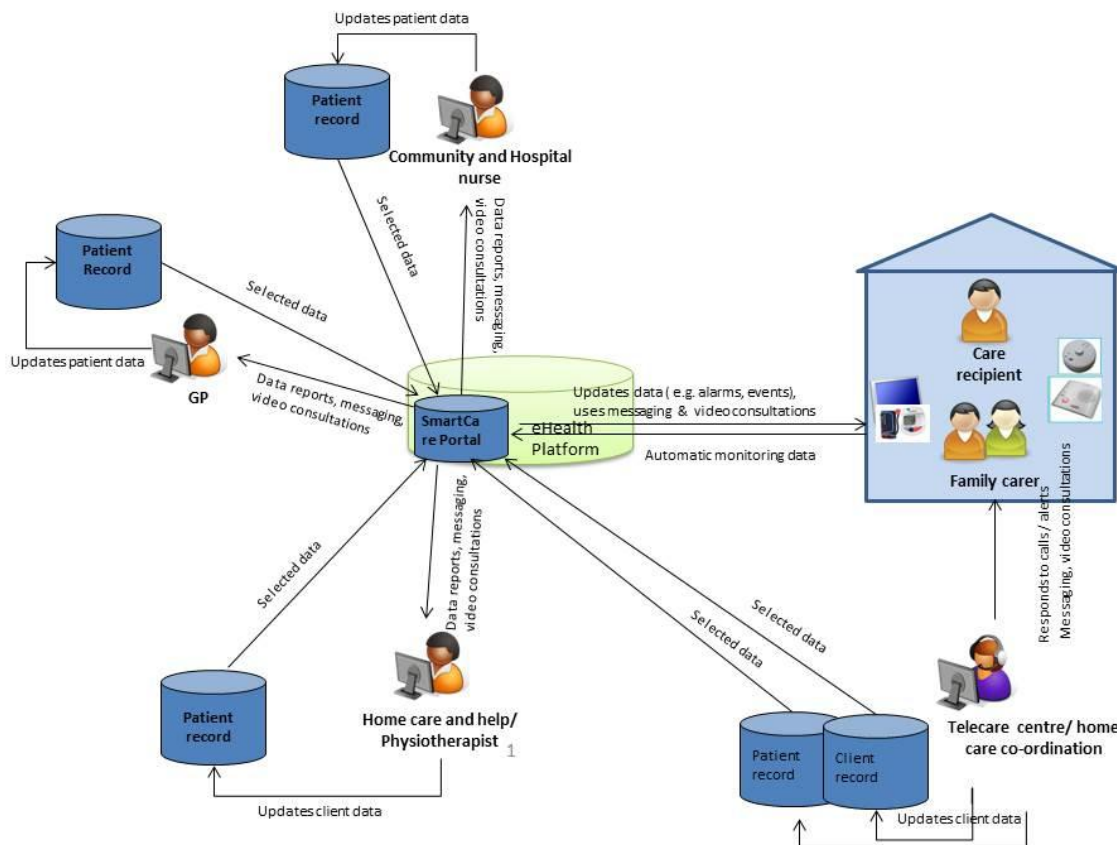


Figure 6: SmartCare service infrastructure implementation in South Karelia

Social care staff and health care staff, employed by Eksote, look up home safety information through the SmartCare integration infrastructure and respond to alarms raised by telecare sensors coordinated by telecare centre. Both social and health care staff could handle alarms etc. Alarms could be from push button alarm or other home safety sensors. Beyond this, video consultations are held with the care recipient if home care client or

relative have request, if needed regularity (e.g. time of taking medicines) or need to check client situation.

Staff of the Alzheimer association utilised the SmartCare system to recruit patient to the pilot and promote to their clients possibilities to develop and exploit telecare services.

6.2 Contextualised implementation of the SmartCare pathways

6.2.1 Entry points

Depending on the individual care needs, SmartCare service will be offered in home care costumer and will be installed in to the elderly home. Case manager in home care will make assessment of service needs to client when there is suspicion of manage at living home. Case manager will assess with client is there any benefit to use Smart Care services. Also home care staff, aging specialists, memory and dementia clinics could find potential clients. SmartCare services will support to client to live at home for longer and it will provide support for those who do not need another social and health care services.

6.2.2 Assessment of the service user's needs for integrated home care

Case managers, home care staff, aging specialists, memory and dementia clinics will assess users to the pilot:

- Does he/she need home care services, criteria based on The Social Welfare Act (710/1982).
- Age - above 65 years.
- Lives in own home; could be supported by home care.
- Suitable for the pilot.
- Willingness to participate.
- Can self understand and give consent to participate in the project trial.

Exclusion criteria:

- Participants under active treatment (chemotherapy, radiation therapy) for cancer or other terminal diagnosis.
- Participants with psychological long-term conditions as for example, schizophrenia or depression.

6.2.3 Enrolment into SmartCare pilot service

Potential participants will be recruited with the home care staff, aging specialists, memory and dementia clinics and local organisations for aging programs and services. In SmartCare integration infrastructure both social and health care professionals has entitlement to use portal, so they have a rights to add new client in the pilot.

6.2.4 Initial integrated home care plan

In South Karelia Social and Health Care District social and health care services are integrated. Based on the Finnish laws social and health care records cannot be integrated directly together. But in home care social and health care professionals use same health care record, where home care plan is available to both professions. SmartCare portal aims to provide a wider opportunity to integrate the functionality of social and health care services.

6.2.5 Coordination of integrated care delivery/revision of the initial care plan

Home care professionals and specially service managers are responsible for managing home care plan and service delivery. SmartCare portal aims to provide a wider opportunity to integrate the functionality of social and health care services.

6.2.6 On-site provision of formal social care

Service managers in Home care will manage and coordinate social care service providing process to elderly. Using SmartCare portal reduce duplication of all parties of formal and informal care givers. Different care or service givers could plan their visit so that not all visit same day in elderly home.

6.2.7 On-site provision of formal healthcare

Home care professionals (registered nurses and practical nurses) will provide health care services to elderly home. Using SmartCare portal reduce duplication of all parties of formal and informal care givers. Different care or service givers could plan their visit so that not all visit same day in elderly home.

6.2.8 On-site provision of informal care

Informal care givers could provide support services to home, like cleaning, shopping help and medication control. Different care or service givers could plan their visit so that not all visit same day in elderly home.

6.2.9 Remote provision of integrated care to the home (telecare, telemonitoring)

Remote visits will be implemented part to the home care service delivery. All professions in home care could do remote visits (registered nurse, practical nurses and social workers in home care). SmartCare integration infrastructure will reduce remote visits when any number of visits can be replaced by remotely connection.

6.2.10 Integrated documentation of home care provided / self-care measures

HCP and SCP could add documentation and measures directly to the EHR. Some information could documented in SmartCare integrated infrastructure; health status, care plan, changes when needed, statistics.

6.2.11 Control /reassessment of the home care recipient

HCP and SCP will do reassessment all the time when they are contacted to the patient. For normally reassessment there is not formalised procedure, but if there is suspicion of a change in the need of services the elderly will be repeated in a wide-ranging assessment of service needs.

Data from SmartCare integration infrastructure is available for a longer period. It helps when professionals could see previously data -e.g. when is usually time to alarms or security calls.

6.2.12 Temporary admission an institutional setting (e.g. hospital, day care centre)

Some CR participates also to day care. Especially those elderly are very suitable for the pilot. Case managers admit a service user to an institutional setting. All professionals in Home care have entitled temporary admissions to the hospital in acute events.

In the SmartCare integration infrastructure enables data over a longer period and support to decision making.

6.2.13 Discharge from hospital

Discharge from hospital is coordinated in Eksote via discharging nurses. Discharging nurses take contact with relatives and home care nurses when they are planning to discharge patient. Discharging nurses they inform the home care professionals when person will be home and then somebody from Home care will visit on clients home. Often the older person return to the hospital because she/he doubts that can succeed at home and even fears being in home alone. SmartCare will give more feeling of security when a person knows that there is help available if something accident occurred.

6.2.14 Exit point

CR will be out of the pilot if he/she doesn't need service any more. This may happen if elderly condition improves or elderly condition goes down and he/she need to move e.g. sheltered housing. A home care professional decides on whether service users exit the pilot service. SmartCare integration infrastructure enables seeing the information for a longer period and help decision making.

6.3 How key regional implementation requirements are met

The following table summarises in what way key implementation requirements identified in the Finnish context (for details see Annex 5) are going to be met.

Table 10: Summary of how key implementation requirements are met in South Karelia

| Type of requirement | Summary of response by the project |
|---|--|
| End user requirements | Create SmartCare Service (including portal, home safety and video connection) which support elderly person coping at home, is easy to use and remove. |
| Organisational and staff requirements | Create SmartCare Service which support home care service delivery, support caring processes, is easy to use and benefit social and health care professionals. Could provide different kind reports from the system (e.g. number of alarms, video connection use/ per patient/per patient group) |
| Legal / regulatory / contractual requirements | Parallels creating SmartCare Service all legal aspect need to capture, e.g. data safety. |
| Technology / functionality related requirements | SmartCare Service need to include all needed services (home safety, video connection and the portal), technical support and maintenance need to be provided by technology provider. Service need to be tested and running in January 2015. Service need to be up and running 95% of the day. |

The following table summarises the approach taken in the deployment region towards negative anticipated potentially emerging from the SmartCare service when compared with current care practices in the deployment region (for details see Annex 5).

Table 11: Summary of how anticipated negative impacts of the SmartCare service are addressed in Aragon

| Stake holder concerned | Summary of approach taken towards anticipated negative impacts |
|-------------------------|--|
| Care recipient | More quality of life. More independently Care recipient. |
| Informal / family carer | More quality of life. Reduce burden. Could take care of elderly even lives far (another city). |
| Formal social carer | More integrated way to deliver home care services. Could use working time more efficiently. |
| Formal health carer | More integrated way to deliver home care services. Could use working time more efficiently. |
| Third sector carer | Could provide assistance to home care client more efficiently and co-ordinated. |

6.4 Main lessons learned in the deployment region

In the following, the main lessons learned during the pilot service and infrastructure definition phase of the overall project are briefly summarised (for a description of workshops conducted see also Annex 5):

- Infrastructure definition phase and tendering process will take lots of time, because SmartCare Service is wide range service, which affects elderly and social and health care professionals.
- Technical providers do not have the product which could be implemented directly. In these circumstances technical providers need to do development work before implementation.
- Workshop to end users and social and health care professionals will be held March 2014.

7. Pilot site #6 -Tallinn

7.1 Contextualised implementation of the SmartCare integration infrastructure

The schema below (Figure 7) graphically summarises how the SmartCare pilot service infrastructure will be implemented in the regional deployment context prevailing in Tallinn (for contextual details see Annex 6).

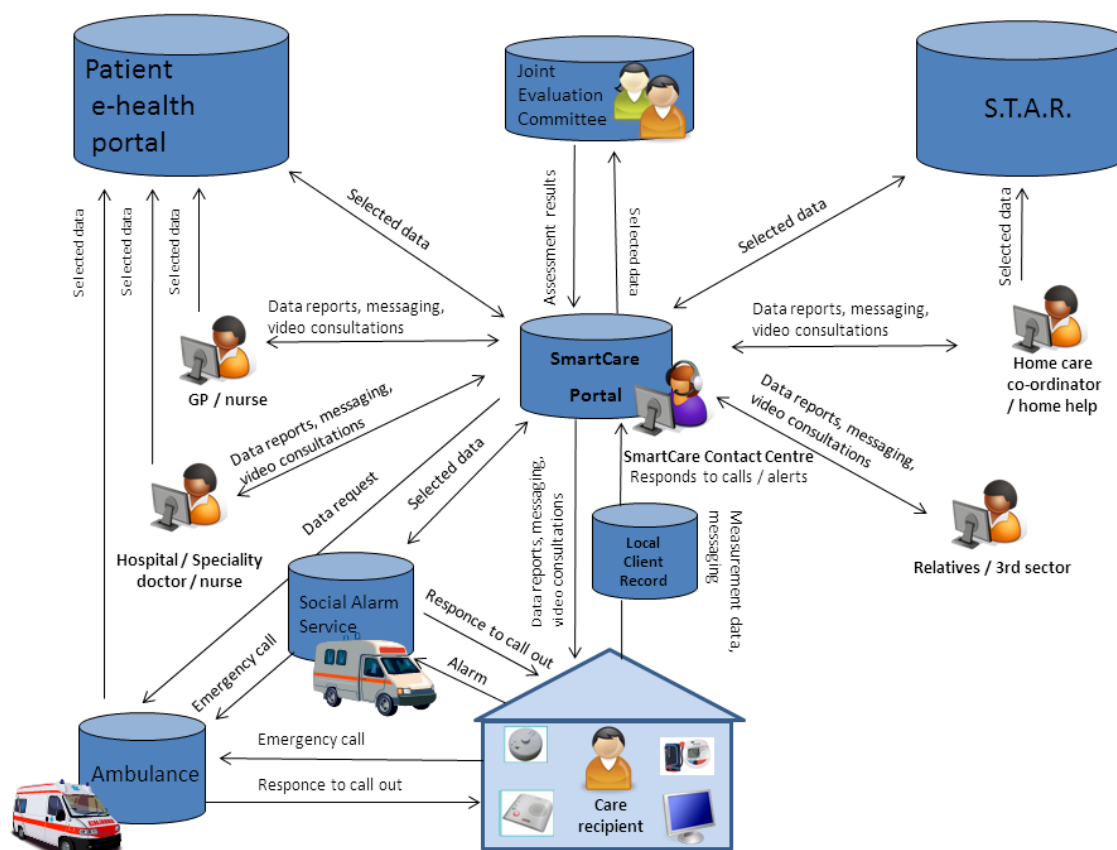


Figure 7: SmartCare service infrastructure implementation in Tallinn

In Tallinn, the SmartCare pilot service addresses older people suffering from chronic heart failure aged 65 years and above. Chosen older people can access the SmartCare integration infrastructure by using the SmartCare equipment installed by the SmartCare technical personal. Users need to access the infrastructure to perform health measurements that have been requested and answer questioners. Users also can contact health and social care providers by requesting a video conference. Improved health situation and stronger sense of security is expected from utilising the SmartCare integration infrastructure. Due to those improvements the independency and well-being of elderly will increase. Decreasing of hospital admissions is also an expected outcome.

Social care for elderly is provided by the municipalities. Social care can be received when the municipalities assign home help to the elderly or when alarm-button is installed and connection with the Social Alarm Service is established.

Home care co-ordinator can use an ID-card to gain access to the SmartCare infrastructure. It is important for a social care provider to have up to date overview of patient's condition. In that way the social care providers can have more information about the

elderly and their work can be planned more beneficially. Through the SmartCare infrastructure social care providers can gain access to the information about the elderly and a notification will be sent out from the SmartCare Contact Centre if any type of emergency occurs. In case of hospitalisation SmartCare Contact Centre will provide the home care coordinator with the name of the hospital the patient is being treated. The social care provider can also add information to the SmartCare portal if some unusual and unwanted changes in the elderly people's health condition occur and send messages to health and informal care providers who have access to the system. Social care provider can enter all interventions done by social care service providers to the portal.

Social Alarm Service responds to the activation of Alarm Button. After the alarm Social Alarm Service tries to establish contact with the elderly. When contact has been established necessary means will be taken. When needed Social Alarm Service patrol, which consists of two social workers, will make a home visit to help the elderly. The home visit is also made when it isn't possible to establish a connection with the elderly. For home visits spare set of elderly's home keys has been beforehand given to the Social Alarm Service. Social Alarm Service enters information to the portal when an alarm button has been activated and what were the reasons and results of that incident. Social Alarm Service also has an access to the SmartCare portal in order to have an overview of the elderly people's condition.

The general practitioners, family and hospital nurses and speciality doctors can have access to SmartCare integration infrastructure and elderly people's data by using the SmartCare portal. The access is granted using a personal ID-card. Access to the infrastructure is needed to upload new information about the elderly and get a well-documented overview of the measured health status in the current time and in the past. Health care providers can access the information uploaded by the social care providers. Health care providers also get an informational e-mail when any type of emergency has happened to the elderly. In that way it is possible to reduce unnecessary and inappropriate emergency admissions of elderly patients.

Informal care providers, mostly relatives, can access the SmartCare integration infrastructure using an ID-card. Doing so, the information about the elderly people's health stats can be easily obtained as far as permitted by the cared-for person. In that way the relatives of cared-for person can have a better overview of his/hers health conditions. They can also request a video-conference with cared-for person or health and social care providers, see interventions that have been done, cared-for persons care plan and medications prescribed. In case of emergencies SmartCare Contact Centre sends out an informational e-mail.

7.2 Contextualised implementation of the SmartCare pathways

7.2.1 Entry point

The entry point or pathway to the project:

- Discharged from hospital and distance monitoring + remote alarm button.
- During the treatment of chronic disease to support living at home.

One hundred care recipients are chosen by the special joint evaluation committee (JEC) to participate in the SmartCare pilot. The special joint evaluation committee always involves of at least one of the SmartCare Contact Centre nurses and a SmartCare Contact Centre social worker. A speciality doctor or a general practitioner is also always involved in the evaluation depending on the type of patient (hospital discharge patient or a long term patient). Informal care giver can also have access to the evaluation and make suggestions if needed.

Fifty hospital discharge patients are chosen from the elderly patients with heart failure that are discharged from East-Tallinn Central Hospital after a stationary stay in the hospital caused by the worsen health conditions. Speciality doctor from the ETCH will make the first evaluation of the patients and informs the patients about the SmartCare project. After gaining acceptance from the patients, proven by the signed informed consent form, the speciality doctor will provide JEC information about the patients for further evaluation. Patients who are suitable for participation in the pilot are at least 65 years old, have no diagnosis of dementia, do not completely depend on others and are willing to participate.

Fifty long term patients are chosen from the data base of the general practitioners amongst the elderly patients who have a diagnosis of chronic heart failure. General practitioners will make the first evaluation of the patients and informs the patients about the SmartCare project. After gaining acceptance from the patients, proven by the signed informed consent form, the general practitioner will provide JEC information about the patients for further evaluation. Patients who are suitable for participation in the pilot are at least 65 years old, have no diagnosis of dementia, do not completely depend on others and are willing to participate.

During that process information is accessible through the SmartCare integration infrastructure. Results of assessments will be accessible through the SmartCare portal.

7.2.2 Assessment of the service user's needs for integrated home care

Special joint evaluation committee assesses the need of users for integrated home care for long term and hospital discharge patients. Both social and health care providers are represented in the JEC. Meetings will be held to make these assessments, virtual meetings will be held if necessary. During that process information is accessible through the SmartCare integration infrastructure. Results of assessments will be accessible through the portal.

7.2.3 Enrolment into SmartCare pilot service

All actors, health-social-informal caretakers can enter the information about the activities any time. The exact workflow will be specified later. The interfacing protocols will be developed to integrate SmartCare platform to receive and send patient data messages:

- Message of admittance to the hospital send to the GP, municipality and existing social information systems.
- Report sent from the municipality to the hospital with additional and relevant information on the patient.
- Rehabilitation plan send to the municipality when the patient is discharged.
- Prescription sent from the GP to the pharmacy.

After the user has been enrolled to the SmartCare pilot service a special joint evaluation committee involving social and healthcare professionals decides what health measurements and in what frequency should be done by the end user, also need for a social alarm-button is evaluated. If there is a need, SmartCare technical personal installs the equipment allocated to the user and training of the equipment will be done. Access to the portal will be provided to the cared-for person, relatives, GP, speciality doctor and a personal social care provider if allocated by the municipalities. During that process information is accessible through the SmartCare integration infrastructure.

7.2.4 Initial integrated home care plan

The initial integrated home care plan is going to be developed by special joint evaluation committee. Health and social conditions of the elderly will be taken in consideration. During that process the medical condition of elderly is thoughtfully examined and needed medical devices with measuring frequency will be allocated. Also the need for a social-alarm button will be assessed. During that process information is accessible through the SmartCare integration infrastructure.

7.2.5 Permanent coordination of integrated care delivery/revision of the initial care plan

The integrated care delivery will be coordinated by the special joint evaluation committee when the need occurs. This can take place after severe health condition changes, medical emergencies or alarm-button activation. Initial care plan can also be revised when one of the stakeholders makes a request. During that process information is accessible through the SmartCare integration infrastructure. Health care providers add information about medical interventions and social care providers about social interventions. Application for care plan revision can be entered through the SmartCare portal.

7.2.6 On-site delivery of social care

Social care in Estonia is provided by municipalities. During the SmartCare project alarm-button will be provided to the end user if found needed. In case of social alarm activation, connection between care receiver and Social Alarm Service is established and situation is evaluated. If the need occurs, social care alarm service will visit the care receiver on-site and help will be given according to situation. It can vary from helping the patient in case of falling to inviting ambulance, police or fire brigade if needed. When a patient receives home care service from the municipalities the social care will be provided according to the home care plan. It can involve providing and preparing the food, cleaning the house, transporting the patient to the doctor and run other errands for the care receiver. During that process information is available from the SmartCare integration infrastructure. Social care documentation will be accessible via the SmartCare portal to all stakeholders. Better access to information gives stronger sense of security and faster communication between actors makes social service planning more efficient.

7.2.7 On-site delivery of health care

In case of emergencies on-site health care is provided when an ambulance brigade performs initial examination and in the need of hospitalisation the patient is transported to the hospital. In some cases home nurse has been allocated to the elderly. Home nurse helps the elderly with treatments and procedures for example wound care and administration of medications. Using the SmartCare portal it is possible for health care providers to enter the information about the activities any time. The documentation is afterwards easily obtained from the SmartCare portal by the stakeholders.

7.2.8 On-site delivery of informal care

On-site informal care is being provided mostly by the relatives. It involves feeding the elderly, cleaning, running errands and helping with all other means necessary for the elderly. Using the SmartCare portal it is possible for informal care givers to have an overview of the cared-for person's current health condition and planned actions for medical and social care. Informal care givers can also contact the health and social care givers regarding the cared-for person's health problems and current condition. Virtual conference between informal care givers and social or medical care providers can be held.

7.2.9 Remote delivery of care to the user's home

There is existing 24/7 service for alarm button for elderly people. The SmartCare services will be added, all services will be combined into one platform. The nurse evaluates the cared-for person's ability to perform home monitoring and if they are judged to be able they are given the opportunity to get home monitoring equipment. This is then ordered from SmartCare Contact Centre. SmartCare technical employees set up the devices at the cared-for person's home and at the same time training regarding the using of the equipment is done. Different kind of monitoring can be offered to the elderly people depending on the need. For example weight scale and pulse and blood-pressure meter could be allocated to the elderly. The home monitoring equipment will be provided by the SmartCare Contact Centre after the JEC assessment. The SmartCare Contact Centre involves SmartCare nurses and a social worker who regularly monitor the measurement data. When the need occurs SmartCare Contact Centre contacts different stakeholders and makes data requests to the ambulance. Collected data will be transmitted to the SmartCare Contact Centre and in case of severe changes in the vitals immediate actions will be taken. SmartCare Contact Centre will be operational during the working hours.

7.2.10 Integrated documentation of care provided

Integrated documentation profiles will be worked out to integrate SmartCare platform into national health information system E-Tervis and data registry of Social Services and Benefits STAR. STAR is an information system and state central data base, that is mainly used by local government social workers and social service providers. The aim of STAR's implementation is to assist case work, administer and exchange information on clients and also collect statistical data about the social sphere. The information about patients can come from different parties. Information about the measurements done by the end users is added to the SmartCare portal automatically. Health care providers add documentation about health care interventions and social care providers about social care interventions.

7.2.11 Control / reassessment of home care recipient

During the SmartCare pilot the home care recipient can be reassessed by the joint evaluation committee. Each involved party can initiate reassessment of the service user. The SmartCare integration infrastructure provides joint evaluation committee with the information about the service user that is needed for reassessment. Initiation for reassessment can also be done through the SmartCare portal.

7.2.12 Temporary admission to institution

The patient can be temporarily admitted to the institution. The information about cared-for person's movements is logged in the SmartCare platform. After an elderly has been admitted to institution he/she or his/her relatives will provide the information needed to the SmartCare portal. Eventually the data will also be available from the E-Tervis system. If other parties, for example institution staff, need to add or obtain information to or from the SmartCare portal special access with an ID-card will be provided. Eventually integration document to the E-Tervis system will be worked out.

7.2.13 Discharge from hospital

After discharge the chosen and suitable user is signed up in the SmartCare platform and suitable set of devices are provided. Also training is done. The cared-for person's data is followed regularly from the SmartCare platform. When the person is already enrolled to the SmartCare the information about the discharge and hospitalisation will be accessible through the SmartCare portal. When discharge takes place the speciality doctor will decide if the person would be a suitable candidate to the SmartCare programme. After the

discharge special joint evaluation committee also assesses the candidate's suitability and produces initial care plan. After the discharge medical data will be provided by the medical care provider and social data by the social care provider. All stakeholders can also add important information about the cared-for person.

7.2.14 Exit point from the Smart Care service

If he/she is not willing to use any more SmartCare services the cared-for person can contact SmartCare Contact Centre any time and refuse the services. Relatives, medical and social care providers can start an assessment to decide if providing the service to the particular person should be refused. It can be a possibility in case the person can't or won't use the equipment as allocated. Application to start the assessment can be entered through the SmartCare portal.

7.3 How key regional implementation requirements are met

The following table summarises in what way key implementation requirements identified in the Estonian context (for details see Annex 6) are going to be met.

Table 12: Summary of how key implementation requirements are met in Tallinn

| Type of requirement | Summary of response by the project |
|---|--|
| End user requirements | Information about the end users is obtained from the E-Tervis database. Willingness to use SmartCare services will be confirmed by the signed informed consent form. |
| Organisational and staff requirements | All staff members are professionals, subscription forms will be gathered. |
| Legal / regulatory / contractual requirements | Approval from the Ethical committee will be requested. |
| Technology / functionality related requirements | Technology used will be innovative and chosen according to the needs of the target group. Each set of equipment provided to the cared-for person will be tested before the installation. |

The following table summarises the approach taken in the deployment region towards negative anticipated potentially emerging from the SmartCare service when compared with current care practices in the deployment region (for details see Annex 3).

Table 13: Summary of how anticipated negative impacts of the SmartCare service are addressed in Tallinn

| Stake holder concerned | Summary of approach taken towards anticipated negative impacts |
|-------------------------|--|
| Care recipient | Thoroughgoing training of equipment and health measurements. |
| Informal / family carer | Thoroughgoing training of SmartCare portal. |
| Formal social carer | Thoroughgoing training of SmartCare portal, explaining the beneficial outcome of the portal. |
| Formal healthcarer | Thoroughgoing training of SmartCare portal, explaining the beneficial outcome of the portal. |
| Third sector carer | Thoroughgoing training of SmartCare portal. |

7.4 Main lessons learned in the deployment region

In the following, the main lessons learned during the pilot service and infrastructure definition phase of the overall project are briefly summarised (for a description of workshops conducted see also Annex 6):

- During the pilot service and infrastructure definition phase the infrastructure and possibilities in the deployment region became clearer.
- It turned out that many medical and social terms are differently understood in different countries and the definitions should be clarified to avoid negative impacts.

8. Pilot site #7 - Attica

8.1 Contextualised implementation of the SmartCare integration infrastructure

The schema below (Figure 8) graphically summarises how the SmartCare pilot service infrastructure will be implemented in the deployment context prevailing in Attica (for contextual details see Annex 1). Here, the SmartCare pilot service addresses citizens suffering of diabetes type II who are aged 50 years and above.

The care recipient (CR) receives personalized information and guidelines in community settings by social and health care professionals in an integrated manner and in various forms. This includes information on condition and status readily available in community settings (data in electronic format). These include a set of generic and personalised guidelines for the self management of his/her condition.

The care recipient has access to the following data and information that are stored in electronic format in the Integrated Care Socio-Medical Electronic Record (ICSMER) and the ATTICA portal:

- Demographic profile.
- Family history.
- Absolute numbers and changes in basic biological indicators related to Diabetes, i.e. blood glucose levels, AP, HbA1c, body weight, height and BMI, other basic haematological and biochemical indicators.
- Medication related to Diabetes.
- Referrals to specialists.
- Clinical follow up.
- Clinical Alerts.
- Nutritional Assessment.
- Nutritional Diabetes Education - Cognitive Nutritional Therapy.
- Nutritional follow up.
- Anthropometrical Alerts.
- Experiences and personal stories of peers.
- Entitlement to Social Benefits, Allowances, Medical Devices and consumables.
- Possibilities for Social Inclusion Activities within the Pilot or at Regional Level.

The CR has access to ICSMER and the portal through tablets that use 3G/4G technology. Telecommunication fees for access to ICSMER and the portal are covered by the pilot's budget. It is expected that the CR will benefit by engaging into a continuous learning process that aims to influence a change in their behaviour and habits (lifestyle related) related to self - management of the disease and empowerment.

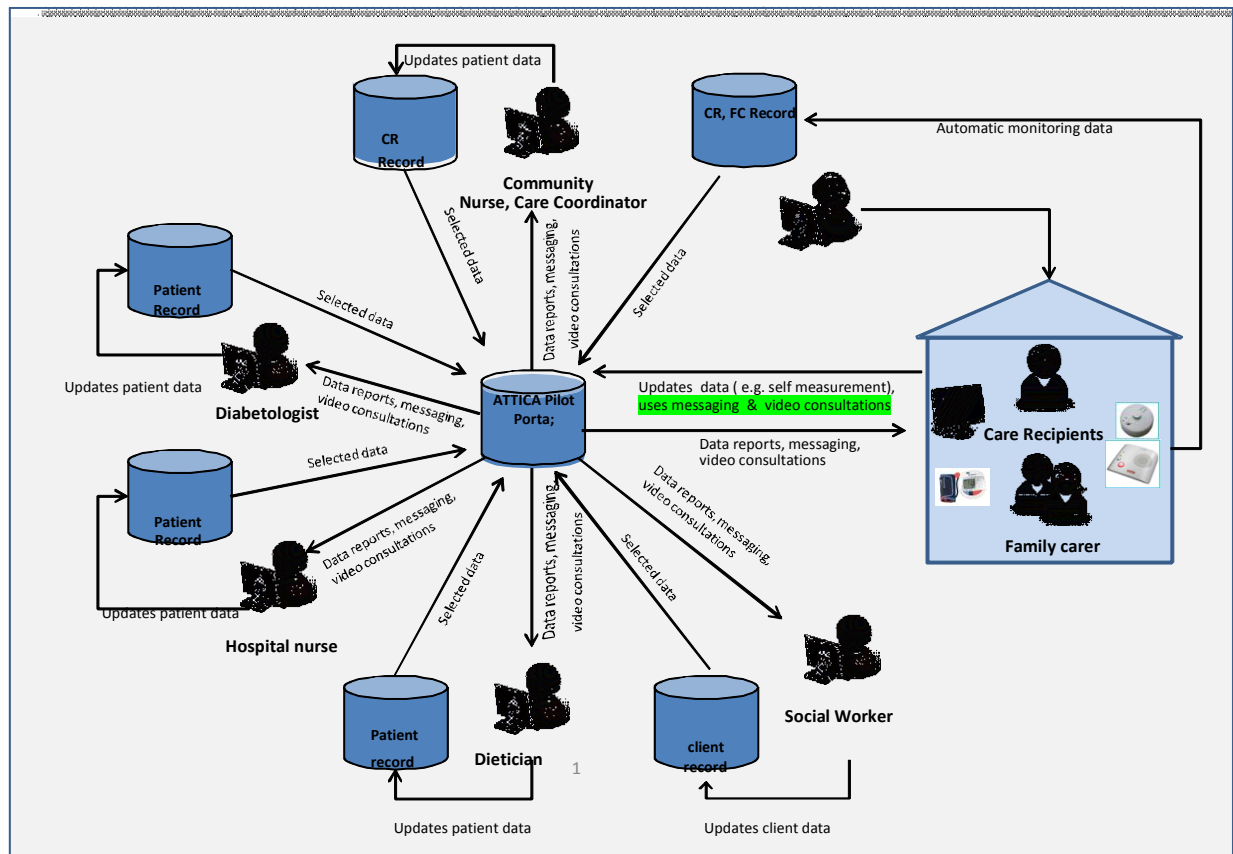


Figure 8: SmartCare service infrastructure implementation in Attica

A family member receives personalized information and guidelines in community settings by social and health care professionals in an integrated manner and in various forms. This includes information about the care recipient's condition and status (readily available in community settings (data in electronic format)). Also, a set of guidelines is available addressing the specific problems of the cared for person and how to better manage his/her condition in the community through a personalized care regime involving the family carer.

The family carer has access to the following information/data in the ICSMER and the ATTICA portal:

- Absolute numbers and changes in basic biological indicators related to Diabetes i.e. BLOOD GLUCOSE LEVELS, AP, HbA1c, body weight, height and BMI, other basic hematological and biochemical indicators.
- Medication related to Diabetes.
- Referrals to specialists.
- Clinical follow up.
- Clinical Alerts.
- Nutritional Assessment.
- Nutritional Diabetes Education - Cognitive Nutritional Therapy.
- Nutritional follow up.
- Anthropometrical Alerts.
- Experiences and personal stories of other carers.
- Entitlement to Social Benefits, Allowances, Medical Devices and consumables for care recipients.
- Possibilities for Respite Care within the Pilot or at Regional Level.

The carer has access to ICSMER and the portal through tablets that are delivered to care recipient and use 3G/4G technology. Telecommunication fees for access to ICSMER and the portal are covered by the pilot's budget.

It is expected that the family carer will benefit by being able to follow better the schedule of the care recipient, cooperate more effectively with him but also with the multidisciplinary team and thus decrease the burden of caring.

Social care staff employed by the municipality provides guidance and support to the care recipient and/or the family carer regarding maximization of social inclusion. More specifically, social workers will be involved in supporting the carer through posting continuous information on the portal about allowances, benefits, reimbursable devices and consumables as well as information about social activities at the local level relevant to healthy eating events, sports events and culture. In addition, they will be engaged real time during work hours in chat rooms with carers and care recipients in order to discuss with them issues such as amelioration of burn out, empowerment etc. Social care staff can also veto decisions made by other parties involved in integrated care delivery for example if during the enrolment phase the care recipient has no interest in engaging in social inclusion activities as mentioned above.

A diabetologist performs clinical assessment of the care recipient, provides prescription for medication and recommends other therapeutic approaches (e.g. counselling), performs follow-up of the care recipient's health status and suggests referral to specialists when needed. The diabetologist has the right to veto the social carer's decision. Through the SmartCare integration infrastructure, he/she accesses the care recipient's demographic data, medical history, habits, Activities of Daily Living, symptoms, diagnostic tests, medication, complications etc, all describing his current condition as well as information on follow up. In addition, he receives automatic alerts when patterns in biological indicator measurement indicate deviation from normality and hence require actions on his site. The diabetologist has access to ICSMER and the ATTICA SmartCare Portal through 3G/4G technology.

The Diabetics and caregivers association P.O.S.S.A.S.DIA do not use the SmartCare integration infrastructure. They are involved in recruitment of care recipients, peer to peer support and dissemination activities in the ATTICA region and nationally?

8.2 Contextualised implementation of the SmartCare pathways

8.2.1 Entry points

The entry points are the municipalities' primary health centre when the ICP LTC pathway is concerned and the Hospital, when the ICP Hospital Discharge is concerned. In both pathways, a Social Needs Description Sheet on ICSMER is electronically generated that is the starting point of the SmartCare pathways.

8.2.2 Assessment of the service CR's needs for integrated home care

The patients enrolled in the service are over 50 years of age and they suffer of diabetes type II. Their service needs are assessed based on recent special diagnostic tests (e.g. HbA1_c and others according to IDF⁴) but also on person centred planning within the SmartCare settings. A questionnaire is applied in order to gather generic information of the needs of potential SmartCare service CRs for integrated health and social care services. The interviews are organized and managed by a Care Coordinator and they take place at

⁴ International Diabetes Federation

the Hospital premises (for Early Discharge Pathway Care Recipients) or at the Municipality Primary Health Centres (for the Long Term Care Pathway Care Recipients). The care coordinator initially assesses the current social care needs using a questionnaire, and an electronic record of the needs assessment is stored in the ICSMER. A request for validation by the social worker is validated and the Social Worker validates or not the needs through a reply message. From then on, if a positive reply is obtained, the diabetologist pops in to validate the medical needs.

8.2.3 Enrolment into SmartCare pilot service

Care recipients are enrolled to the SmartCare service by a diabetologist at the local hospital (in case of the Hospital Discharge Pathway) or at the Municipality Primary Health Centre (in case of the Home Care Pathway) Enrolment needs satisfying a number of inclusion criteria, both medical and socio-demographic. The enrolment data, together with the signed consent form are stored in ICSMER and are accessible to the Health Professionals and the Social Care Professionals, albeit at different levels of access.

8.2.4 Initial integrated home care plan

After enrolling into the SmartCare service and based on the needs assessment an individual care plan is set up in cooperation between the care recipient, the family carer, the diabetologist, the dietologist and social care staff. To this end Person Centred Planning is going to be used⁵. At the centre of the integrated home care plan, is the care recipient himself, his wishes and aspirations (i.e. where he wants to go, what he wants to do in his everyday living). In addition, the integrated home care contains tools to support fulfilment of the care recipient's aims and the outcomes that are to be measured and are meaningful to him/her. Each individual home care plan is linked to a review procedure in order to continuously monitor what is working and what not, what is important for the care recipient now and in the future. In collaboration with the family carer and professionals changes are agreed when required.

The person centred plan is stored in an electronic format that is accessible to the Care Recipient, the professionals and the Carer. The care coordinator is the person that initializes the process of care plan completion, cooperates with other health and social care professionals, CR and I/FC in setting out the outcome indicators related to the care recipient, describe the aims, means and tools to achieve the desired outcomes, monitors the progress of the care plan by continuously communicating with patients, carers and professionals so that targets and milestones are met.

When the Person Centred Planning approach goes ahead for each SmartCare CR, the social worker with the CR or the CR together with the carer should develop the personal support plan, which essentially is a record of the decisions the CR has made about how he wants to spend his personal budget to achieve the aims and outcomes that have been defined in the integrated care plan.

The Initial Integrated Care Plan, the Support Plan and the Review Plan are all stored electronically per carer in ICSMER and can be changed according to review requests by the care coordinator and upon discussions with the care recipient and the other professionals.

⁵ Putting People First, NHS, 2010, "A continual process of listening and learning about what is important to and for the person - now and in the future, and in alliance with family and friends - and making changes based on this"

8.2.5 Coordination of integrated care delivery/revision of the initial care plan

The IT based SmartCare platform (ICSMER, Integrated Care Socio-Medical Electronic Record), caters for the coordination of integrated care delivery via the various menus and discreet access privileges for all enlisted CRs. Specific monitoring points in time are observed in a similar to milestones way from where the decision making process regarding the efficiency and potential revision of the initial care plan is addressed. Information from the SmartCare Platform will be used for the review procedure which is a part of the person centred planning approach mentioned above.

The Care Coordinator has the responsibility to coordinate the process of integration by continuously monitoring the progress in target realization set by professionals together with the patient in the Integrated Care Plan which is accessible to the care coordinator through ICSMER. In addition, the Care Coordinator monitors the progress of the support plan (i.e. the personal budget dedicated by the patient for the realization of at least some of the targets e.g. attaining a diet richer in vegetables and poorer in carbohydrates per week) and when there are changes in the initial integrated care plan, the coordinator is responsible to monitor them in the review plan and become certain that they are followed by the patients. Chatting with the patients through the platform as well as sending e-mails are means of ensuring the targets are met.

8.2.6 On-site provision of formal social care

The municipality's social worker visits the care recipient first time at home, involving the family carer upon consent, in order to provide information and clarifications about the service as far as required. In addition, the social service is accessible to the care recipient and/or the family carer upon request. Provided the care recipient agrees, the family carer is involved at all stages of the person centred planning approach within Care (i.e. needs assessment, plan design, support planning, outcome setting and review of the plan).

The electronic Social Care Plan is part of ICSMER. It outlines the services that are available in the local community or nationally for Diabetes Type II care recipients, relative to benefits, allowances etc. It informs the care recipient on these and navigates him on the prerequisites for obtaining them, eligibility criteria, application forms, contact information with authorities etc. According to the profile of each care recipient (e.g. is it insulin dependent care recipient, does the care recipient take anti diabetic pills, is the care recipient feeling socially excluded, is the care recipient under the threshold of poverty), the social care plan contains the aims for individual social support tailored to his/her needs.

8.2.7 On-site provision of formal healthcare

The diabetologist visits the care recipient at home very rarely and only in cases where he/she cannot visit the municipality's primary health centre. Other health care professionals also visit the care recipient's home to follow up with the care plan or to assist with specific tasks (e.g. monitoring of glucose levels). Also, dietician and psychologist services at PALFALIRO primary health centre are accessible the care recipient upon request. Health professionals are involved at all stages of the person centred planning approach within SmartCare. Both a diabetologist and a Dietician care plan are developed as part of ICSMER. They, just like the social care plan, have targets that need to be reached at specific time points by the care recipient, of course with support from the multidisciplinary team.

8.2.8 On-site provision of informal care

The informal carer accesses the care recipient's data on line, upon consent. The family carer has access to the initial and the reviewed integrated care plans in order to be better informed about the progress of the care recipient within the SmartCare settings. Access is restricted to overseeing of information stored and is subject to permission authorised by the care recipient.

8.2.9 Remote provision of integrated care to the home (telecare, telemonitoring)

The care recipient regularly measures (on average of once per day) his/her blood glucose levels and his blood pressure with the smart devices that can automatically transfer the results to his Integrated Care Socio-Medical Electronic Record. The family carer may help in this task by performing the measurements. The diabetologist assesses the measurements from his gateway either at the municipality's primary health centre or in his private practice or even at home throughout the day. Reminders are sent to the cared recipient's smartphone or laptop (or even Maria's) for appropriate and timely medication uptake, or other therapeutic approaches on a regular basis. In addition, alarms are generated for health and social care professionals in case an immediate action is needed (e.g. if trends in glucose levels are not appropriate, weight management is not good, involvement in social activities are not the ones agreed upon in the plan etc).

8.2.10 Integrated documentation of home care provided / self-care measures

Various guidelines in the form of documentation will be issued relative to the personalized, integrated socio-medical care of the care recipient's condition. The basic documentation means is the Person Centred Plan, together with the Review Plan, the Personal Support Plan and the Outcome Monitoring Plan. The documentation has as focal point diabetes management and self-management at home addressing also the situations that can lead to re-hospitalisation. The issuer of documentation also varies covering the spectrum of integrated care i.e. ranging from health care professionals to social care professionals. The documentation is utilised either by the care recipient or the family carer (or both) as well as the social and care professionals.

The Person Centred Plan is the same as the Integrated Care Plan, the Personal Support Plan is a plan to spent financial resources available by the patient for realisation of targets set in ICSMER, the Review Plan is the Integrated Care Plan after targets are reset for each care recipient, and the outcome monitoring plan is part of the ICSMER on which primary and secondary outcomes of the interventions per care recipient (e.g. HbA1c, QoL measurements, satisfaction data etc) are stored. All above plans are part of the SmartCare Integration Infrastructure.

The Integrated Care Plan contains information that is inserted by all health professionals and the social care professional. The purpose of the Integrated Care Plan is to allow for all targets set to be monitored in time and for outcomes of the interventions to be followed as well.

8.2.11 Control /reassessment of the home care recipient

The assessment criteria applied to an individual care recipient concern both medical and social care dimensions, as set during the person centred planning. Apart from blood glucose levels and BP, glycosylated haemoglobin is also measured at regular intervals (once every 4 months).

The targets set for each care recipient at the integrated care plan are continuously monitored through the SmartCare Platform. All professionals are able to overview progress in target achievement.

8.2.12 Temporary admission in an institutional setting (e.g. hospital, day care centre)

In the event of the care recipient’s temporary admission to the specific hospital the same procedure will be followed, as above. On identification of the care recipient as a SmartCare service user, all relevant information in the ICSMER are available to the diabetologist. In addition, relevant information throughout hospitalization is available to the municipality’s health and social professionals as well as informal carers so that they can monitor the care recipient’s care pathway in the hospital environment. Temporary admission to a hospital or another institution (other than the local, private hospital) is not a reason for exiting the SmartCare service, but the care recipient needs to update the diabetologist and the rest of the team on the necessary medical information during hospitalization in order to inform ICSMER.

8.2.13 Exit points

A service user exist the pathways:

- When the care recipient or the family carer (if existing) withdraws consent form;
- When one of the criteria of enrolment is not satisfied;
- When the care recipient passes away or enters another healthcare setting (e.g. another hospital or nursing home) for long term hospitalization.

In order for a care recipient already enrolled to exit the pilot, the multidisciplinary decides jointly provided that the care recipient is no longer in need of services because he/she has accomplished the targets set or because an unfavourable medical condition arises e.g. a medical emergency that requires hospitalization or a rapid deterioration in health of the care recipient.

To support this process, ICSMER notifies the care coordinator in case the exit criteria are met, and initializes the process for exit from the pilot.

8.3 How key regional implementation requirements are met

The following table summarises in what way key implementation requirements identified in the Danish context (for details see Annex 7) are going to be met.

Table 14: Summary of how key implementation requirements are met in Attica

| Type of requirement | Summary of response by the project |
|---------------------------------------|--|
| End user requirements | A strict set of criteria using a basis the inclusion criteria will be developed and translated into guidelines targeting the appropriate user recruitment process. |
| Organisational and staff requirements | The ATTICA Pilot Steering Committee (APSC) has been set up, bringing together all stakeholders of the pilot, in order to monitor all managerial, legal, ethical, organizational and financial issues emerging from the Pilot. Nomination of members and publishing of a Rulebook on the activities of the ATTICA Pilot Steering Committee has been agreed upon and became functional as of February 2014 |

| Type of requirement | Summary of response by the project |
|---|---|
| Legal / regulatory / contractual requirements | The ATTICA Pilot Steering Committee (APSC) has been set up, bringing together all stakeholders of the pilot, in order to monitor all managerial, legal, ethical, organizational and financial issues emerging from the Pilot. Nomination of members and publishing of a Rulebook on the activities of the ATTICA Pilot Steering Committee has been agreed upon and became functional as of February 2014. |
| Technology / functionality related requirements | Extensive testing will be performed before actual launch of the pilot operation. All test results will be reported and if serious flaws are found then consequent actions for restoration of normal operation will be taken. |
| Other requirements | In the Attica pilot case, other requirements derived from a series of focus groups held in the municipality and they were then reported. A check list is generated and handled by the Attica Pilot Steering Committee already set up and now in control of the implementation of other requirements as well. |

The following table summarises the approach taken in the deployment region towards negative anticipated potentially emerging from the SmartCare service when compared with current care practices in the deployment region (for details see Annex 3).

Table 15: Summary of how anticipated negative impacts of the SmartCare service are addressed in Attica

| Stake holder concerned | Summary of approach taken towards anticipated negative impacts |
|-------------------------|---|
| Care recipient | A very carefully designed interface with emphasis on user friendliness to compensate for the potentially increased effort in order to cope with a strict regime. |
| Informal / family carer | A very carefully designed interface with emphasis on user friendliness along with various targeted support actions to compensate for the potentially increased effort in order to cope with the care recipient's strict regime. |
| Formal social carer | Motivation for self-fulfilment in order to compensate the increased work effort. |
| Formal health carer | Motivation for self-fulfilment in order to compensate the increased work effort. |
| Third sector carer | N/A |

8.4 Main lessons learned in the deployment region

In the following, the main lessons learned during the pilot service and infrastructure definition phase of the overall project are briefly summarised (for a description of workshops conducted see also Annex 7). It is still too early in the project's life cycle for the Attica region to draw any meaningful conclusions however the one and of critical importance lesson learned so far is about the timeframe of planned actions: It has to be at least six months long in order to accommodate bureaucratic delays hindering the recruitment of personnel and the purchase of equipment.

9. Pilot site #8 - The North Brabant

9.1 Contextualised implementation of the SmartCare integration infrastructure

This chapter describes the plan for the North Brabant site of the SmartCare project during the deployment phase in which the ICT will support the various pathways. North Brabant is one of the southern provinces of the Netherlands. The schema below (Figure 9) graphically summarises how the SmartCare pilot service infrastructure will be implemented in the North Brabant deployment context (for contextual details see Annex 8).

Many hospitals and GPs are used to EHR software already. Nevertheless, home care organisations often only have administrative and financial systems, and make use of paper files and paper care plans. Care coordination is done mostly by personal contact between professionals also across organisational borders. Transfer nurse of the hospital and the home care / nursing home nurse will inform each other through some kind of hand over documentation. In case of questions or specific treatment and care options, there will be a phone call with the care professional. The situation is, however, slowly changing: care organisations start to make use of electronic files and experiment with e-transfers. In this way the organisations are moving towards client oriented EHR systems.

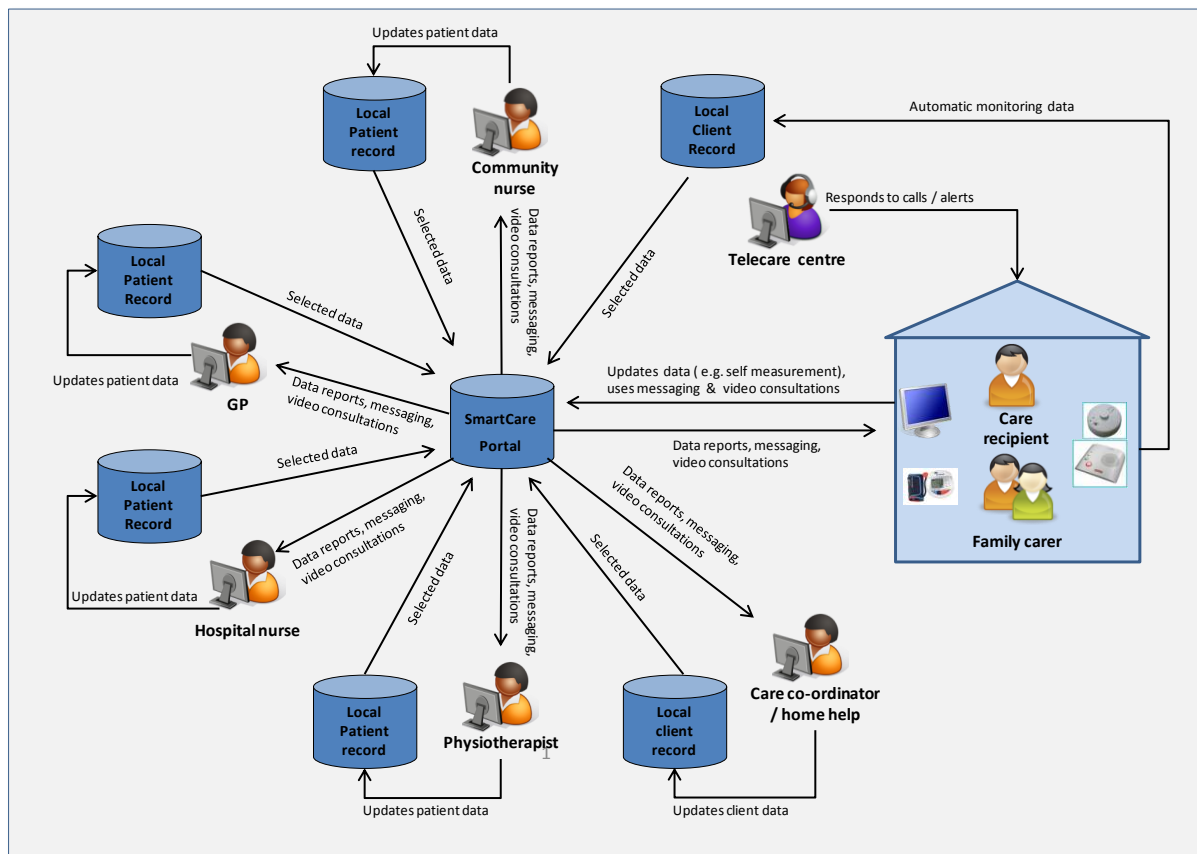


Figure 9: SmartCare service infrastructure implementation in North Brabant

For all care coordination various systems are used. In SmartCare North Brabant a secure environment is offered for safely exchanging patient’s health data among the various participants. All stakeholders in the SmartCare project can use this facility and the various electronic messages for admission to, monitoring of and discharge from medical / social care. All stakeholders will be able to share data and participate in the integrated pathways, including patients themselves, or where required their informal carers.

This pilot site focuses on care recipients with a chronic heart failure (CHF), but the pilot might be open for patients with other heart conditions. Care recipients are aged 65+ and have a high probability of complications and/or destabilisation. Co-morbidities are the rule in this population. The high prevalence for exacerbations for level II and III patients can justify the extra costs for home equipment and care coordinator support. Further enrolment criteria to the SmartCare pilot service include multiple (≥ 2) admissions in the last 12 months (included index hospital admission). Persons with dementia and psychiatric conditions are not enrolled to the service. The care recipient accesses the SmartCare ICT platform for consulting care related data in their personal record. Information accessible to the care recipient also includes diagnosis, measurements taken by themselves or by professional caregivers, data on lifestyle and social issues, treatment plans and notes. Besides medical data consultation, the SmartCare ICT care recipient portal will serve as a services platform for a wide variety of interactive apps to increase quality of life, social connectedness, self-management, a healthy lifestyle, e-inclusion, etc.

The care recipient plays an active and prominent role and stays in control of the private data. He decides who to give access to which piece of information. He can include informal carers, social workers and care professionals in the treatment and permits access to the electronic data in the SmartCare platform. The care recipient defines the access rights for each relevant stakeholder.

Upon consent by the care recipient, relatives and/or friends can have access to the electronic data through the SmartCare ICT platform. In principle, they perform all tasks for the care recipients on permission the person they care for.

Social workers involved in service delivery to the older care recipient include care coordinators and the health centres. They deliver different types of on-site support such as education in lifestyle, including diet, exercise, and alcohol and smoking behaviour. A number of SmartCare users receives home care services such as cleaning, food delivery, bathing, shopping and support for other daily activities. Finally some of the patients have a care coordinator from the municipality, who helps the patient navigating in the system and helps them to implement lifestyle changes when necessary. These social workers have access to selected pieces of information (stored by other care providers such as hospital staff and GPs) about the care recipient's disease and self-care capabilities. They might also leave notes in the care recipients' personal record, set up goals together with the patient and help with filling out self-assessment questionnaires.

Health care providers who are involved in the Dutch SmartCare pilot service include general practitioners and hospital staff, being cardiologists and heart failure nurses (HFN). However some health care services are also organised by home care organisations helping with measurements and nursing care. All health care providers have a different role. The cardiologist and HFN are in charge of acute heart problems, specialised treatment as well as discharging and following up on the patient after discharge for a period of typically 3 months. After 3 months, the general practitioner takes over. He is responsible for the long term check-up and the general communication with the patient about their health. Home nurses have responsibility in lifestyle coaching, support and homecare activities related to healthcare.

To optimize multidisciplinary care after hospital discharge, it is of great importance that all care providers communicate and collaborate well. Therefore, care professionals will share data from their individual systems, use the SmartCare ICT platform to support their workflow across sectors and to view data from the different caregivers. Information shared from the hospitals and GPs could be lab-results, measurements, notes, symptoms and diagnosis as well as goals set with the patient, activities, questionnaires, reports and self-care indicators. They will also be able to see the information provided by the different

actors such as care recipients, informal carers, home care organisations and social workers.

The SmartCare ICT platform will be an extended version of the ICT infrastructure developed in the Dutch project Open Data for Health (OD4H). The OD4H infrastructure offers a tool for exchanging patient data and multidisciplinary discussions among care professionals. The infrastructure is realized, and ready to be configured for specific patient groups or use cases. OD4H interconnects patients with care professionals. Whereas the OD4H infrastructure is originally healthcare oriented, the system will in the SmartCare project grow towards an open platform that combines formal and informal healthcare, social care, informal care and self care. The aim is to realize a user-friendly care recipient portal as an open service platform offering interactive apps for care and self-management, for e-inclusion, social participation and entertainment.

9.2 Contextualised implementation of the SmartCare pathways

9.2.1 Entry points

Due to effective and efficient home support and telemonitoring, the number of days in the hospital could be decreased. Care recipients are supported, coached and monitored remotely via the SmartCare ICT platform (OD4H) instead of inside the hospital, which would lead to cost reductions. Due to self-management modules in the platform, continuous monitoring of patients' style of living and vital signs, regular interim video-communication sessions with a care coordinator and/or psychologist, and usage logging of the home support platform services, exacerbations could be dealt with in an early stage. Consequently, readmissions can be avoided.

9.2.2 Discharge from hospital

Primarily, the care recipient's health condition needs to meet certain standards before discharge from hospital can be considered. In order to decide upon the health of the care recipient various protocols are developed and used. Besides, also the living situation is a great influencing factor. Of course, the decision about hospital discharge relates to whether the care recipient lives in a centre for intramural care, has an extensive network of informal carers nearby or whether he is totally dependent on himself and eventual home care services. Also other chronic diseases and/or age-related changes might affect the decision. This context is generally mapped during the anaesthesia procedure already which proceeds medical surgery.

Through the SmartCare ICT platform (OD4H) all parties have access to the care recipients' data. In this way, all involved parties - when this information is relevant - are continuously informed about hospital admission, discharge and home care plans.

9.2.3 Assessment of the service user's needs for integrated care

Within SmartCare, responsibility shifts towards care recipients themselves, supported by informal carers, a care coordinator and self-management modules in the SmartCare ICT platform. Whereas telemonitoring enables to recognize symptoms in an early stage, measuring vital signs is not the complete solution. Complexity and differences within the care recipient group and treatment phases should also be taken into account. User's needs are dependent on interpersonal differences, the living context, social network and self-management capabilities. Therefore, home monitoring should also lead to awareness and self-management. This is where the care recipient portal comes into play, combining both telemonitoring (BP, weight, HR, etc.), coaching and self-management services. Due to better home support and telemonitoring, the number of days in the hospital could be decreased.

Each individual is different, and so are patients suffering from cardiovascular diseases. From a medical point of view, heart failure patients are divided in 4 categories (NYHA). Additionally, some of them suffer from other chronic conditions, or have to live with age-related changes (eye-sight, hearing, cognitive decline, immobility, etc.). All these aspects can influence their ability to cope with devices for telemonitoring and with a self-management platform. In the older age-group, also large differences exist in terms of computer skills.

Within SmartCare specific user needs have to be investigated, in order to compose a suitable set of tailored home care services. This will be organized by a care coordinator. This practice nurse, who has access to a care recipient's EHR, will have an acquaintance home visit (or in the hospital) to investigate individual care needs.

9.2.4 Enrolment into the SmartCare service

Based on medical history, current health situation and the needs for social support and services, the care coordinator decides whether a heart failure patient meets the inclusion criteria to take part in the SmartCare pilot in North Brabant. This pilot site focuses on care recipients with a CHF-level II and III: the high prevalence for exacerbations can justify the extra costs for home equipment and care coordinator support.

9.2.5 Initial integrated home care plan

For each individual care recipient a dedicated home care plan is developed. These integrated home care plans, developed by the care coordinator, will be shared with all relevant actors in the care process via the OD4H infrastructure. Each plan will be periodically reassessed and adjusted by the care coordinator. When necessary, the care coordinator can consult the multidisciplinary team of care professionals.

9.2.6 Permanent coordination of integrated care delivery/revision of the initial care plan

In the SmartCare project in North Brabant all care recipient data is collected in the OD4H infrastructure containing an EHR and functionalities for interprofessional communication and data exchange. This communication and information portal for care professionals will be linked with a suitable and intelligent portal for care recipients. The combination of these ICT systems offers a wide variety of new opportunities and added value. It realizes an open platform that offers secure communication and information exchange among care recipients on the one hand, care professionals on the other hand, and between carers and care recipients.

Thanks to the linkage of both ICT systems, all information is accessible for those who need it to improve efficiency and quality of care. Besides this joined-up ICT platform, the care coordinator is the central link between medical care, social care, informal care and self-care. He is responsible for the integration and coordination of the integrated care plan for the CHF patient. He is the central access point for both the care recipient and the formal and informal caregivers.

9.2.7 On-site provision of formal social care

On-site social services delivery (in patients' homes) is avoided as much as possible to minimize travel time and costs. Nevertheless, a face-to-face intake conversation at location is important to realize personal bonding and to investigate specific user needs.

9.2.8 On-site provision of formal healthcare

On-site social services delivery (in patients' homes) is avoided as much as possible to minimize travel time and costs. Via the portal care recipients can make use of e-consults, order medication, perform vital sign measurements, and have access to their EHR.

The number of consultations at the cardiologist or HFN could possibly be decreased by telemonitoring. When no deviations occur, patients do not have to come for a visit. By early detection of and reaction on risk bearing changes, frequency of exacerbations can be decreased.

The quality of an e-consult is seen as high as a face-to-face consult. The cardiologist evaluates the health condition of the care recipient based on a heart monitoring video and the results from a cycling test. The video capturing and cycling test are performed together with an assistant or with the heart failure nurse. When the consult is organized screen-to-screen, there is no need to have the tests and the consult on the same day. This leads to more flexibility for the care recipient to have the tests done when suits him best.

9.2.9 On-site provision of informal care

In SmartCare an easy and user-friendly portal will be developed for the care recipient. In this way, care recipients are empowered to do more tasks themselves, without needing the support of formal or informal carers. On the other hand, the care recipient portal will also offers functionalities and services to support the care recipient remotely, so that informal carers can help care recipients from home. In this way, the informal carer and the care recipient can spend more quality time when visiting each other.

9.2.10 Remote provision of health / social care to the home (telecare, telemonitoring)

Via the portal, the care recipient is in close contact with the care coordinator (screen-to-screen communication). The care coordinator follows up telemonitoring data, supports and monitors the platform services like the calendar with social activities, good morning service, self management services, etc.

In addition, e-consults can be organized with psychologists and dieticians and care recipients can participate in online physiotherapy sessions, because a healthy lifestyle is important as well.

In North Brabant, remote health and social care services will be provided via the care recipient portal, offering functionality for secured data exchange and video-communication. Via the platform the care recipient is able to make use of social services and coaching modules for self-management, quit smoking program, physiotherapy and psychological support.

Via remote vital signs measurements (blood pressure and weight) patients will be monitored and supported by the care coordinator. Besides, care recipients can consult the care coordinator, a psychologist and a dietician through screen-to-screen communication for questions and for extra support.

9.2.11 Integrated documentation of home care provided / self-care measures

Telemonitoring data, outcomes from the online training program, self-management modules and interventions made by the various parties are documented in the SmartCare ICT platform (OD4H) and made available to other parties. All documentation is monitored

and coordinated by the care coordinator. When necessary, she will discuss the situation with other care professionals and update care plans accordingly.

To fulfil all legal and regulatory requirements with respect to integrated documentation and data exchange, a mature plan will be designed to ensure privacy and security (identification, authentication, encryption, etc.). Additionally, due to the delicate nature of patient data, access will be subdivided according to categories of caregivers.

9.2.12 Control / reassessment of the home care recipient

Telemonitoring data, outcomes from the online training program, self management modules and interventions made by the various parties are documented in the SmartCare ICT platform (OD4H) and made available to other parties. All documentation is monitored and coordinated by the care coordinator. When necessary, she will discuss the situation with other care professionals and update care plans accordingly.

9.2.13 Temporary admission / re-admission to institutional setting

Due to the central role of the care coordinator and a shared communication and data exchange ICT system, all parties involved are immediately updated about the new situation.

9.2.14 Exit point

Within the SmartCare project in North Brabant, all involved parties are connected with the patient and with each other through the role of the care coordinator. The current situation (health condition, care plan, treatments, medication and use of services) is continuously updated and communicated via the shared ICT system.

Since heart failure is a chronic condition, patients have to live with it for the rest of their lives. Therefore, passing away is the only real exit point. Nevertheless, the care coordinator could change a patient's care plan and exits one or more specific services. Via the shared SmartCare ICT system, this change will be visible for all.

SmartCare is mainly targeted at supporting people in extramural care settings. Since the portal for care recipients offers many opportunities for social interaction, e-inclusion and participation in society, the partners in North Brabant would like to offer an alternative for patients who move permanently to permanent intramural care.



10. Pilot site #9 - Kraljevo Serbia

10.1 Contextualised implementation of the SmartCare integration infrastructure

The schema below (Figure 10) graphically summarises how the SmartCare pilot service infrastructure will be implemented within the deployment context prevailing in Kraljevo Serbia (for contextual details see Annex 9). Here, the SmartCare service addresses people aged 60 years and above who have social care needs and long-term health conditions. Care recipients enrol in SmartCare programme to receive wider care service using new services that will be developed. From the integrated care record which is aimed to provide better social and health service with more complete information on the person's social and health condition to several ICT solutions that will provide care recipient with the increase quality of life and increase of independent living.

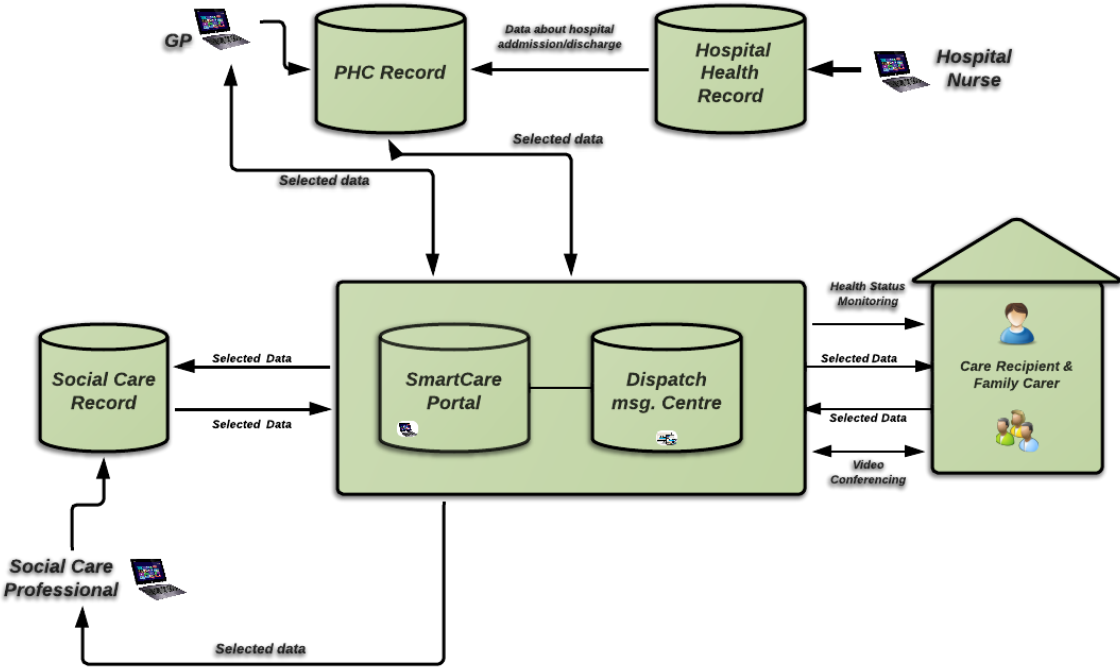


Figure 10: SmartCare service infrastructure implementation in Kraljevo Serbia

Social care workers are employees of Centre for Social Work Kraljevo. They provide CR with standard set of services and will use integrated SmartCare platform to access integrated care record of the individual which include selected set of information about medical condition of the CR. Care provider will enter information in integrated care record regarding CR therapy notes, measurements or any other event that can be of use for other actors. Health care professionals agree on which set of data shall be included in integrated care record and what information will be seen by other users of the system. GP employed with primary health care institution in Kraljevo will have access to CR integrated care record, for entering information regarding CR therapy, his medical condition and other relevant data that can be of use for social care providers or informal carers. If involved by a written consent, informal carers of the CR they will have possibility to provide better care, with real time reminders, possibility to communicate with social and medical professionals, give timely alerts for either social or medical needs etc.

10.2 Contextualised implementation of the SmartCare pathways

10.2.1 Entry point into the pilot service

Potential integrated care recipients are identified by health or social professionals; they will jointly discuss which individuals will enter into integrated care programme. SmartCare Evaluation Committee will be formed by Health and Social care professionals (GP, homecare service professional from GP, Social Care providers, Gerontology Centre professionals) and will choose users for the current Social care users which fill inclusion criteria. Then, patients or care recipients will be asked to sign enrolment paper. When providing social services professional staff recognizes if elder person need health care and notifies relevant staff at the home care department or the emergency medical service. Also, health professionals who are in contact (at home, polyclinic, hospital, etc.) with an older person identify if that person needs social care, and if that person is involved in integrated care, that will be automatically messaged to the health professional. In that case the health professional notifies the admission office in the centre for social work Kraljevo through integrated care system with possibility to write additional information.

10.2.2 Initial needs assessment

Health providers, GP or specialist or Head of Home care department of medical centre define home care need for a patient, and all forms of therapy needed. Definition for home care plan is made by using patient medical record from hospital and GP.

Social care workers at the admission office prepare documentation for the care recipient and forward this to the Office for Adults and elderly, where CR will be assigned to a social care professional. This professional is responsible and coordinates the specific CR case and does an initial need assessment. To create initial needs assessment and social care professional contacts CR and/or his informal/family carer, and consults with selected data about CR integrated care records.

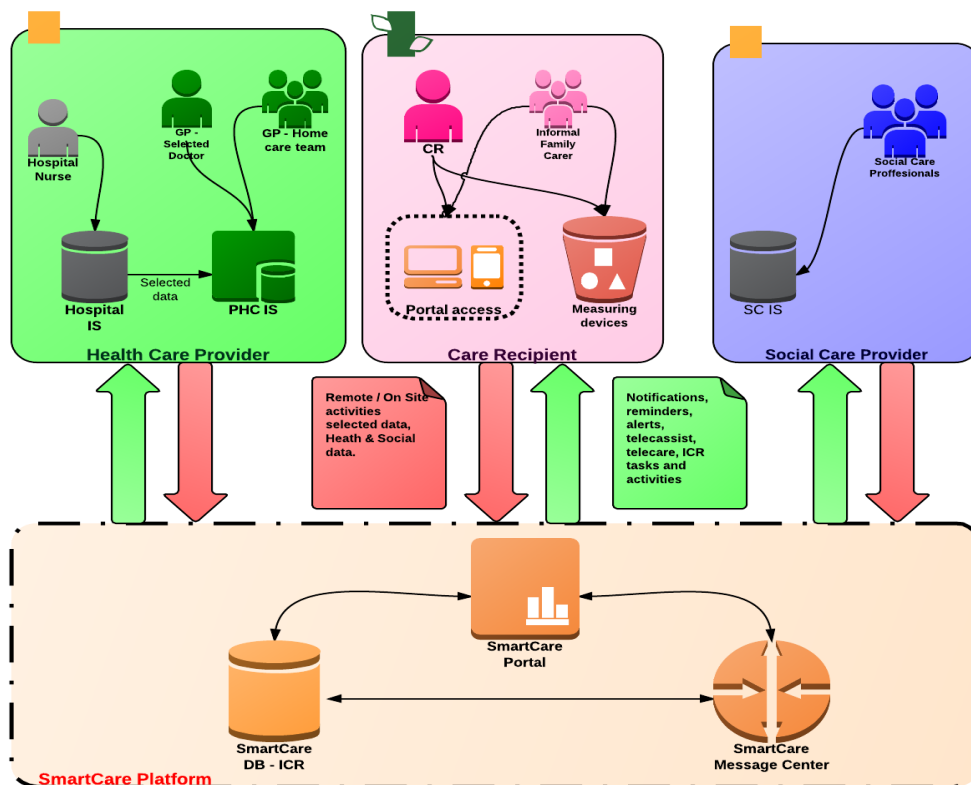


Figure 11: SmartCare Data Flow

10.2.3 Enrolment into the SmartCare service

If CR needs hospital treatment, his selected GP create referral for hospitalization and notify all actors (SCP and I/CR) to timely respond and prepare for needs assessment. In emergency case, information about CR admission/discharge to/from hospital will be shared by smart care system to all actors through Smart Care portal for integrated care.

Criteria for people who can participate in smart care pilot services are:

- Health criteria for care recipient:
 - people with disabilities (wheelchair, blind, ...);
 - people with chronic disease;
 - post-hospitalisation with long term care/monitoring needs.
- Social:
 - elders 60+
 - live alone;
 - live with partner or cousin who is/are also elder or people who are also dependent of the health or social care or carer's allowance;
 - live with family but family doesn't want to engaged to provide care;
 - A person who provides care due to illness or absence, is temporarily prevented to provide;
 - Elderly person living in a family in which the expressed dependence on alcohol, drugs, or psychiatric illness;
 - In the family there is a suspicion or risk of abuse and neglect of the elderly;
 - Elderly person who is a financial and/or residential threatened.

To use SmartCare service requires the consent of participant (older person) or his guardian. Identified patient or care recipient seen potential participant would be informed about the SmartCare project. Information will be delivered to him by his SCP or GP. Patient will have to give written signed consent to participate on the pilot programme. Relevant data regarding person's enrolment will be shared to interested parties through integrated care portal and all participants will have timely notification trough SmartCare message dispatch centre.

10.2.4 Initial integrated home care plan

Each CR enrolled in SmartCare project will have his integrated care record, which will hold records of conducted and planned activities by home care department of GP and Social services. Activities will be defined having in mind medical condition of the person, and his social position if he can live independently or not. All actors should be equally involved in the process, from care recipient, health providers, social care providers, third parties and informal carers, and therefore scheduled task allocation will be needed. Care recipient will get a contact person to which he can communicate with carers if needed.

10.2.5 Permanent coordination of integrated care delivery & revision of initial home care plan

The team for integrated care who is responsible to provide care to CR includes:

- social care professional assigned by Adults and elderly office (and if necessary other social care worker - depending of CR needs);
- health care professional (selected doctor, medical home team, ...);
- informal or family carer (if they exist).

Depending of social and health status of CR, the team for integrated care will define initial integrated care plan. Team for integrated care is responsible for coordination and care delivery. The goal of the integrated care system is that new services will be deeply integrated in existing work environment of the parties involved, which will ensure that no significant additional workload on participants, and what will ease coordination between social and health professionals. SmartCare service will be integrated in existing information system of PHC and social care. For example, GP will during its regular work procedures and environment be able to see information from SmartCare portal, to edit data, plan and change activities. Besides that, SCP will use SmartCare portal for their everyday work, and will be able to adjust their activities according to the changes entered by GP. Finally, family/informal carer will be able to see relevant activities planned for CR and to enter his comments and observations concerning the care.

10.2.6 On-site delivery of social care

On site social care is delivered by Social care professionals and informal carer/ family carers. Depending of health situation of the patient SCP will have selected information and will have possibility to adjust care according to the changes entered by HCP. Existing types of social services provided by SCP:

- Service for home care (house cleaning, preparing quick and easy meals, washing and ironing, help with personal hygiene, food supply, medicines and other supplies, walking assistance, communication with other institution of importance for users, contacts with HC and SC).
- Short term financial support.
- Regulating the rights of social welfare and family legal protection (right to receive and increase other care and help, social assistance and care protection, etc.).
- Urgent accommodation in emergency situations (impairment health status, the service cannot meet the need of CR in accommodation) shelter for the elderly mentally ill, urgent foster care, urgent accommodation in Gerontology Centre.
- Long-Term housing in appropriate institution, if it's the only solution to the current situation of the user.

10.2.7 On-site delivery of healthcare

Onsite health care is delivered by home care department of GP, which will have access to SmartCare integrated record, and will be able to coordinate and plan on site activities. Any changes in social needs of CR detected by on site health care will be added in Smartcare system, and will notify automatically to the SCP and informal carers.

Types of healthcare:

- Visits and medical examination of the CR by the home care team (doctor - nurse).
- Electrocardiographic examination.
- Preparation for Parenteral therapy in home condition.
- Wound treatment in the field
- Installation and replacement of catheters and flushing of the bladder.
- Patient care education.

10.2.8 On-site delivery of informal care

Types of services for informal carer (IC - informal carer) and CR (self-care, if CR is capable):

- Home support (house cleaning, preparing quick and easy meals, washing and ironing, help with personal hygiene, food supply, medicines and other supplies, walking assistance, communication with other institution of importance for users, contacts with HC and SC).
- Part of the work that Health Care works in field (blood pressure, sugar blood and other health care...).
- Timely notification HCP and SCP on health and social condition of CR.

Family members or other informal carers, will be able with CR request to access the SmartCare system and share relevant information. This will enable them to actively take part in care process and will have better possibilities to monitor and share information on CR situation.

10.2.9 Remote delivery of care to the user's home

Remote delivery of care currently does not exist in pilot site, therefore telecare/teleassist will be piloted to the users homes by SmartCare project. Both health and social CP will be involved in this process and will be able to collect vital signs of CR on field. Depending on the needs of the CR and defined in the integrated care plan can be obtained CR and remote care delivery such as telecare or teleassist. These services will reduce or allow for better preparation and more effective implementation of on-site delivery care (through advice, appointments, reminders, alarms). The majority of the care recipients is unable to use advanced technology has required the help of FC, SCP or HCP. In that sense, lectures (capacity building) and training is provided, e.g. about telecare/telemonitoring/teleassist and their benefits of importance of quality improvement and extension of independent life. Both health and social care providers will respond to the remote care service, social service professional will access CR or I/FC Marko through video link, and health care provider can obtain more information on the same way.

10.2.10 Integrated documentation of care provided

All activities in the integrated care plan are inserted in the Integrated Care Record (visits, interventions and activities by HCP, SCP, FC and CR (self-care)). Depending on the actor role in the system, enables the different views of the Integrated Care Record. All conducted and future activities will be documented by acting parties. Access to those activities will be profiled according to the role of service user. HCP will have access to all medical activities of hose care as well as comments entered by SCP and CR or I/FC. At the other hand, SCP will have access in selected data from CR medical record mainly concerning therapy, scheduled appointments, warning messages, allergies etc.

10.2.11 Control / reassessment of home care recipient

By creating an Integrated Care Record with defined reminders and alarms feature, enables HCP and SCP effective control of health and social situation of CR. Depending of level of CR ability to self-care the professional care may be reduced and future plan for care may be more efficient. Every 3 to 6 months (depends of case) Integrated care service (on SmartCare portal) will closely follow usual health and social activities defined by HCP/SCP and make any change in plan if needed. SmartCare will, unlike current processes, give more comparable data which will help in making change plan decisions.

10.2.12 Temporary admission to institution

Depending of integrated care plan, CR could be temporary admitted to the hospital / specialized institution of social care / foster family. According to the changes on the condition of the patient (either social or worsening of the clinical status) there may be an

admission to a hospital or social institution. Those cases will be evaluated by the Social and Health care providers. Hospital staff will be automatically notified about patient integrated care record by automatic through SmartCare message dispatch service.

10.2.13 Discharge from hospital

Usual practice is that CR who is already receiving treatment at the hospital - the nurse filled out the admitted / discharge letter in electronic form. This letter provides information about the patient and the medical history and condition of the discharge from the hospital, followed by the possibility of long-term treatment. SmartCare message system (part of SmartCare integration infrastructure) will notify GP and Social care about CR admission/discharge. Certain activities during hospital treatment will be available on SmartCare Portal. Since currently no electronic connection exists between Social care providers and GP and Hospital professionals regarding hospital admission/discharge, these services will enable timely informing and adjustment of social care.

10.2.14 Exit point from the Smart Care service

Project will enable exit point from SmartCare service in cases when person is no longer needs medical or social care, if person change his mind in participating in the project, or if he feels concerned or uncomfortable in participating in the process.

10.3 How key regional implementation requirements are met

The following table summarises in what way key implementation requirements identified in the Danish context (for details see Annex 9) are going to be met.

Table 16: Summary of how key implementation requirements are met in Kraljevo

| Type of requirement | Summary of response by the project |
|---|--|
| End user requirements | To share data between themselves. To have better and faster communication. To have electronic connection between SCP and HCP, currently they do not have it. Patients/CR will receive better care. |
| Organisational and staff requirements | Project will try not to impose additional effort to normal functioning of the existing services, and to incorporate in current organization with minimal changes in the business processes. Education and building capacity of SCP and HCP. |
| Legal / regulatory / contractual requirements | SmartCare services will adjust in current legal environment and regulations. |
| Technology / functionality related requirements | SmartCare will significantly upgrade technological infrastructure keeping in mind their current capacity for maintenance and management. |
| Other requirements | N/A |

The following table summarises the approach taken in the deployment region towards negative anticipated potentially emerging from the SmartCare service when compared with current care practices in the deployment region (for details see Annex 9).

Table 17: Summary of how anticipated negative impacts of the SmartCare service are addressed in Kraljevo

| Stake holder concerned | Summary of approach taken towards anticipated negative impacts |
|-------------------------|--|
| Care recipient | Adapting to the new technologies might be difficult. Maintaining the equipment in their houses. |
| Informal / family carer | Technical background is questionable. |
| Formal social carer | Additional education is needed. Feeling of additional workload without compensation. |
| Formal health carer | Additional education is needed. Feeling of additional workload without compensation. |
| Third sector carer | N/A |

Annex 1 - Aragon

The current service landscape in the deployment region

Servicio Aragones de la Salud (SALUD) runs a screening program at Barbastro's Hospital to detect situations of frailty or risk of lack of attention of their patients. This program starts when a patient is admitted and a healthcare professional (usually a specialist, but open to all professionals) detects the need of care for a patient upon his/her discharge. The healthcare professional then alerts the social staff working at the Hospital. If the requirement is considered as a required need and after the patient's consent, the social agent initiates the procedures to attend the request of care upon the patient's discharge. From that moment on the social services provider will be responsible for providing care to the patient, and the healthcare provider remains outside the patient's continuity care plan, remaining as a provider of services upon the physical presence of the patient into a healthcare centre. At the same time, the social care provider owns a database which holds the patient's data referring to social attention, but has no access to the patient's medical records or information that may be useful and in some cases important, on the decision making. In the same way, social providers and healthcare providers maintain separated records of the assistance procured and services consumed by patients, without access or data sharing among them, therefore, there is no horizontal inter-organization integration, making the coordination of activities more difficult. Against this background, the contextualised implementation of the SmartCare pilot service aims to provide a common framework that allows the coordination of health and social professionals, along with common patient data set that permits to provide an integrated type of care, not only for discharge cases but with monitoring chronic patients at home and long term care.

Key implementation requirements identified in the deployment region

End user requirements

Identification of users is prior to any development must comply with the legislation and organisation normal procedures. Digital certification through the patient electronic ID must be established.

Organisational, staff and business related requirements

Existing workflows at the part of the service provider organisations involved may need to be adapted, at least partially. Staff concerned may need to be qualified and trained respectively. The social provider and health providers already have information systems to coordinate the attention they provide. It will be necessary to create an upper layer that permits the interoperability among these systems. Agents involved on the SMARTCARE project will have to follow a training program on the use of the technological devices.

Legal / regulatory / contractual requirements

Apart from general data protection requirements, specific requirements concerning privacy and security of health related data imposed by national regulation need to be met. The individual service provider organisations involved may need to enter into a contractual relationship with each other in order to determine rights and responsibilities of each party involved, including liability related aspects. The service needs to comply with quality requirements set out in the co-funding rules established under the national care funding/insurance schemes. Established consent procedures currently followed at the part of the service providers involved need to be followed and where necessary adapted. In any case, patients have to give their written consent. The SmartCare project has to be

evaluated by the Clinic Research Ethics Committee of Aragon (CEICA) that evaluates all research made in the territory.

Technology / functionality related requirements

Data transmission over secure connections may be required, at least when health related data are concerned. Interoperability of legacy systems operated at the side of the various service provider organizations involved needs to be ensured (e.g. call centre software, hospital information systems). Interfacing with different end user devices used across the different service organizations involved may be required (e.g. mobile phones used by staff of the rescue service and desk top PCs used by the social care manager). The portal will have to have different views according to the user profile login in.

Any other requirements

The need for developing/purchasing required technology components that are not available ‘off the shelf’ may time wise conflict with the project schedule

Expected pilot service impacts on local / regional actors

| Type of actor | Positive impacts | Negative impacts |
|---------------|--|--|
| CR | Enhancement of the QoL | Loss of privacy/ accommodation for receiving visits at home / Feeling of worsening of health status due to constant help needed |
| I/FC | Empowerment of people permitting them to better perform their care role. | Taking over new tasks. |
| SCP | Enrichment of their role through the acceptance of the low-value HCP tasks. | Taking over new tasks |
| HCP | More specialization and lighten of the low-value tasks thanks to the transfer of these tasks to other roles. | Effort of adaptation to the new more specialized role. Fear to lose competences. Fear of unauthorized practice of the health profession. |
| TSCP | Enrichment of their role making them participant in the care act of elders. | Assuming a new role and new tasks. |

Annex 2 - Friuli Venetia Giulia

The current service landscape in the deployment region

Friuli-Venezia-Giulia (FVG) is an autonomous Italian region and, as such, has developed, over the years, a coordinated healthcare sector with some pilot implementations of ICT solutions. However, the system is still partially fragmented and shows room for further integration both in terms of ICT and inter/intra-team communication.

The public FVG Health Service is divided into 6 Health Authorities, 2 Hospital-University bodies and 1 Hospital Authority; 20 Districts acting as reference centres for all the services provided by the NHS Authority, besides ensuring the integration between health and social services, and coordination of Social Workers as well as private and volunteer organisations.

Within this framework, GPs and most specialists are an integral part of each District. A spoke hospital may act as the intermediate health reference point of one District. Within the District Services, a District door (Single Access Point) has been established to guarantee access to welfare facilities. This entrance point is being managed by healthcare and social care staff. Home health services are being provided by nurses and rehabilitation therapists in collaboration with GPs, social workers, home assistants, physiotherapists, specialized physicians, volunteers and other medical and social operators.

District medical residential facilities (RSA) for intermediate care provide assistance for the rehabilitation of hospitalized patients suffering from serious multi-pathologies (e.g. orthopaedic, neurological, pneumological, cardiovascular pathologies, etc.) as well as for patients with stable, or temporarily major social problems requiring 'relief' for family members and/or patients with prevailing end-of-life issues, i.e. terminally ill patients. A territorial cardiology service attends to patients discharged from different hospital structures (e.g. ER, Cardiology, 118, etc.).

Key implementation requirements identified in the deployment region

End user requirements

So far, the experience we have acquired on integrated hospital-territory care allowed identifying a number of requirements that can be summed up as follows:

- **Communication:** There is a need for quick and easy access to relevant patient's health and -social information both by healthcare providers and patients/caregivers. Communication flow needs to be made easier, integrated and comprehensive through a coordinated Smart Care platform. A better communication will undoubtedly improve the active role played by patients/caregivers/volunteers.
- **Education:** Each actor involved in the multidisciplinary team, CR and caregivers needs to be formed/educated and kept updated on system use and different modalities of data access and integration.
- **Monitoring:** Continuous monitoring of clinical, social and environmental parameters plays a paramount role both in care and self-care process. Improving quality and intensity of monitoring allows to keep people at home, preventing instabilisations and re-hospitalisations.
- **Technical accessibility of the platform:** In order to reach an effective process both from health and social point of view, an integrated platform needs to be easily accessible and easy-to-use.

Focus groups will better help identify, clarify and integrate specific needs arising from the implementation of the Smart Care platform.

Organisational, staff and business related requirements

The use of ICT supporting integrated care needs first to be experimented and adopted into the regional framework of integrated care and thus to inform the Local Plans for integrated care of each local health authority. Also, the use of SmartCare implies the definition of specific tasks and goals for the care providers in their existing service model and the implementation of their skills and competences. Adoption of ICT personal devices (smartphones, tablets and other devices) among caregivers in order to allow the data sharing will be vital as well. The promotion of the use of (already existing) public funds for autonomy and independent living in to the SmartCare service model will be an important issue. In a business oriented perspective SmartCare will be adopted by the regional and national cluster on AAL, as an innovative tool in order to reduce the gap between industrial research and provision of integrated services (which represents also a regional commitment into the D4 working group “age friendly cities and environments in the EIP-AHA). In particular a strong effort has already been ensured in order to assume the “ICT driven care services” in to the regional process of implementation of a smart specialization strategy as requested by the rules regulating the use of EU structural funds 2014-2020.

Legal / regulatory / contractual requirements

Because of the very complex framework of national and regional legislation and legal aspects (mainly related to data ownership and privacy), an institutional panel will be set up made up of legal representatives of local health and social facilities, public authorities in charge with privacy issues, and local patients’ as well as human rights’ representatives. An incentive plan for adoption of integrated care into the regional health authority framework and for continuous education and training of different actors involved in patient’ care will be asked to regional authorities.

Technology / functionality related requirements

Aspects relating to definition of the technologies and their integration into care services are currently being finalized in the context of the public requirements that will be published in the public services platform in October. In summary the main components of building blocks of ICT-based integrated care model are:

- Integrated, Electronic, Web-based Care Record.
- Input from health and social care actors.
- Interfaces to (o at least update from) different ICT tools.
- Sharing clinical, scheduling, monitoring information.
- Integrated into care planning and management processes.
- Training delivery/learning pathways / plans for professional and/or patient self-care training.

Any other requirements

Further issues that have arisen are related to ethical issues include the following:

- Should the patient pass away, protocol to shut down platform access should be drafted.
- Timing of access to lab data on the platform should be carefully assessed so as to allow sensitive information to be appropriately delivered to the patient/caregiver by the healthcare provider.

Expected pilot service impacts on local / regional actors

| Type of actor | Positive impacts | Negative impacts |
|---------------|--|---|
| CR | <p>The patients will no longer need to re-discuss their clinical/social information with every contact person they meet because that information will be made available and constantly updated in the Smart Care record. Hence, all actors involved in the patient’s care will be able to have a better understanding of the patient’s situation prior to meeting the patient. They will also be able to access the patient’s own notes and get a holistic insight into the patient’s life, making coordination and implementation of care more efficient and effective. Those patients who wish to play a more active role in the management of their own disease will be able to do so. This will reinforce the therapeutic alliance, increasing patients’ self-efficacy, empowerment and promote self-management skills (including better adherence). Windfall effects are expected also on the patients’ caregivers, who may feel less isolated and less burdened by the stress of caring for a seriously ill loved-one; this will make patients feel less guilty about their own inability to provide for themselves, helping them maintain their sense of self.</p> <p>Other advantages could be: Shorter hospital stay. Avoiding admission in intermediate care or retirement homes. Integrated, real time, monitoring and sharing of information Prompt intervention if needed</p> | <p>Some patients may feel ill-at-ease about entering and accessing information in the system. They might feel confused and uncomfortable when presented with a lot of information presented in a matter specifically intended for use by healthcare professionals.</p> <p>Some patients may feel uncomfortable having to share their personal information with different actors inside different organisations.</p> <p>Some patients may not be proficient in using a pc or a tablet and may feel more isolated.</p> <p>Patients may have access to an amount of technical data which they do not understand and which may potentially make them feel even more unsecure, increasing anxiety and misconception about their health condition.</p> <p>Some medical/social information may be sensitive in nature and cause psychological distress.</p> <p>Hence, access to patient’s data will have to undergo filtering in regard to data-access (input and output).</p> <p>Other disadvantages could be: Reduce of time of “intensive care” by shortening hospital stay or avoiding intermediate care admission. Emergent intervention delayed (in comparison with hospital stay)</p> |
| I/FC | <p>Relatives and friends will be able to better assist the patient, gain insight and feel better supported</p> | <p>Some relatives may feel overwhelmed by the amount of data and get confused.</p> <p>Some may feel the platform and devices as an extra burden</p> <p>Delivery of prompt intervention if needed</p> <p>High Workload</p> |
| SCP | <p>Social care workers will have easier and updated access to their patients’ environmental and social needs</p> | <p>Some professionals may lack computer skills and may feel overwhelmed by data entry requirements.</p> <p>They may not fully understand the impact and the goals of the integrated approach.</p> <p>Delivery of prompt intervention if needed</p> <p>High Workload</p> |

| Type of actor | Positive impacts | Negative impacts |
|---------------|--|---|
| HCP | Integrated health care plan Real timesharing of information | Compliance with devices and monitoring and EPR Delivery of prompt intervention if needed Health care workload and responsibility |
| TSCP | If involved, they will be able to better assist the patient and heighten their sense of purpose and of belonging to the social/healthcare team | They might feel uncomfortable entering data and might not feel qualified to use the platform. Delivery of prompt intervention if needed High Workload |
| Other | n.a. | n.a. |

Event # 1

SmartCare focus group for healthcare and social care professionals

Annex 3 - Scotland

The current service landscape in the deployment region

Scotland intends to use the prevention and management of falls as the focus for our SmartCare pilot across 7 local health and care partnership areas. With an ageing population, falls and the consequences of falls are a major and growing concern for older people and health and social care providers. Recurrent falls are associated with increased mortality, increased rates of hospitalisation, curtailment of daily living activities and higher rates of institutionalisation (ref Dept of Health Economic Evaluation, 2009). Falls are the leading cause of accident related death in older people (ref WHO, Europe 2004). Falls are a common problem amongst older people with long term conditions, including dementia.

Falls and fractures, in people aged 65 and over, account for over 18,000 unplanned hospital admissions and 390,500 hospital bed days each year in Scotland. Average lengths of stay for falls and hip fracture admissions exceed those for other emergency admissions in the same age groups: average lengths of stay for falls and hip fractures in the 75+ population are 25 days and 36 days respectively (compared to an average stay of 13 days for a COPD admission in the same age group) (2010/11 data provided by ISD Scotland).

Department of Health (DH) data (2009) reports that 30% of the population aged 65-79 years and 45% of those aged 80 years and over fall annually. Applying these assumptions to the Scottish population gives an absolute risk of 0.34 falls per person for those aged 65 years and over.

Around 1% of falls result in hip fracture (ref Cumming, Neville and Cummings 1997); although the percentage is low, this amounts to over 6,000 hip fractures in Scotland each year. The acute management of hip fracture alone costs NHS Scotland in excess of £73 million each year. Twenty percent of older people who sustain a hip fracture die within six months (ref: SIGN 2009); approximately half will never be 'functional' walkers again (ref: WHO, 2004).

In addition, in the over 65 population, falls cases are the largest single presentation to the Scottish Ambulance Service (over 35,000 presentation each year), one of the leading causes of Emergency Department attendance, and are implicated in over 40% of Care Home admissions (ref: American Geriatrics Society, British Geriatrics Society, 2001). Post - fall syndrome, a combination of fear of falling, anxiety, loss of confidence and depression is prevalent, leading in many to an inability to carry out day to day activities and social withdrawal and isolation.

Despite these statistics, falls are not an inevitable consequence of old age. An individual's risk of falling or fracturing is determined by a complex interaction of multiple risk factors relating to the ageing process, the presence of long term conditions, lifestyle choices, risk-taking behaviours and the surrounding environment. Well-organised services delivering evidence-based care can help to prevent future falls. Recognising and modifying an individual's risk factors is crucial in preventing falls and injuries, including fractures. In many cases early identification of risk and timely intervention can prevent falls and fractures and improve outcomes for older people, retaining or restoring independence and reducing health and social care needs.

Prior to SmartCare being introduced, Scotland has in place a National Falls Programme to support local health and social care partnerships to implement a co-ordinated, evidence-based and person-centred approach to falls and fracture prevention as described in the 2010 NHSQIS resource, Up and About. A national Programme Manager is in place who

currently works with a network of mainly health staff e.g. local Falls Leads, Rehabilitation Co-ordinators, AHP Directors/Leads and other key stakeholders to support the development of local falls and fracture prevention care pathways in the community setting. Partners in this work have already included the National Telecare Development Programme.

Scotland also has a national eHealth Strategy and a National Delivery Plan for Telehealth and Telecare. We have an established Scottish Centre for Telehealth and Telecare (SCTT) which will support SmartCare activities and the expanded use of telehealthcare and ICT within integrated care and to support informal carers.

Currently within the majority of Health Boards in Scotland, falls prevention and management is provided by generalist assessment and rehabilitation services for older people, such as community multidisciplinary teams and day hospitals for older people. Even where dedicated falls services exist, other members of the health and social care team have an important role to play in falls and fracture prevention and management. It is essential that a more integrated approach to care is developed which address the key components of the Up and About resource and other related good practice guidance such as “Telehealthcare and Falls”.

A national mapping exercise of local arrangements for falls prevention and management and fracture prevention for older people was undertaken in 2011, which aimed to;

- Identify the extent to which recommended practices to prevent and manage falls and fragility fractures are built-in to the wider systems of care for older people in Scotland.
- Capture good and promising practice as well as common gaps in service organisation and provision, and where possible, identify developments and changes since a previous mapping in 2009/10.
- Inform recommendations for the improvement of services in Scotland.

A 100% response rate was achieved, with all 35 CH(C) Ps in Scotland participating. The findings of this exercise were published in May 2012 and identified that in some areas modest steps have been taken since a previous mapping in 2009/10 and that there is much improvement work in progress. However, the findings also showed that there is still unacceptable variation in service provision and quality, and in some localities services remain poorly developed. Scotland still has much to do to provide older people with equitable, high quality services for fall and fracture prevention.

The aim of SmartCare in Scotland is to focus the current activity on falls prevention/management and ICT development, and to use this to develop more robust local pathways which support integrated care across health, social care and informal carers. SmartCare in Scotland will focus on improving data sharing, co-ordination and communication and will involve:

- Building on evidenced good practice and local mapping to implement four care bundles for secondary falls prevention in the community. This approach is based on an approach first developed and introduced in Wales. The bundles aim to ensure that falls prevention and management activity is clearly aligned with the 2 high level SmartCare pathways, and that appropriate assessment and interventions are delivered consistently and in line with current guidance. The introduction of the bundles, in combination with a Model for Improvement, a local measurement framework, and the SmartCare evaluation will help services to systematically monitor, evaluate and improve the quality and effectiveness of the care they provide.

- Expanding the use of telehealthcare technologies and other ICT systems to support efficient delivery of effective and integrated care pathways for falls prevention and management across different organisations and locations. This will improve access to home based technology solutions, assist with the early identification of people who are at risk of falling, support self care and self management, enable effective responses to those who do fall, and improve care co-ordination, communication and service planning.
- By joining these elements up and by expanding the care pathways and interventions to a large scale population, we anticipate positive impacts on our organisational resources, and the health and wellbeing of our citizens.

In summary, falls prevention and management has been identified by Scotland as the focus for SmartCare as:

- This activity area is already clearly recognised as an important area for integrated care in Scotland at an individual, local and national level i.e. there is a common desire for improvement across all the key stakeholders and willingness to be involved in achieving shared benefits. The project will be used to inform and refine a roll out of robust falls prevention and management activity right across Scotland.
- There has been significant good practice developed around care pathways, care bundles and the effective use of technology services within Falls prevention and management in Scotland which can be built upon and expanded to evidence quality integrated care.
- It will provide an ‘added value’ contribution to the EIP on AHA Action Groups on Integrated Care (B3) and Personalized Health Management starting with a Falls Prevention Initiative (A2).

Key implementation requirements identified in the deployment region

End user requirements

An information pack on SmartCare and training programme/processes for end users, carers and community based staff will require to be developed to aid recruitment and effective targeting. This will include inclusion criteria and referral/enrolment process. Self management and care information needs to be easily found, easy to understand and use and be presented in ways which are positive and engaging for users and informal carers. We anticipate using the developing Living it Up portal for this element, and will need to ensure appropriate localised information and tools are included. SmartCare participants will contribute their experiences and skills to develop effective, integrated care solutions that work for them. The published results and reports from the Living it Up Community Engagement events will help inform end user requirements and preferences.

Organisational, staff and business related requirements

ICT support colleagues need to be engaged and involved from the outset to identify opportunities or technical challenges to be overcome. All key stakeholders need to develop and ‘sign up for’ a common vision, objectives and feel involved or the project will be very hard to deliver at scale. This can take some time at the initial stages of a project, but ultimately make implementation easier. The current SmartCare project timescales may not accommodate this adequately across a large scale project involving multiple organisations and stakeholders, and is a matter for shared learning. Scotland is implementing SmartCare at a significant scale, across a complex range of service providers and geographies. This will require detailed project planning, end to end processes aligned to the 2 high level pathways to be developed in partnership with all key stakeholders,

building on existing strengths, identifying common gaps and the most effective ICT role. A degree of local flexibility will be important. Changes in organisational responsibilities and workflows will be required.

Legal / regulatory / contractual requirements

Any data to be exchanged will need to conform to local information governance requirements and local tendering process followed for procurement requirements. Develop a common format for undertaking multifactorial assessments and sharing a summary as part of SmartCare recruitment requirements.

Technology / functionality related requirements

The work undertaken to redesign the falls pathway highlighted key gaps or areas to be strengthened in the existing pathways. ICT solutions to support the service redesign are being developed and will promote the integration and co ordination of health and social care.

The SmartCare digital service will enable the person to be as independent as possible and reduce delays in decision making due to the lack of key information being available at critical times. The service model will promote the recovery from a fall and will reduce the risk of falls. The model will avoid duplication and provide the person, their carer and relevant professionals and agencies with the following tools:

Diary/Calendar

This is a tool that can adapt to each stage of the persons journey on the falls pathway. The diary will record appointments both social with friends, family, health, and social care agencies. It can also be used to record events such as minor falls and minor misses or other health problems. This information can then be shared with the GP, home care/enablement team, community nurse or relevant agencies who can amend or develop the person's intervention/delivery plan as required.

The diary will be developed in a way that it can interact with health systems in the secondary and primary care sectors as well as other organisations the person determines access is beneficial to them. The objective of the diary is:

- Improved co ordination of self-care and self-management.
- Improved co ordination of care across agencies reducing duplication and making better use of resources.
- Where homecare is a service, link with real time systems.
- Support to manage self directed support payment. Including financial management.

Maintain an accurate record of falls/near misses and the circumstances e.g. in the evening after certain medication, going to the bathroom through the night. This information is critical to the prevention of falls and is not always available to the assessor or in an emergency.

This information in the person's diary can be share with whoever they deem important in the coordination of their recovery and care. The agencies that are likely to have access to the person's diary are.

- Family and informal carers.
- Intermediate care team/community rehabilitation.
- Community nurse.
- General practitioner.

- Social worker.
- Community AHPs.
- Telecare response service.
- Telehealth.
- Home care both public sector and private sector.
- Voluntary/third sector agencies - community leisure, red cross.
- Podiatry.
- Hairdressers.
- Beauty therapist.
- Complimentary medicine.

The type of information which will be shared will depend on the frailty of the person and their level of engagement with statutory services. Below are a range of examples of people who will use the diary. They are at different stages of frailty because of falling and will use the digital tools available in different ways:

- A. Initially the person may only need support with confidence and improving their stamina. Apart from their GP and possibly secondary care services to manage or diagnosis a long-term condition, their engagement with services will be limited. Their diary will be used to coordinate their recovery programme, which could consist of taking more exercise in the local park and swimming. Getting out and about more socialising to improve their mood, confidence and sense of well being. The diary will link with the GP practice, primary and secondary care to make and reorganise appointments. It will link with leisure service and advise them of activities that are on, which they may wish to attend.
- B. Someone who has been relatively fit and independent but falls, fractures their hip, and requires hospital admission for a replacement. They will be able to share the information they have been maintaining about their daily routines/ level of activity/health issues/ circle of support into hospital in a digital format which can be shared with all relevant personnel. This should keep to a minimum the number of days the person needs to spend in hospital. The nursing staff, allied health professionals. Consultant will have a very clear picture of their previous lifestyle and supports and be able to assess with improved accuracy how well the person will cope at home. The AHP's in hospital will have clear information regarding the person's previous level of fitness and plan a programme of intervention that is person centred and outcome based when preparing for discharge. If the person is not a previous user of the SmartCare diary then a hospital admission will be the ideal time to introduce them to the diary. On discharge, it will help them and their carer to coordinate the many follow up appointments that are required for a hip replacement. It will also help primary and secondary care. Coordinate their input reducing missed appointments and duplication.
- C. A person over 80 who has several long term conditions including dementia and has already fallen on several occasions and is at high risk of falling again will use the diary to coordinate the range of different agencies who are now involved in their care. This could include many on the list provided above. The diary becomes particularly useful when there is memory loss and the person wants to retain as much control and independence in their life as possible. In this instance, the diary will be shared with home care service the falls response team, the CPN. The GP. The diary becomes a tool to ensure the person has support and is safe. Several of the local areas now have "real time" home care systems, which indicate when the formal carer arrives, and leaves. Promoting safety

and providing reassurance for families. The intention is the diary will link to these systems where they are available locally.

Community Connections

This will include the facility to see the events in their area and encourage people who have lost confidence to get out and about to get out and about. We will use the already well developed platform of Living it Up, Discover and include the geographical areas of the SmartCare pilot. The SmartCare person will be able to find out what is happening in their local community. Events that the person is interested in can be moved to the diary to aid memory and co-ordination of appointments. Connect currently available on LiU will also be made available to the SmartCare person Skype/ video-conferencing will be made available as part of the site and give people easy access to friends, relations and professional consultations. This information will populate the diary and populate the persons profile and where relevant their personal record of care. The enablement team can use this site in collaboration with the person to encourage them to get out and about improving their stamina and local contacts who can also become a source of informal care e.g. picking up some shopping on a icy day when the person is not safe to go out. It encourages informal support through community links rather than statutory services being used.

Rehabilitation and enablement

In this section, self-assessment will be available for falls and other services such as telecare and meals at home. We will also improve the existing tools used by health social care, housing and third sector to determine the risk of falling. This would include screening questions, the multifactorial assessment and the interdisciplinary or multi disciplinary assessment. This information will populate the person profile/care record and will be shared with the relevant agencies as determined by the SmartCare user. This section will also include apps for exercise, improving balance and transfers. The falls leads within the local area will approve the apps. It will also contain motivational games, which relate to health and well being and personal goals/outcomes.

- Self assessment fast access to telecare -&equipment.
- Basic screening information.
- Triage tool.
- inform multidisciplinary assessment and hospital admission.
- Intervention record.
- Personal goals /outcomes.
- Apps for exercise, personal targets/outcomes, diet.

In the main, this section will be used by AHPs and leisure facilities in collaboration with the SmartCare user. This section provides a choice of interventions to improve recovery and reduce the risk of future falls. It will connect with diary, for example to highlight the days when an exercise class is happening and that you are booked in or an appointment with the physiotherapist to review progress. It will also connect with and populate the personal profile/record of care. This information will be shared with the GP, homecare enablement teams. Telecare service and third sector where appropriate.

Personal profile / record

This aspect of Digital falls service will be the most challenging aspect to develop although the personal profile KIS is already in existence so we will build on that. We will start with the personal profile, which sits within LiU. All health and care workers, including medical staff, will be requested to input to the Person held file. For example, if the person visits an orthopaedic surgeon, the consultant will be expected to input to the person held file

the outcomes of the consultation. The Community Nurse visiting to carry out any intervention requested by the GP would record the intervention was carried out into the person held file, for example, changing a dressing.

Other requirements

Development and/or linkages to supported self management and care information and resources to be developed e.g. strength and balance training and classes.

Expected pilot service impacts on local / regional actors

| Type of actor | Positive impacts | Negative impacts |
|---------------|--|---|
| CR | Improvements in health and wellbeing Timely access to appropriate services. Comprehensive and integrated approach to care Better informed and more confident in self managing their health and care | Less individual people visiting them at home Lack of confidence or initial unease about technology applications |
| I/FC | Less stress and concern for the person they care for Enabled to manage the other priorities in their lives Their needs are better considered and their contribution better recognised in the care planning process | May feel excluded or less important Need to understand and learn different ways of doing things |
| SCP | Better informed about the wider care contributions More effective and targeted use of limited resources More integrated care provision More efficiently managing case load A clearly established baseline of ‘fallers’ from which improvements can be measured | May be less involved in the individual cases May have to learn different ways of doing things An increase in the number of identified fallers which could be perceived as a service failure |
| HCP | Better informed about the wider care contributions More effective and targeted use of limited resources More integrated care provision More efficiently managing case load A clearly established baseline of ‘fallers’ from which improvements can be measured | May be less involved in the individual cases May have to learn different ways of doing things An increase in the number of identified fallers which could be perceived as a service failure |
| TSCP | Better informed about the wider care contributions More effective and targeted use of limited resources More integrated care provision More efficiently managing case load | May be less involved in the individual cases May have to learn different ways of doing things |
| Other | ICT support services will need to be closely involved in designing and developing pathways so clear where the role of ICT contributes best. Adapt and develop solutions | Concerns about increasing workload or additional costs and competing priorities. |

Work shops

Event #1: Stakeholder Event

Date: June 2013

Venue. Fenick Hotel. Kilmarnock, Ayrshire

Duration 10.00 am-

No of participants

Type of user groups involved

Event #2: Users and Cares Conference

Summary profile of event

Date: 29th October, 2013

Venue: Hampden, Glasgow

Duration: 10.00 am - 3.30pm

No. of participants: 120

Type of user groups involved: People over 50 with long term conditions e.g. COPD, Heart Failure, Osteoporosis, neurological disorders and Dementia. Cares and carers support organisations

Recruitment criteria/rationale applied: representation from local groups of service users and carers from each region. Industry suppliers of Technology product which are relevant to Falls and SmartCare objectives/integration of information and coordination

Brief summary of the main themes discussed

The main themes that were discussed should be summarised. These may be presented in a bullet point format. As far as appropriate, key arguments/stand points put forward by the participants should be summarised in a generic manner as well.

Main themes discussed included:

- Aims and Objectives of SmartCare
- Concept/service model so far
- User and carers requirements to support falls prevention and management
- How to get involved in coproduction
- Next steps in implementation

Synthesised list of requirements on the envisaged service

Service process related requirements

- Single entry point
- Database to collect details of people and trends
- Existing systems and potential for interoperability eg telecare, cm2000, Equipu.
- Acknowledge each area is progressing at a different pace with redesign.

Technology/functionality related requirements

- Shared Diary/calendar to support coordination
- Person held File
- Tools to support early detection of risk, assessment, recovery and prevention
- Accessible for hearing and visually impaired
- Secure data

Other requirements

- Affordable
- Sustainable
- Fits with national agenda e.g. integration of health and Social Care reshaping care, falls guidance, SDS, reablement
- Access to Smart devices
- Access to internet

Other issues that came up

- Older peoples familiarity with and use of technology
- Opportunities for intergenerational working
- Remote areas with currently no access to internet.

Event #3: Show and Tell conference

Date: 29th January 2014

Venue: Hampden, Glasgow

Duration: 10.00am - 4.00pm

No. of participant: 187

Type of user group involved:

Industry suppliers of technology similar to SmartCare requirements, health and Social care teams who currently deliver falls services, telecare services, telehealth services, home care.

Third sector providers who provide support services and facilitate access to Smart devices and Coaching/mentoring in use of devices.

Independent sector care providers who are providing home based care to older people.

Recruitment criteria/ rationale applied:

- industry suppliers and academia who have products which can support the requirements of the SmartCare falls pathway.
- statutory agencies and third sector, independent sector who are involved in delivering services to people who have fallen or are involved in falls prevention.

Main themes discussed included:

- How well developed is the industry/suppliers. What solutions do they have to offer
- Falls work across Scotland the national picture.



- Models of falls pathways in local areas
- Smartcare concept - requirements
- Living it up - what is offers and how we will use it as a platform for Smartcare.
- Co-production - how service users and carers have been involved and will be involved in the future

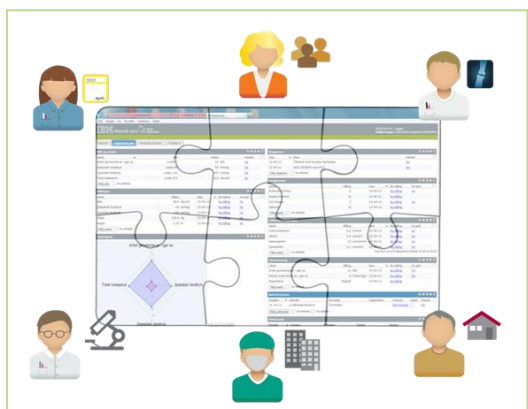
Annex 4 - Region South Denmark

The current service landscape in the deployment region

In many ways Denmark is a front-runner when it comes to ICT solutions and coordinated care in the health sector. However, the Danish healthcare system today is as many other systems with many actors a partly fragmented one. There are three major care deliverers; the hospitals managed by the regions, the general practitioners and the municipalities, each with their own organisation and IT systems.

For patients with a chronic disease or patients with many contacts in the three sectors this means that they experience a somewhat fragmented treatment. Even though the Danish healthcare system has a well-established system of electronic messages each actor typically has their own IT system and not all are able to share and see relevant patient data. Especially the municipalities are large organisations with difficulties in communicating across departments even though they share the same patients

The patients can be roughly divided into two groups. Patients with low self-care ability or issues of both physical and social character have many contacts in the three sectors and have to carry much of the information themselves. The second group, patients with high self-care ability are expected to take an active part in their disease and treatment and need access to information in order to do that.



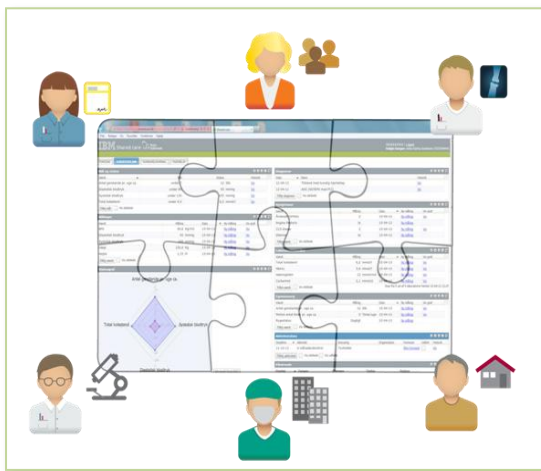
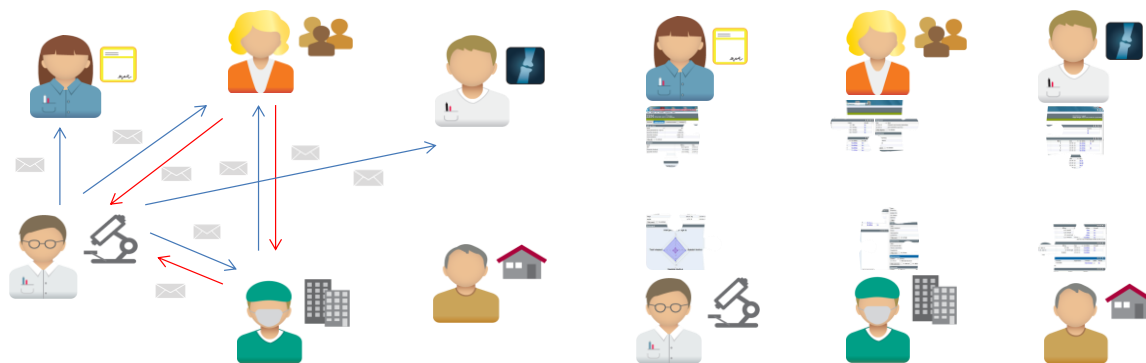
A strong ICT infrastructure in the Region of Southern Denmark (RSD) creates the foundation for interoperability in health and social care, as 65.000 standardised electronic messages are transmitted daily in RSD. In order to IT-support the care of the patient and the cross-sectoral cooperation, the transfer of information, and aggregation of data, standardisation is required. This is based on the nationally adopted standards and wherever possible on internationally recognised standards.

The electronic communication today consists mainly of the secure Danish Health Data Network, where standardised electronic messages are shared according to a joint agreement based on the patients flow between the three major actors. Examples of such messages are:

- Message of admittance to the hospital send to the GP and the municipality.
- Report send from the municipality to the hospital with additional and relevant information on the patient.
- Rehabilitation plan send to the municipality when the patient is discharged.
- Prescription send from the GP to the pharmacy.

In addition to this messaging system there are a wide array of national databases and standards for exchanging data between systems. At the same time there are a number of national initiatives such as the newly implemented shared medical record, where the patients' medicine is kept updated and shared to the actors centrally, in order to make sure that only updated medical information is available to the actors. The patients today have access to parts of their health data through the public web portal Sundhed.dk, where they can see appointments, test results and other information.

The purpose of the SmartCare service in the Region of Southern Denmark is to supplement the existing system with the Shared Care platform. The platform's purpose is to gather all the relevant data in one overview, to support the health agreements on how to share treatment of patients with a chronic disease and to make data available at any time to as many actors as possible, including the patient. It is designed for the patients that are in need of more than what the existing system is able to provide. The platform is highly focused on integration with the existing systems and databases, so that information only should be entered once, but shared with more people. So the Shared Care platform offers an opportunity to collect data from the patients' homes and to involve the patient and their relatives more in the care and collaboration between the parties. It is also a way to share data more dynamically between organisations, such as municipalities regardless of their other IT-systems.



The schemas illustrate the existing data, the need for the Shared Care platform and the role of the Shared Care platform. SmartCare will allow for coordination to become more fluent and will be based more on the patient's needs than on the standardized agreements. It will also allow care professionals to see a more complete picture of the patient across multiple diseases as these are all collected in the Shared Care platform. Today many electronic messages are sent between the caregivers, however not including the patients themselves. This means that each actor has their own part of information in the entire puzzle of information about the patient.

The Danish healthcare system is tax-based and builds on the welfare state. As the Regions cannot collect taxes themselves, the health expenses of the Region are financed through subsidies from the state and the municipalities of the Region:

- Block subsidy from the state: 75%.
- Payment by the state - depending on the activity: 5%.
- Basic contributions from the local authorities: approx. 10%.
- Local authority payment - depending on consumption: approx. 10%.

The economic framework for the Regions is decided on in the yearly financial agreement between the government and Danish Regions. The provision of care is divided between the regions and the local municipalities. The Region is responsible for the hospitals (including psychiatry and social services) and the practices (general practitioners and dentists) of the

region. Also, the Region prioritises the various areas of treatment, and establishes principles for the management of hospitals, quality assurance, service levels, etc. It has the responsibility for the working relationship between the hospitals and private medical practices. On account of their responsibility for prevention, rehabilitation and subsequent care at home, and their share in the joint financing system, the local authorities (municipalities) are key partners in the area of health. The Region advises the local authorities on prevention.

Further to this the Danish health and social care system can be characterised by the following features:

Governance: The development of the healthcare system in Denmark has always been a collaborative effort between all parties involved. In 2010, the Danish Regions and the Danish Government agreed on a number of changes in the organisational setup in the field of eHealth. The main focus of the agreement is to ensure a clearer division of labour between all parties involved including the Ministry of Health and the five regions. The agreement states that the Ministry is responsible for overall development and national coordination and prioritisation. Within this framework, the regions are responsible for investments in and the implementation of specific eHealth solutions.

Primary care: Most primary care in Denmark is provided by general practitioners, who are paid on a combined capitation and fee-for-service basis. The regions determine the number and location of general practitioners, and their fees and working conditions are negotiated centrally between the physicians' union and the government. The municipal health services provide health visitors, home nurses and school health care.

Secondary care: Hospital care is mainly provided by hospitals owned and run by the regions. There are also private hospital providers in Denmark, but these are only used to a very limited extent.

Central government role: The central government 's main functions are to regulate, coordinate and provide advice, and its main responsibilities are to establishing goals for national health policy, determining national health legislation, formulating regulation, promoting cooperation between different health care actors, providing guidelines for the health sector, providing health and health care-related information, promoting quality, and tackling patient complaints.

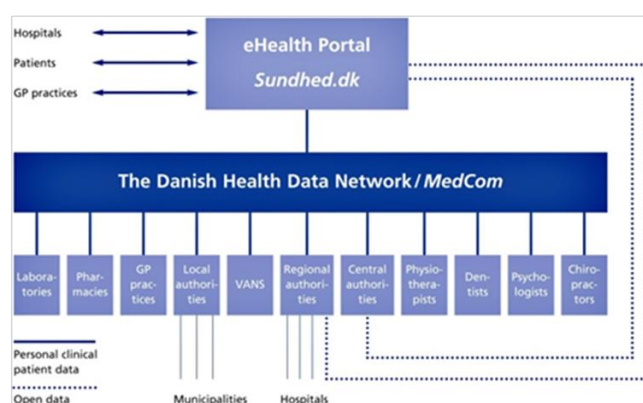
- **Regulatory framework:** As a part of the structural reform in 2005 the Health Act was established. The Act regulates the responsibilities of treatment, prevention, and health promotion in the Danish healthcare system.
- **Guidelines for the treatment of chronic diseases:** In 2008, an agreement was signed between healthcare and social care professionals (the region and the municipalities) in the Region of Southern Denmark in the area of chronic conditions, which is considered to be one of the largest groups of patients. This agreement ensured development of pathways and a consistent workflow for each disease defined as a chronic condition.
- **The chronic care pathways support a unified process. Included in this is a generic model, which stems from SAM:BO** that describes how a unified cross-sectoral, cross-disciplinary, and coordinated health effort is crucial. The pathways are supporting integrated care and the cooperation between the different healthcare and social care sectors and the patient.
- **SAM:BO** is based on the need for introducing programmes for the continuity of care for the patient groups that enter the hospital and when leaving need services from home care. In addition, there is a need for supporting patients' ability to care for themselves in their own home. The chronic care pathways have been developed to

ensure coherence between the different health-related interventions in the course of a disease. Thus, the pathways aim at achieving high quality interventions and patient safety in the entire course of the disease as well as an appropriate utilisation of resources.

Health outcomes are improved through the cooperation between the different sectors of the healthcare system. This cooperation is enabled through the IT-infrastructure of the Region. The infrastructure is described below and is a huge factor when it comes to standardised electronic communication and interoperability. All players in the healthcare sector use ICT as a tool of their trade; a large proportion communicate electronically via the health data network: 98% of laboratory orders and resorts are electronic; 89% of all prescriptions are electronic. The five Danish regions are responsible for regional IT solutions. A number of public-sector IT organisations develop joint solutions nationally, which the decentralised players undertake to implement. ICT is very commonly used throughout all branches of the Danish health service, and today IT supports a great many work processes, including processes that reach across organisations and sectors. This has also helped to make a large number of services available for citizens and healthcare professionals alike.

Alongside personal contact with the GP, the web portal sundhed.dk (sundhed = health) is the citizen's most important interface with the healthcare sector. Here citizens have direct access to knowledge and advice about their own condition and treatment, and about illnesses and health in general. Digital services to citizens are based on the fact that a considerable amount of communication between healthcare professionals - hospital wards, GPs, specialist doctors, laboratories, pharmacies, and physiotherapists - has become digital over the past 15 years.

It began with electronic exchange of messages between healthcare professionals via MedCom standards, nationally agreed upon standards (www.medcom.dk). Communications such as prescriptions, referrals, laboratory orders and responses, etc., are exchanged daily. In the month of January 2010, more than 5 million communications were exchanged. Over the years, the repertoire of communications has expanded considerably, and the infrastructure has been extended to include more and more aspects of the healthcare services. Concurrent with this, Internet technology has been adopted, so now communications also include web services, and telemedicine solutions are rapidly being developed. Throughout the development process, efforts have remained focused on giving healthcare professionals access to flexible knowledge searches and internal communications, and, at the same time, enhancing the quality of the services that the healthcare sector is able to offer to citizens.



The history of MedCom - the Danish Health Data Network (DHDN) - goes back to the late 1980s, when interest in electronic communication among healthcare providers grew. It is a long-term project that enables effective data transfer between several actors of the health service, including stakeholders of the community-based social care system. This national network allows fast information flow in the form of reliable data exchange of

EDIFACT or XML-based messages among the respective software systems of the participating healthcare providers. Agreements on interface specifications as well as certification of software compliance with agreed upon standards and syntax allow for optimal interoperability. Data transfer begins at the point of care for patients and GPs.

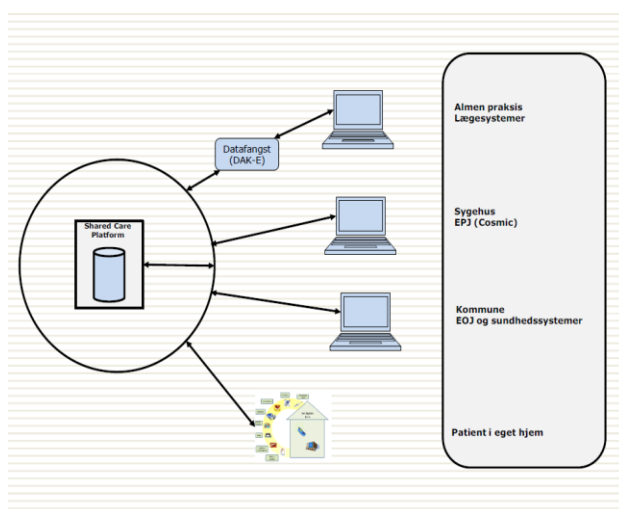
From there, services that citizens may need access to include pharmacists, diagnostic services and specialist consultation at hospitals, referral to and discharge from a hospital, and transfer to home care and residential care services. Effective access to these by citizens depends on the efficient exchange of messages between health and social care providers and other actors. One of the main prerequisites for establishing a coherent and cooperating health care system is to ensure that all health care professionals dealing with a patient have easy access to relevant patient information where and when it is needed. This strengthens the base for decision making and enhances patient safety.

Digitalisation is the key element in achieving this goal by giving health care professionals access to data and examination results across the entire health sector. eHealth is also vital for leveraging secure, efficient work processes, high productivity, and high standards of health care delivery. The Region used this as a back-drop to invent and to innovate new services, such as the collaboration agreements SAM:BO and the Shared Care solution.

In order to give the best patient care and to ensure a high quality of life for the citizens in the Region of Southern Denmark, the Region has implemented SAM:BO, which is an agreement on collaboration between all players in health and social care, based on new innovative ways of providing services and new ways of communicating electronically. The goal of the regional cooperation is to ensure consistent citizen/ patient care pathways between health sectors in the region and thus achieve higher quality, efficiency, and patient satisfaction with the health services provided. It is also to strengthen the cooperation between GPs, local authorities, and hospitals regarding the individual citizen/patient and his/her progress through the healthcare system, and ensure dialogue and coordination between them and with the greatest possible involvement of patients and relatives.

SAM:BO entails requirements and expectations concerning content and timing of the electronic communication sent between the municipality and hospital during a patients' hospitalization. The overall objective of this exchange of information is to optimize hospitalization with a particular focus on discharge, enabling continuity once the patient is discharged and the municipality/home care takes over the care.

The citizen must experience consistency from the very beginning in the process where the general practitioner is contacted, to the diagnosis and treatment at the hospital and until the citizen is back in his/her own home for the follow-up rehabilitation therapy. The starting point is the individual's needs, so that treatment is offered on a needs basis.



For the complex patients with one or several chronic diseases, the Region of Southern Denmark is in the midst of implementing an innovative solution that runs on the backbone of SAM:BO. This solution supports the integrated approach as outlined and is established on the basis of the chronic care guidelines that have been issued both nationally and internationally. The Shared Care system is an ICT system that supports the Danish “programmes for the continuity of care” and thereby also supports the cross-sectoral collaboration (communication and sharing of data) for patients with chronic diseases.

The Danish National Board of Health has issued “chronic care guidelines” to support a unified process for patients with a chronic disease. Included in these is a generic model that describes how a unified cross-sectoral, cross-disciplinary, and coordinated health effort is crucial. Therefore, a process has begun to underpin this model with electronic communication and shared care records, thus connecting all the stakeholders in the health and social care continuum in a collaborative effort to secure that the right information is available for authorised caregivers anywhere and anytime. This is what the Shared Care supports. The process involves the primary care sector, the regional hospital sector, the municipal social care sector, and the patients themselves.

The solution thereby supports the integrated care approach and adopts the common and nationally agreed upon dataset standard for citizens with a chronic disease. In addition, the solution utilizes the existing national infrastructure and optimises the workflows among the players in the health care sector, and care service delivery processes.

Key implementation requirements identified in the deployment region

End user requirements

In several projects concerning the barriers for a more coordinated treatment there has been collected information on the patients’ and caregivers needs and experiences. In this regard the following information is based on these projects - including a survey done in the municipality with interviews of 60 caregivers and patients and a survey done in the largest hospital in the region involving more than 1500 patients. The results can be divided into two major groups. The first group is the patients and their relatives, and the second group the care professionals. The requirements are briefly summarised below.

- Patients and relatives:

Their main input is making sure that the professionals communicate and not having to retell their story many times. Also the patients are not always aware of the organisational set-up, so the focus for them is meeting prepared and understanding healthcare professionals that can guide them through the system. A lot of the patients also want more information on their treatment and the possibility of communicating with the caregivers about their goals and everyday experiences more informally. They feel frustrated when they have to wait or struggle to find the right contact person, and then have to inform them about their situation.

So the patients and relatives requirements to the Shared Care platform are for the professionals to be able to find relevant information about their background, disease and treatment, so that they will not have to retell their story or be concerned with whether or not the caregivers are “up to speed”. They also wish to have a visual view of their goals and to be able to talk about their progress with the care professionals. The possibility to write notes and to put in data to be checked by the care professionals and to see a list of who to contact are also important factors. For the patients that are not able to use a computer a tablet could be a way to include them. Finally they hope that home monitoring and videoconferencing possibilities will minimize travelling as this can be both expensive and difficult for chronically ill patients.

Below some quotes from the performed interviews:

- “Everything was better when everybody started working together and started thinking outside the box”
- “We find it difficult to get in touch with the right people and actually we cannot even find the phone number of our municipality”
- “We need a type of database that the professionals will keep updated with the newest knowledge. It can be difficult to search online and find the right

information. It would be preferred if it is a mix of professionals and patients to get closer to the relevant issues”

- “A system that can support me in performing actions to prevent additional disease”
- “Safety that what needs to happen actually happens”
- Care professionals:

They main focus for the care professionals is access to relevant information in one single place and a clear overview over involved contact persons from the different sectors. They express the need to see information from the other caregivers in order to better plan the treatment with the patient and to better enter into a collaboration - also to provide security for the patient when expressing the understanding of the patients’ entire treatment. They also request an IT tool to better support the workflow described in the Health Agreements. For many care professionals the information they have about the patient is either placed in many different systems or carried by the patient themselves. This means that they spend a lot of time trying to get the full picture and will often have to ask the patients themselves.

The system should therefore provide an overview with all relevant data, activities and contact persons from the other sectors. The system should be user friendly and support the existing work-flow without too many extra tasks. It should be integrated with existing systems and databases to make sure data is updated and only needs to be registered once.

Below some quotes from the performed interviews:

- “An on-line updated version of the chronically ill patients’ record available for every professional at all times”
- “We need a place to communicate across professions and to see the updated information”
- “It’s hard for patients with low self-care abilities - they have to tell their story over and over to the different care professionals”
- “It is impossible to coordinate care if you do not have information from the different care providers”

Organisational, staff and business related requirements

There will need to be made specific analysis of the end-users current workflow and the changes that will be made to that when implementing the Shared Care platform. That will be different from each organisation even though the SmartCare project also will make efforts to align some of their current often paper based tools. In that process end-users will need to be involved and documents describing the new workflow will be produced and made visible before using the portal. For the hospital in Svendborg this process has been made and there are no additional tasks when implementing the portal, so this is simply a matter of learning to use the system instead of paper and memo-recorders. As the Shared Care platform generally supports the care pathways outlined in the Health Agreements it will naturally also support the overall workflows.

The system will have to be available - this means an analysis of the number of computers per professional, so that there will not be any unnecessary waiting. Also the system must be reliable and easy to access. This means that the staff can use their existing log-in known as the staff-certificate. They will also need sufficient training and guides as well as a support system when preparing to use the platform.

We regulate the collaboration and reimbursements in the Health Agreements - a part of a large process where the Danish Health services control the collaboration. We strengthen

the system within the given frames. We need clearer descriptions of how to handle the rules and the agreements regarding economy.

Legal / regulatory / contractual requirements

In Denmark there are two basic regulations to follow in this area - the act on processing personal data and the Health Legislation. The first act is to ensure that sensitive information surrounding the patient is not distributed electronically without purpose and permission from the patient. This can be allowed if the patient signs a consent form where it has been made clear who sees the data, what is shared and to what purpose. There are some issues regarding the sharing of data that many systems now wish to support and the legislation. This means that your consent form has to be very specific for the patient to actually know what permission they are giving.

The two basic Danish regulations that are relevant for the SmartCare project are the following:

- The Danish Act on Processing of Personal Data: The Act on Processing of Personal Data sets the boundaries for how public authorities must process personal data. This applies in cases such as when public authorities collect and register data about citizens e.g. when the municipality processes a citizen's application for social care benefits. The Act includes many specific rules that relate to processing of personal data.
- Consent: To enter a patient into the Shared Care platform they have to sign an informed consent. The content of the consent can be done whenever the patient has signed a consent form. However the consent has to be very specific and specify who the data will be transmitted to. The consent will be repealed after a year in relation to the Health legislation. The question is how you define a pathway/course of disease/course of treatment when a patient has a chronic disease.
- Health Legislation: The most important element regarding the Health Legislation is patient confidentiality. It is the same principle as in the Danish Act on Processing of Personal Data but it has been specified more clearly what each health professional is responsible for. To ensure good treatment of the patient it is necessary for the health professional to pass on some information regarding the patient. There are rules specifying which other people that are allowed access to the system. Therefore it also says which people who can read what other health professionals have written and furthermore when it is allowed to transmit information. The Health Legislation focuses on transmission of data and retrieval of data.
 - Retrieval of data, Health Legislation §41: Look-ups in an electronic system are used only for current treatment of the patient. It has been specified which groups of people are allowed to access the data and also what the certain groups of people are allowed to access. They are only allowed to see what is necessary for the current treatment. There are limits since it is only health professionals treating the patient that can access the data. It is not allowed to read everything about a patient if it is not relevant for the individual health professional in the treatment of the patient. E.g. a chiropractor cannot access the patients' health history but only the current treatment. There has been made a distinction regarding which health professionals can do what. There has been made an expansion regarding who can access historic patient data.
 - Transmission of data, Health Legislation §42A regarding transmission of data and §43 regarding transmission of data for other purposes. E.g. the paper file will be collected from a filing cabinet and a decision is made on what data you as a health professional want to transmit. It is allowed to transmit data in relation to current treatment and in relation to receiving unemployment benefits and when having a disease because the municipality has the authority to retrieve that

information. It is not possible to make a wide and covering consent to get round the authority.

- Legal issues deserving particular attention:
 - Who owns the data?

The person who uses the data controls the data. Therefore it is also the person deciding how much data that can be collected and transmitted. This problem is related to both The Danish Act on Processing of Personal Data and the Health Legislation. The Shared Care platform is consistent with the present legislation. It is only our use of the system that can cause problems and therefore it is our responsibility to ensure all aspects.
 - The patients entering their own data

There are a lot of safety issues related to the fact that the patient can enter his/her own data or when data is transferred automatically from devices. It is very important to ensure that the quality of the data being entered by the patient or other medical devices. It might be necessary to have a person that can be responsible for securing the quality of the data to make sure that treatment will not be made based on unreliable data. There is legislation regarding medical devices.
 - Who can access what?

When a health care professional searches for a patient in the Shared Care platform then he/she might have access to all the data. It is relevant to create different interfaces for the different users that only show the relevant data for that individual health professional. In this regard we need a definition of what relevant data is?
 - Additional information: There will be a logging function in the Shared Care platform so it is possible to trace all movement by individuals in the platform. This is a legal requirement. The patient has to feel safe and has to be sure that no information will be shared that can harm the patient in any way.

Technology / functionality related requirements

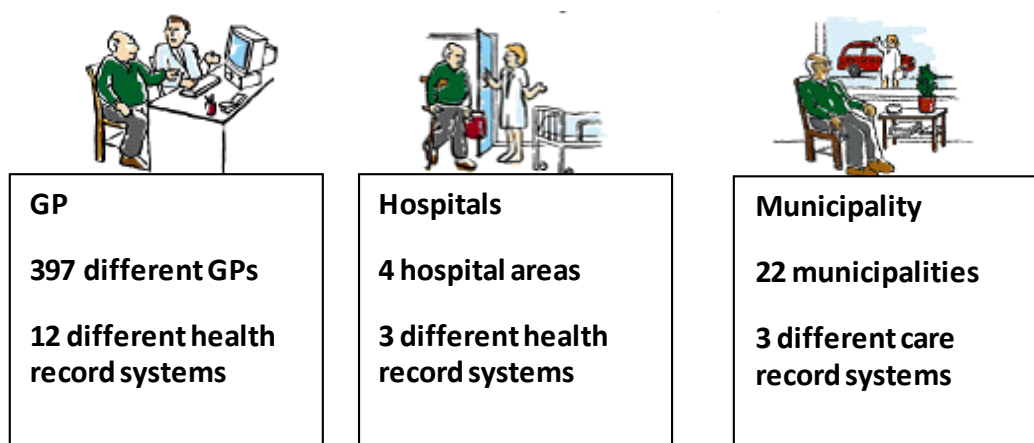


Figure 12: Danish IT care landscape for GPs, hospitals and municipalities

In short the Shared Care platform will need to accommodate existing standards, integration to existing systems and databases and be both fast and reliable on the internet. Below the model illustrates the different partners and their type and number of IT-systems, which the platform needs to exchange data with.

The following are demands for the Shared Care platform, which has to:

- Function inter-regionally and cross-sector and not be tied by specific systems. The solution supports a lot of different stakeholders by providing data to be fed into and across a lot of different systems.
- Support a multiple supplier strategy when it is controlled by a third party. In the same way, maintenance and development of new modules can be done by another supplier.
- Focus on the fact that a lot of different actors need to be able to access the platform. This is something that cannot be done to the same extent if using a client-server system.
- To avoid double registrations and to make it is possible for the involved parties to work within their own systems as much as possible, a system for synchronising all the relevant systems involved is necessary as a part of the solution to ensure that all the systems have the relevant information regardless of where the data originally comes from.
- To be flexible, configurable, scalable and portable
 - Flexibility means that the data in the interface is based on roles and the specific course of disease. The solution can also support a multiple channel strategy and mobility. The view of the data has to be configured to specific units - both static and mobile units.
 - Configurability means that the view of the data should be configurable to fit specific roles through a portlet-technology. Furthermore it will be possible to configure the rules and the patient pathways.
 - Scalability means that the solution has to be able to be scaled when the number of patients rises. The solution is based in components that enables development over time e.g. if a simple module has to be changed to a more advanced module to support new needs. The supplier has developed a wide range of standard components to support flexible patient pathways, modelling processes, rule based engine and integrations that have been well-proven through tests and can function on a large scale.
 - Portability means that the solution can function on several IT platforms and e.g. be moved from Linux to UNIX or Windows with little effort.
- Will be based on confidentiality and security regarding patient related data.
- Include a number of integrations from the CPR register (Register of Social Security Numbers) to the systems in the hospitals and the systems used by specialists, general practitioners and also a home monitoring database. Therefore it is a solution with a great deal of integrations. These integrations that, mostly have to follow the MedCom standards including "the good webservice" are essential to get a solution that can be used cross-sectorial, regional and national
- Deliver IT support to the patient pathways with focus on chronic conditions.
- Give access to a common set of data when having cross-sectorial and cross-disciplinary patient pathways.
- Be a common tool to health professionals in the different sectors, to the patients and the management.
- Support the coordination of the individual pathways starting with the patient pathways and the support of the decision makers.
- Give the patient the opportunity to become an active participant in his/her own pathway including the possibility of home monitoring.

- Be able to integrate with existing and future relevant systems e.g. Electronic Patient Record systems (EPR), systems used by the general practitioner and the specialists, Electronic Care Record systems (ECR), laboratory systems etc.
- Has to function as both an integrated tool for the existing EPR, existing general practitioner systems, specialist systems, ECR systems and as an individual system for that actor who does not use another relevant IT-system e.g. the patient.
- Use the existing open standards.
- Offer a high level of accessibility.
- Support a multi-supplier strategy.

The platform needs to be highly focused on integration with existing systems and databases, and the following systems must be included:

- Integration to Cosmic via CloverLeaf (not an individual module because the integration is made through standard integrations in a basic module).
- Integration to the systems used by general practitioners and specialists through Sentinel data gathering.
- Integration to the laboratory portal.
- Integration to data provided by home monitoring.
- Integration to Shared Medication Record.
- Integration to the client's CPR component.
- Integration to NemLog-in (A secure and personal access for all individuals).

Other requirements

In the course of requirements analysis we have become aware of some ethical issues that need to be taken into consideration in the future process. These include:

- There needs to be a delay in the laboratory values before being visible in the Shared Care platform since these values may have significant importance and meaning, which would be problematic for patients and/or relatives to see before consulting a professional.
- Giving the relatives access to the Shared Care platform also presents a challenge if the patient dies - in that case there should be a support organisation in place that shuts the platform access down.
- It is important to create a user-friendly access that is not dependent on the patient's internet connection to ensure that as many patients and relatives can use the Shared Care platform in order to minimize the increase in inequality in health services.

Expected pilot service impacts on local / regional actors

| Type of actor | Positive impacts | Negative impacts |
|---------------|---|--|
| CR | <p>The patients will no longer need to make sure that they tell their story the correct way to every contact they meet because the information will be available in the Shared Care record. This means that the caregivers across sectors will have a better understanding of the patient's situation and will be able to prepare before meeting the patient. They will also be able to see the patient's own notes and get an insight into the patient's life with their disease. The patients with a desire to be more involved in their treatment and life with a chronic disease will be able to get more insight into the data and take a more active part.</p> <p>The service can create comfort for the CR since he/she can see that all relevant actors are involved and can access the relevant data. Furthermore the patient can see that they interact within the Shared Care platform.</p> | <p>Some patients might feel insecure in entering and seeing information in the system. They might be confused when presented with a lot of information presented in matter which is typically intended for health care professionals.</p> <p>Some patients might feel unsure of what information is shared with which actors in the different organisations.</p> <p>Some patients might feel that the relation in the check-ups or other contacts is less personal when the professional is using a pc or tablet.</p> <p>The patients with less knowledge about IT will have a hard time when they primarily have to use IT.</p> <p>The information is not made directly for the patients since other actors use the data as well. Even though the patients can access a lot of data it does not mean that they understand it.</p> |
| I/FC | <p>The relatives will be able to better assist the patient and gain insight and to have a better dialogue with the caregivers.</p> <p>The service gives the I/FC the possibility of being a part of the patients/relatives course of disease. Furthermore the I/FC can provide active support, comfort and help weak patients.</p> | <p>Some relatives might be overwhelmed with the amount of data and get confused.</p> |
| SCP | <p>The staff in the municipalities such as home care professionals, educators and care coordinators will be able to see a complete picture of the patient's treatment and will be able to enter and use especially the self-care ability indicators to monitor and adjust the amount of homecare services and support.</p> <p>The municipality considers it an opportunity to have a closer dialogue with the citizens - especially the ones that have IT-skills who can view their data in the platform instead of using e-mails and phones. The municipality can share data internally between departments which is not possible today.</p> <p>The personal pathway coordinators will be phased out and their function will be taken over by a better IT supported collaboration between the different actors. The patient's access to their own data will also assist in phasing out the coordinators.</p> | <p>Some professionals might be insecure in what information they should enter if it is shared outside their own organisation.</p> <p>Some professionals might feel that they use additional time when having to use a pc instead of a piece of paper.</p> <p>Some professionals might feel that the communication is less personal when using a pc or tablet.</p> |

| | | |
|-------|---|--|
| HCP | <p>The hospital staff gets a tool that better supports the workflow as agreed in the Health Agreements and to see the full picture of the information from the GP and social care part of the municipality. Also they are able to set goals with the patient and follow-up in the portal.</p> <p>Automatic surveillance that will send notifications if a reaction from a health professional is needed.</p> <p>They will have the opportunity to share information and to get a quick overview of the whole pathway/course of treatment e.g. co morbidity and the possibility of a more dynamic coordination between the actors.</p> | <p>Some professionals might be insecure in what information they should enter if it is shared outside their own organisation.</p> <p>Some professionals might feel that they use additional time when having to use a pc instead of a piece of paper.</p> <p>Some professionals might feel that the communication is less personal when using a pc or tablet.</p> <p>Some health care professionals might not consider the data entered by the patients themselves as valid.</p> |
| TSCP | <p>If involved they will be able to assist the patient by getting access to the patients information and treatment.</p> <p>TSCP does not play a significant role in the Danish system. Therefore they have not been taken into account to any great extent in the Shared Care platform.</p> <p>The patient has to take initiative to involve any TSCP.</p> | <p>They might be overwhelmed over the amount and complexity of the information.</p> <p>They might not feel qualified to assist the patients in using the platform or the home monitoring devices.</p> |
| Other | n.a. | n.a. |

Work shops

Event #1: Workshop for hospital staff

Summary profile of the event

- Date: 17/1
- Place: Regions office, Odense
- Duration: 4 hours
- Participants: 5
- Doctors, nurses and secretaries
- Staff from the hospital involved in the heart rehabilitation group

Brief summary of the main themes discussed

- The current workflow and collaboration with other caregivers
- The possibilities for IT supported functionality in the Shared Care platform
- Integrations and registrations in existing systems
- Data to be shared with other caregivers
- Data to be shared with patients

Synthesised list of requirements on the envisaged service

A list of requirements on the envisaged service should be derived from the group discussions/questionnaire. They should be structured according to three sub-headings headings as follows:

- Service process related requirements
 - Report to be printed out to the secretary until integrations are up and running

- Activity for the patient to make an appointment at their GP
- Easy access from individual system to the Shared Care platform
- Ability to set up unique rules to support the workflow
- Possibility to send and receive messages to and from the patients
- Technology/functionality related requirements
 - Sorting of the diagnosis and information (i.e. primary diagnosis at the top)
 - Possibility to enter the patient's health story at the beginning
 - Renaming of headlines
 - Response time of the system should be high
 - User friendly mobile access for the patients
 - Possibility to enter questionnaires from the mobile access
- Other requirements
 - Reports for the patients should be more user friendly
 - The system must comply with existing legal regulations

Other issues that came up

A list of current requirements still to be met and used as a status sheet can be provided.

Event #2: Workshop for municipalities

Summary profile of the event

- Date: 8/10
- Place: Regions office, Odense
- Duration: 3 hours
- Participants:
 - 12
 - Care managers, consultants, physical therapists, nurses
 - Staff from 3 municipalities involved in the heart rehabilitation group

Brief summary of the main themes discussed

- The current workflow and collaboration with other caregivers
- The possibilities for IT supported functionality in the Shared Care platform
- Integrations and registrations in existing systems
- Data to be shared with other caregivers
- Data to be shared with patients

Synthesised list of requirements on the envisaged service

- Service process related requirements
 - Clear on legal issues, including the patients consent
 - Meetings with collaborators on how to send messages in the platform instead of existing channels
 - Integration of the medcom messages
 - Same test results to be taken at the beginning at the hospital and at the end at the municipality and compared
 - Possibility for the system to be used as cross sectional evaluation as to where patients drop out of the rehabilitation pathway
 - More information on the patients social life and elements

- Technology/functionality related requirements
 - Integration to the joint medication record
 - Quick way to see if there is new information concerning the patient
 - More available search criteria
 - Different sorting of the information
 - Possibility for the patient to work with goals together with the caregiver and to follow up on them easily
 - More textual goals and more testresults
- Other requirements
 - Differentiation of roles and information to be shown
 - Inclusion of the physical therapists at the hospital and the general practitioners

Other issues that came up

Minutes and list of functional requirements in Danish (can be provided if needed).

Event #3: Workshop for patients

Summary profile of the event

- Date: March 20 2014
- Place: Regions office, Odense
- Duration: 4 hours
- Participants:
 - 7 Patients
 - Currently using the Shared Care platform and/or in heart rehabilitation

Brief summary of the *main* themes discussed

- Evaluation of the existing functionality
- Sorting and relevance of information
- The user interface and possible improvements
- Additional functionality for supporting the patients

Annex 5 - South Karelia

The current service landscape in the deployment region

In Finland elderly persons' long time care is mainly part of the home care. The same applies to the discharge process from a hospital. Each municipality or district organises services independently, which means, that they are responsible for organising home help, housing services, institutional care and support for informal care. The way that services are organised may vary (for example municipalities can provide services independently themselves, they can organise/provide services together with another municipality, or they can provide a voucher to service users so they can buy services from a private service provider).

Home care is labour-intensive and depends on an assortment of different inputs to provide a variety of clinical, psychological and social services in the home setting. These providers are a combination of professional and non-professional personnel, such as nurses, volunteers, spouses, dieticians, physicians, social workers, therapists and home care assistants.

Likewise, discharge processes from the hospital need to be improved by considering the patient's needs in the community. More efficient support at patient home reduces length of stay in hospital, and minimise unplanned readmission to hospital.

Coordinating the services provided by various operators to the customer's own home enables supporting living at home from a sufficiently early stage. Compiling individual services (distribution of medicines, meal services, monitoring the capability to function) into service packages makes their provision more cost-effective. Home care plays an important role in supporting the living at home of senior citizens.

From the organisational point of view, all social and health care is already integrated in South Karelia but the integration could be further implemented in the care processes all over the area. By getting easier contact to caregivers and relatives, elderly people can take more responsibility for their own life and daily activities.

Home care is a very important sector in South Karelia Social and Health care District (Eksote) Strategy. We want to keep all elderly persons at own home as long as possible. ICT systems are one tool to solve this issue without increasing the number of health care professionals. In Finland many home care costumers live by themselves and are suffering from memory problems and physical impairments. Based on the above issues home care is increasingly under pressure to take care of all its customers. The SmartCare solution will support this care process.

New care processes supported by technology will include:

- Home safety services such as fire/smoke alarm, cooker monitor, bed sensors and front door alarms with presence in the home, etc.
- Medicine dispenser help to control is medication.
- Indoor safety with the Panic button that elderly can press on him wrist.
- Outdoor safety with a GPS can show the position of the elderly through the portal if he/ she get lost when going for outside.
- Alerts/Alarms that were distributed to care-givers by SMS/email and shown on the portal.
- Video services for contact with care-givers.

Technology will guarantee that elderly person can live at home and information between elderly home and formal/informal care giver will be consistently available. SmartCare service will be installed to costumers based on assessment of service need made by social/health care professional.

Key implementation requirements identified in the deployment region

End user requirements

- Easy to use, usability requirements.
- Easy to remove.

Organisational, staff and business related requirements

- workflows need to reform to take advantage technical system.
- Training for the professionals.
- Professionals user interface need be easy to use.
- User interface need to support service processes.
- Time required for procuring need to be foreseen and aligned with the project time plan.

Legal / regulatory / contractual requirements

SmartCare services related legal requirements

- Personal data act 22.4.1999/523.
- Act of Status and Rights of Patients 1992/785.
- Act on the Protection of Privacy in Electronic Communications 516/2004.
- Legal requirements must be added to the invitation to tender.

Technology / functionality related requirements

- Usability need to meet criteria.
- automated processes.
- Need to meet quality requirements.
- Data protection need to meet criteria.
- Performance need to meet criteria.
- Maintenance and portability need to meet criteria.

Expected pilot service impacts on local / regional actors

| Type of actor | Positive impacts | Negative impacts |
|---------------|---|---|
| CR | more safety home, Quality of Life, improvement of managing own life, decrease of loneliness, get better compliance for the medication | need to learn new way to receive services |
| I/FC | Improving quality of life (relative), could reduce the burden of relative, give more information from elderly home, | Need to learn new technologies |

| Type of actor | Positive impacts | Negative impacts |
|---------------|--|---|
| SCP | More integrated way to deliver home care services, Some of the current nurse visits could be replaced by the videophone connection. Less travelling means more cost efficient home care. | Need to learn new technologies, Care processes will be changed → training |
| HCP | More integrated way to deliver home care services, Some of the current nurse visits could be replaced by the videophone connection. Less travelling means more cost efficient home care. | Need to learn new technologies |
| TSCP | One volunteer could offer assistance more elderly people | Need to learn new technologies |
| Other | | |

Annex 6 - Tallinn

The current service landscape in the deployment region

The Estonian healthcare system today is fragmented between the care providers. There are three major care deliverers, the hospitals, the general practitioners, which control healthcare services and the municipalities which control the social care delivery, each with their own organization and IT systems. Estonia has national health care system eTervis where all needed information can be sent and accessed centrally.

The health information system is a database that is a part of the state information system. The health care related data is processed in this database in order to conclude and execute the health care services provision contract, ensure patients' rights, protect public health and quality of health care services, to maintain the registers of health conditions as well as to manage health care (The Health Services Organization Act and Associated Acts Amendment Act, §59¹ section 1).

According to the Health Information System Statute, the processor of the Estonian National Health Information System is the Ministry of Social Affairs and the authorized processor is the Estonian eHealth Foundation.

The health care services providers have to conclude a contract with the Estonian eHealth Foundation in order to be interfaced with the Estonian National Health Information System.

The integration between the systems is an ongoing process; unfortunately the information about the activities done at home is currently not accessible. There exists also a patient portal where patient have access to parts of their health data through the public web portal e-Tervis, where they can see epicrisis, radiology reports and different kinds of procedure information sent by the health organization centrally. There are also no standards or profiles to integrate data (medical or social) gathered from homes.

There also exists alarm button service in Tallinn City area, which is provided by Tallinn city social and welfare department. There are about 200 elderly using the system now:

- The goal of this service is to call for help primarily in situations where the person is unable to move by him/herself and to open the door for the helpers, for example.
- Sudden need for medical help, with an immobilising effect.
- Sudden need for so-called personal help (falling, temporary inability to move, becoming trapped in inner rooms, etc.).
- Situations necessitating rescue services (fire, explosion, etc.).

The alarm button service will be extended with SmartCare services platform together with the East Tallinn Central Hospital and GPs in the area. To sum it up, the objective of the SmartCare service in Tallinn is to enable elderly people to live as long as possible a complete life in their own home. It will gather all the relevant data in one overview, to support agreements among health professionals on how to share treatment of patients with a chronic disease and to make data available at any time to as many actors including social carers and informal carers as much as possible. The system will implement an ID-card solution to make it secure for the stakeholders. In this manner the SmartCare platform is a supplement to the existing systems. It is highly focused on integration with the existing systems and databases, so that information only should be entered once, but shared with all needed actors.

Key implementation requirements identified in the deployment region

End user requirements:

- Willingness to use SmartCare services.
- Living alone in Tallinn.
- With diagnosed chronic heart failure.
- At least 65 years old.
- No diagnosis of dementia.
- Do not completely depend on others.

Organisational, staff and business related requirements:

- Data protection law should be followed.
- Need for patient subscription form.

Legal / regulatory / contractual requirements

- Ethical committee approval.

Technology / functionality related requirements

- Easy to use.
- Safe for users.

Expected pilot service impacts on local / regional actors

| Type of actor | Positive impacts | Negative impacts |
|---------------|--|--|
| CR | Better overview of measured health stats, stronger sense of security, increased independency and well-being | Making measurements can be time consuming, special training may-be needed to understand the data, patient may experience discomfort while using the equipment because of its unfamiliarity |
| I/FC | More information about the cared-for person's health condition, prescribed medications and treatment plan, easier to access social and medical care providers | Special training may-be needed to understand and analyse the data. |
| SCP | More information and better understanding about the cared-for person's health condition, prescribed medications and treatment plan, more efficient work planning | Special training may-be needed to understand the data, using the portal may be time consuming and may need getting used to |
| HCP | Information about important health measurements are gained regularly, information about the cared-for person's social aspects are easily obtained | Special training may-be needed to understand the data, using the portal may be time consuming and may need getting used to |
| TSCP | More information about the cared-for person's health condition, prescribed medications and treatment or social care plan, easier to access social and medical care providers | Special training may-be needed to understand the data |

Work shops

Event # 1: Stakeholder meeting

Summary profile of event

- Date: 25.11.2013
- Venue: Meeting of all SmartCare stakeholders in Estonia
- Duration: 8 hours
- No. of participants: 10
- Type of user groups involved: Health care providers (Hospital, General Practitioners), social care providers (Municipalities), SmartCare technical support (Hospital)
- Recruitment criteria/rationale applied: The main organizational groups were represented in the work shop

Brief summary of the main themes discussed

The main themes that were discussed should be summarised. These may be presented in a bullet point format. As far as appropriate, key arguments/stand points put forward by the participants should be summarised in a generic manner as well.

- Selection of long term patients
- Selection of hospital discharge patients
- Equipment selection
- Technical workflow scheme
- Working order in the Contact Centre

Synthesised list of requirements on the envisaged service

A list of requirements on the envisaged service should be derived from the group discussions/questionnaire. They should be structured according to three sub-headings headings as follows:

- Service process related requirements
- Technology/functionality related requirements
- Other requirements

Other issues that came up

Next meeting will be in 2014 1st quarter.

Annex 7 - Attica

The current service landscape in the deployment region

The focus of the Attica pilot site is on adult (over the age of 50) patients suffering from type 2 diabetes who might also risk falling due to their condition (especially in the older participants amongst them). In this care pathway, the steps involve such citizens who are already living in community settings for a period of time.

The procedure so far was as following:

- The cared for person (CR) “Yiannis” lives in his family house in PALFALIRO. On a regular basis, he checks with his treating Diabetologist, Dimitris and even at home on regular time intervals vital parameters such as BP and Blood Glucose Levels (using appropriate devices). He keeps a personal paper record, but the results of measurements are not readily available to Dimitris for assessment.
- If during one of the visits to the specialists’ practice a need for further exams, tests or treatment options are required, Yiannis, under guidance from Dimitris and with the help of his carer (wife in this case) Maria, performs all required tasks. Arrangements with Social Insurance Funds, reimbursement for any required interventions both therapeutic and diagnostic, are dealt with either by him or Maria who is legally entitled to handle such issues.
- Although Yiannis follows the guidelines that Dimitris has written out for him, he feels that there is no continuous flow of information between them and sometimes he feels “frustrated”. In many instances, long periods of up to 3 - 4 weeks pass since the two of them meet and follow up on Yiannis condition. As a result, Maria, who does not know how to support her husband, also feels depressed and experiences a burn out situation.
- Although Yiannis intention is to have a holistic approach for the management of his disease, he has no care plan that encompasses all necessary steps that can guide him, like a compass, through the current system. He cannot connect various elements of his care plan together, he does not know in clear and well structured way vital information that is important to the management of his condition. The same is true for Maria, she believes she has no real potential to really care for her husband. Instead of helping him and supporting him, she feels she is doing things that are ‘not scientifically correct’.

This procedure lacks the following elements:

- Continuum of care in community settings in an integrated fashion, based on collocation and coordination of care services.
- Systematic registration of data concerning chronically ill patients.
- Continuous and timely support of CRs according to both social and health needs related to their current status.
- Systematic, timely and scientific information on self management of the condition.
- Active involvement of carers and CRs in decision making and care planning.

Key implementation requirements identified in the deployment region

A set of implementation requirements have been identified so far deserving particular attention in the given local context.

End user requirements:

- The end users should be residents of one of the three municipalities (Palαιο Faliro, Ag. Dimitrios, Alimos) constituting the Attica pilot site.
- They are covered by public insurance.
- They will have to be well accustomed with Internet Technologies and Mobile Phone Technologies or their carers and have a connection to the internet.
- They should be owners of smart phones, laptops or other gateways or again their carers should be holders of these devices.
- Living alone is not an exclusion criterion for users but they can also live with or supported by carers living in different settings.
- Last but not least they have to be ready to accept changes in their lives on an individualized basis during the SmartCare Pilot.
- Questionnaires were also designed in order to gather generic information of the needs of potential SmartCare service CRs for integrated health and social care services. The general needs assessment procedure is based on focus groups whereby interviews with both patients and carers took place (a second wave in September 2013 may follow).

Organisational, staff and business related requirements:

- The main requirement for all staff involved is the fluency in English language otherwise communication with the other members of the consortium will be rather prohibited.
- Additionally and in terms of organisational effort, a multidisciplinary team covering the three municipalities will be set up in order to coordinate all personnel related issues (temporary shortages, overlapping of functionalities).
- The ATTICA Pilot Steering Committee (APSC) will be set up, bringing together all stakeholders of the pilot, in order to monitor all managerial, legal, ethical, organizational and financial issues emerging from the Pilot. Nomination of members and publishing of a Rulebook on the activities of the ATTICA Pilot Steering Committee will be agreed upon and become functional as of January 2014.
- Because of the importance of the pilot for the Greek Health and Social Care System, a Project Communication and Dissemination Committee is going to be established in ATTICA. Leading the Committee will be the Pilot Communication Officer who has large experience in implementing and monitoring communication plans.
- The entities constituting the Attica site are of Public nature and this turns them somehow inflexible to radical organisational changes hence all processes developed will have to maintain a certain degree of compatibility with the existing situation. However, a change management plan needs to be designed and put into action as soon as possible and by no means later than January 2014, because changes in culture of municipalities' attitudes and ways of working will be significant and furthermore, will be a critical success factor to the pilot itself.
- Physical and virtual collaboration of various Health and Social Care specialists and if possible co-location of services needs to be ensured.
- A continuum of interrelated services spanning both social and health related needs must be provided to the patient in a three tier system: Home Care, Physical Visits to the Municipality Medico - social Centre and e - services.

- There is a need to create and support peer - to - peer support and self - help groups.

Legal / regulatory / contractual requirements:

- All sensitive personal data that will be stored in the electronic platform will undergo anonymisation process in order to be later used for statistical analysis and overall evaluation of the pilot.
- Tenders should be made in order to ensure availability of equipment and related software prior to the pilot's set up.
- Finally all national procedures for contracting external specialised professional (e.g. Diabetologists, dieticians etc) for the pilot operation will be respected. These will be according to the special legislation regime under which the municipalities function.

Technology related requirements:

- Broadband internet services availability in the pilot region is the main technology requirement. This requirement is envisaged to be met without serious problems as Attica site enjoys an exceptionally high penetration level of these services both in public institutions but also at residents' homes.
- Access to easy to use gateways (PDA's, laptops, smartphones) needs to be provided.
- Training needs to be provided in using gateways in order to access e -services of SmartCare.
- Timely and scientific information on self management, welfare benefits management, individual care plan development and management need to be made available.
- Behavioural change needs to be achieved - Reminders, Repetition, Understanding behaviour changes; Personalized behavioural changes.
- Social Interaction needs to be enabled with various stakeholders such as doctors, other professionals, carers, peers (for peer - to peer support) through electronic means (chat rooms, blog posts, social media), particularly relevant to younger patients.
- Easy to use monitoring devices need to be made available.
- User friendly software needs to be put in place.

Other requirements:

- Another critical requirement is that the process-wise transition towards the new integrated service model will be achieved as smoothly and seamlessly as ever possible, so that the functioning services will not be interrupted, but integrated with the new ones.
- The IT security plan needs to be concluded as soon as possible, and not later than November 2014. Also, permission needs to be granted by the Hellenic Data Protection Authority for using personal information of users in an electronic format, a process that might take up to 6 months after submission of the relevant dossier for evaluation.
- Particular emphasis needs to be put to the implementation of the Communication Plan as Greece is hosting the E.U. Presidency during the first 6 months of 2014 and everything needs to be in accordance with the Projects' objectives.

- Financial sustainability of the services after the pilot needs to be addressed right from the beginning.
- Policy Makers need to be convinced to reimburse the service if outcomes are good.
- Further roll out need to be planned at an early stage in order to cover many more users.

The above requirements were derived from a first focus group with Diabetes type II, over 50+, patients. It took place on the 3rd of July 2013, at the premises of the Municipality of Palaio Faliro (PALFALIRO):

- The focus group lasted for 45 min.
- A total of 12 participants were involved.
- The user groups were mixed. Both patients with a diagnosis of type II Diabetes (n=6) and health and social care professionals as well as industry representatives were involved (6).
- The recruitment criteria were the same as the ones described in documents.

Expected pilot service impacts on local / regional actors

| Type of actor | Positive impacts | Negative impacts |
|---------------|---|--|
| CR | Improved personal disease management and increased sense of empowerment towards the condition. Strengthening of social relations with fellow patients, a sense of caring in the local community, improved knowledge of oneself and abilities. | A lot of effort to abide by a strict regime to improve well being |
| I/FC | Lessen the burden of care, increased community support, acquiring new knowledge | A fuller everyday schedule with the new activities foreseen during the pilot service |
| SCP | Improved daily work's management, increased sense of personal achievement through the participation to a European funded programme, better understanding of chronic patients and their needs, acquiring experience on integrated care as an extra qualification for further improvement | Increased workload |
| HCP | Improved daily work's management, increased sense of personal achievement through the participation to a European funded programme, acquiring experience on integrated care as an extra qualification for further improvement, research activities potential through participation, acquiring a certain level of positive exposure in the local community | Increased workload |
| TSCP | Increase the level of awareness of diabetics and carers relative to the Pilot, helping with empowerment of CRs and carers | - |

Annex 8 - North Brabant

The current service landscape in the deployment region

Like in many other countries, in the Netherlands costs of long term care are ever increasing. The question how care delivery can be organised in a more efficient way has therefore been on the policy agenda for quite some time. In this context, the identification of needs for early and preventative interventions has received particular attention by key actors at the regional level. A strong body of evidence from scientific studies, including a meta-analysis, has for instance demonstrated the relation between physical capability, health status and mortality of older people^{6, 7, 8, 9, 10, 11}. Mapping risks for health deterioration and large scale screening are therefore considered to be of great importance.

Heart failure (decompensatio cordis) is a clinical syndrome that exists due to a reduced pump function of the heart. The heart muscle is permanently weakened and the peripheral organs do not get enough blood flow. As a consequence, the heart tries to compensate for this problem by working even harder. Common symptoms are shortness of breath (dyspnoea), fluid accumulation (oedema), pulmonary congestion and fatigue. In addition, emotional symptoms can be experienced such as anxiety and depression.

In Europe, the prevalence of heart failure is high among elderly: 0,4 to 2,0% (Nieminen et al., 2006). In the Netherlands, the Rotterdam cohort study showed that from 1997 until 1999, the average prevalence of heart failure was 7% for people above 55 years old. In addition, another study showed an increase in the prevalence percentage due to ageing (i.e., 1% prevalence: age 55-65 until 17,4% prevalence: age 85 and above) (Bluemink, Knetsch et al., 2004). The expectation is that heart failure prevalence will increase due to ageing and a life expectancy rise and will have an impact on the health care sector (Kempen et al., 2008). The prognosis of heart failure is that about 45% of the patients survive in an average of 5 years. There is 40% mortality or recurrent hospitalization for heart failure patients who are hospitalized within 1 year. In the Netherlands this leads to nearly 1% of the total health care costs. Besides the high prevalence and bad prognosis, studies have also shown that heart failure patients' health related quality of life is lower compared to healthy individuals (Ekman & Fagerberg, 2002).

⁶ Studenski S, Perera S, Patel K, Rosano C, Faulkner K, Inzitari M, Brach J, Chandler J, Cawthon P, Connor EB, Nevitt M, Visser M, Kritchevsky S, Badinelli S, Harris T, Newman AB, Cauley J, Ferrucci L, Guralnik J. Gait Speed and Survival in Older Adults. *JAMA*. 2011;305(1):50-58. doi:10.1001/jama.2010.1923

⁷ Cooper, R. Objectively measured physical capability levels and mortality: systematic review and meta-analysis. *BMJ* 2010; 341:c4467 doi: 10.1136/bmj.c4467

⁸ Penninx BW, Ferrucci L, Leveille SG, Rantanen T, Pahor M, Guralnik JM. Lower extremity performance in nondisabled older persons as a predictor of subsequent hospitalization. *J Gerontol A Biol Sci Med Sci*. 2000; 55:M691-7

⁹ Perera S, Mody SH, Woodman RC, Studenski SA. Meaningful change and responsiveness in common physical performance measures in older adults. *J Am Geriatr Soc*. 2006;54:743-749.

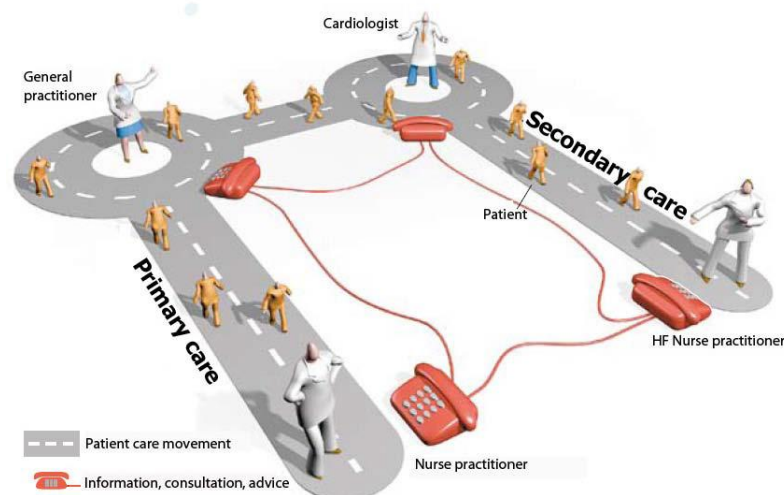
¹⁰ Guralnik JM, Simonsick EM, Ferrucci L, et al. A short physical performance battery assessing lower extremity function: association with self-reported disability and prediction of mortality and nursing home admission. *J Gerontol*. 1994;49:M85-M94.

¹¹ Guralnik JM, Ferrucci L, Simonsick EM, Salive ME, Wallace RB. Lower-extremity function in persons over the age of 70 years as a predictor of subsequent disability. *N Engl J Med*. 1995;332:556-561.

Cardiology research also has moved forward, and in the last thirty years new treatment methods and technologies (e.g., pacemaker, implantable cardioverter defibrillators [ICDs], and stents) have been used with the result better heart recovery. As a consequence there is also a decrease in systolic (i.e., the heart muscle has difficulty contracting) heart failure. In contrast, the last few years has been discovered that diastolic (i.e., the heart muscle has difficulty relaxing) heart failure has increased significantly due to hypertension and overweight. Systolic and diastolic heart failure can differ in medication treatment, but the instructions and life-style rules are mainly identical. There has been considerable progress in the management of systolic heart failure, yet, the management of diastolic heart failure remains difficult due to limited trial data (Chatterjee & Massie, 2007¹²; Zile & Gaasch, 2013¹³).

Treating patients with heart failure is complex and therefore there are specialized heart failure departments at some hospitals. The specialized departments include one or more HFNs and cardiologists. Stakeholder analysis has shown that HFNs have a dominant role in preventing exacerbations and hospitalization for heart failure patients, because otherwise the prognosis will get worse. A process analysis has shown that methods used for preventing exacerbations are medications, living according to specific life-style rules, health examinations, educating self-management so patients can recognise signs and symptoms of heart failure and are able to intervene on time. Home monitoring systems can support this process by extending the information, health examinations and instructions outside consultations in the hospital and providing them inside the home.

In the Netherlands, there are two possible treatment phases: a just diagnosed heart failure patient is treated in a specialized heart failure (or cardiology) department at the hospital (secondary care). When the heart failure patient is stabilized or immobile the general practitioner takes over the treatment with help of HFNs (primary care). The 'quattromodel' gives a clear overview which stakeholders are involved in primary and secondary heart failure care.



In the Netherlands, the general practitioner (GP) is part of primary care. Primary care means that care is close to home, so also the first contact of a person when having health problems and/or questions. The GP's working hours are from 8.00 until 17.00. Regional GP's have worked together to form General Practitioner Centres (in Dutch: huisartsenposten) for emergency care during evenings, nights and in weekends. In

¹² <http://www.phys.mcw.edu/documents/paper9diastolicandsystolicheartfailure.pdf>

¹³ <http://www.uptodate.com/contents/treatment-and-prognosis-of-diastolic-heart-failure>

addition, the primary HFNs are employed by GP's or a group of GP's for dedicated support for patients with chronic illnesses. The main tasks of a GP are:

- Being the contact point when there are problems with the health of patients.
- Keeping an overview of the total situation of the patient. The strength of the GP is his broad health knowledge and his in-depth patient knowledge (i.e., the family members, the environment, the social situation, medical background, other doctors and caregivers and more). Most of the time, the GP knows the patient for many years. Looking at all the problems the GP has to handle, 90% is done by himself, and the other 10% of patients is referred to another doctor or specialist.

A cardiology department is in most hospitals divided into several specialized sections based on heart problems, such as heart failure. Treatment in this specialized heart failure department is only via referral. The main stakeholders involved are the cardiologist and the heart failure nurse (HFN).

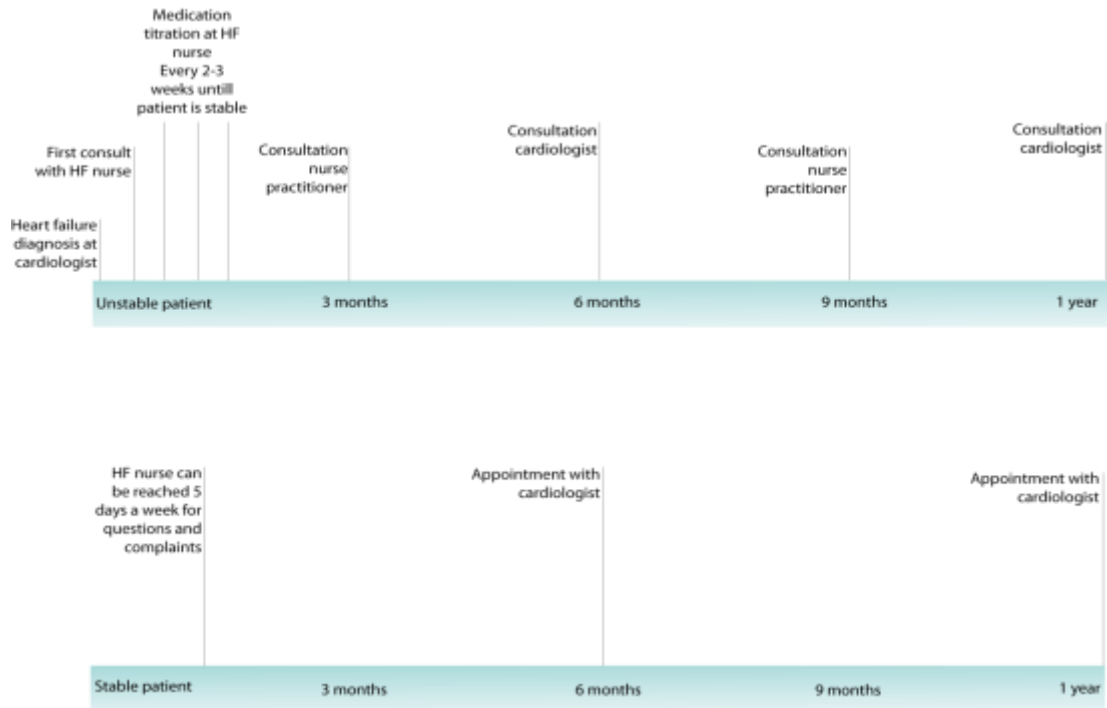
A cardiologist is specialized in all the different heart diseases. The HFN takes over most of the routine consultations and practices to take away the work pressure of a cardiologist. The cardiologist and HFN therefore work closely together in the hospital. The main tasks of a cardiologist are:

- Searching for the cause of the patients symptoms and complaints based on examinations.
- Diagnosing the heart disease (in this case heart failure).
- Treating the heart disease (surgery, medication).

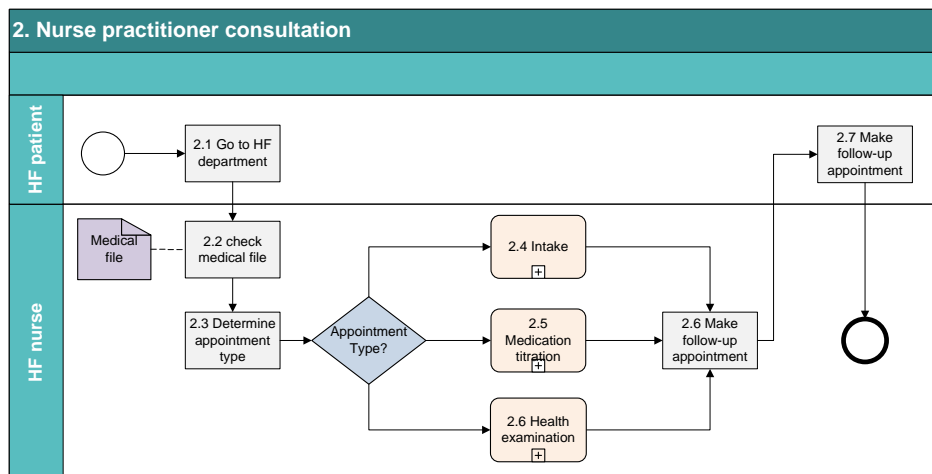
HFN are advanced practice registered nurses who have completed additional training beyond that of registered nurses. The authority of the heart failure nurse depends on the type of education and trainings. However, in general they have the authority to do certain health examinations and make medical decisions based on the treatment plan developed by the cardiologist. The routine consultations are done by the HFN to support the cardiologists. The HFN is also a preferred go-between the GP and the cardiologist. She can directly inform the GP and discuss whether the patient can stay at home or should be referred (back) to the cardiologist.

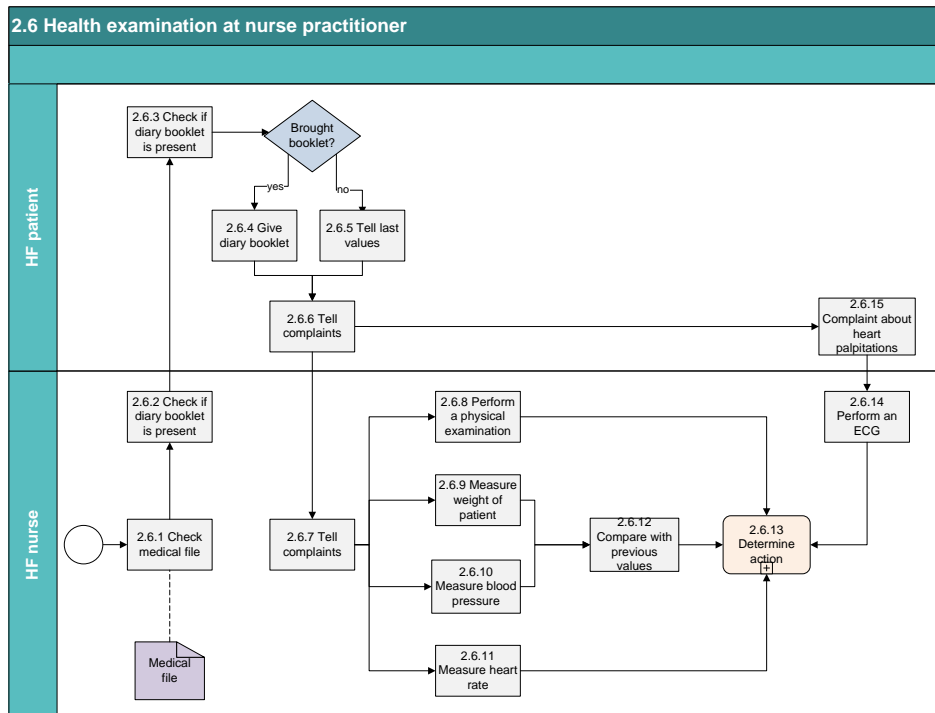
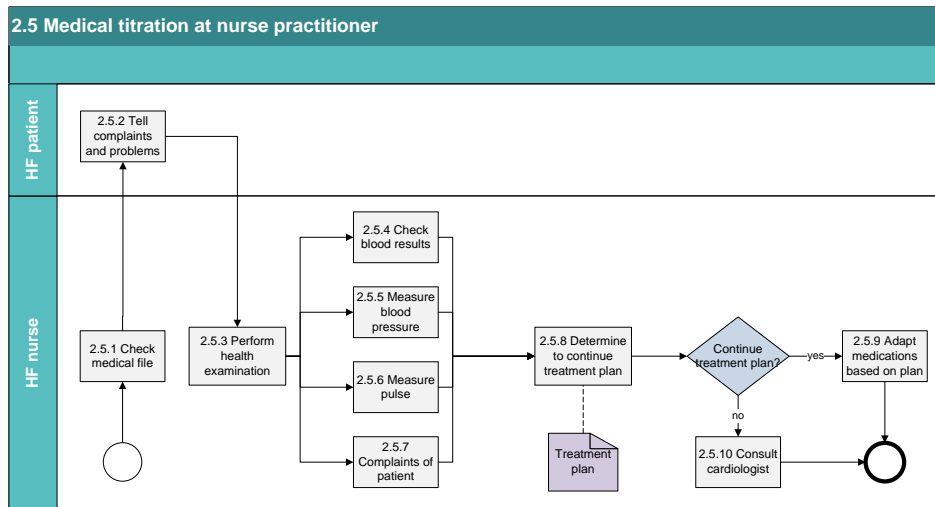
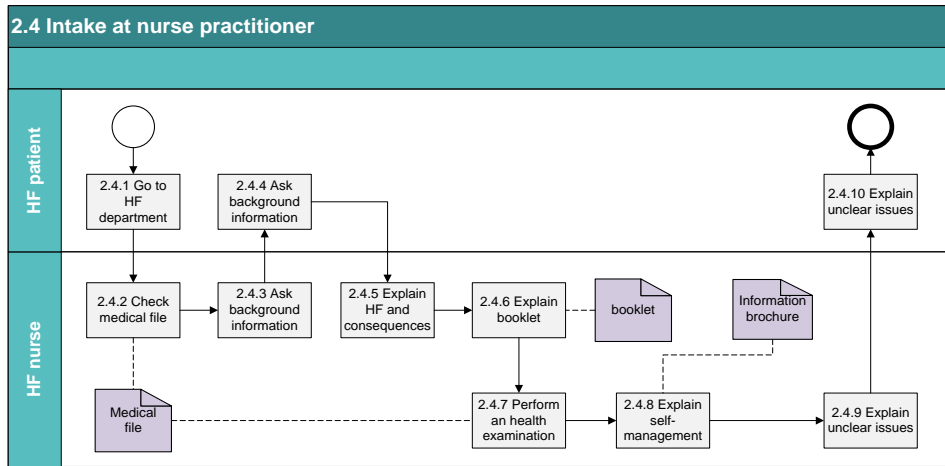
Figures below show an overview of the heart failure care process visualized in a timeline of 1 year. The timeline starts at the moment the patient is diagnosed with heart failure. There is no golden standard for diagnosing heart failure. With help of different examinations (i.e., ECG, blood examination [BNP value], echocardiography and more), the cardiologist has increased diagnostic certainty to diagnose heart failure. After diagnosis, the cardiologist develops a treatment plan, which is important for the HFN to take over the follow-up routine consultations. The follow-up routine starts with an intake and every 2-3 weeks medication titration consultations. Every 3-6 months the patient goes to the HFN for a health examination. As can be seen, the patients health status (i.e., stable or unstable) determines the frequency of consultations and treatments. The reality, however, is often somewhat different: after 3 months intensive treatment by the cardiologist the patient is referred to the GP. Since there is no concrete follow-up plan, patient's health condition is hardly monitored till the next cardiologist visit one year later.

While risk varies with age and gender, most of the common chronic diseases are caused by dietary, lifestyle and metabolic risk factors that are also responsible for the resulting mortality. Therefore these conditions might be prevented by behavioural changes, such as quitting smoking, adopting a healthy diet, and increasing physical activity.



To get back to the processes; there are different HFN consultations; an intake, consultation for medication titration, and health examinations. The actions in the intake and health examinations have overlap. The intake consultation is different, because it is the first time the HFN meets the heart failure patient. Therefore, more time is spent to explain heart failure, self-management (e.g., booklet with information) and conduct health examinations. In the health examination consultation, this information is repeated but more specific to the needs of the patient, and health examinations are compared to previous values. The consultations about medication titration start after the diagnosis and are very frequent (i.e. every 2-3 weeks) until the patient is stable.





The main task is to prevent patients to exacerbate (i.e. become unstable) and to end up in the hospital more than necessary. The most common symptom is increasing dyspnoea mostly because of fluid retention (edema). The following methods are used by the HFN to prevent that the heart failure patient exacerbates:

- **Coaching and instructing self-management:** this includes understanding everything about heart failure and the symptoms, receiving a booklet with information and a weight diary, recognize signs of instability.
- **Life style rules:** a certain sets of rules can be adapted to prevent exacerbations. For example, reduce salt intake and fluid intake, stop smoking and more.
- **Medication titration.** This means that the cardiologist will start with an initial low dose of stimulant and carefully adjust the dose upwards to adequate levels. Titration helps the body adapt to the medication; it can reduce common side effects and helps the doctor find the optimal dose to improve daily functioning. This is a very unstable period for the patient, which means that the patient needs close monitoring to check how the body reacts based on physical and health examinations. Today, the medication titration consultations are every 2-3 weeks until the patient is stable. These consultations also include medication education: understanding the function of the medications, the side-effects and short-term/long-term effects and consequences.
- **Health examinations:** every few months the HFN checks the patient's health by measurements, but also to auditory and visual information from the patient. Auditory information can give information about complaints, but with visual information the HFN can see if a patient is for example very tired.
- Being **accessible** when a patient has problems and/or questions. The HFN has a phone consultation for these situations, but many patients prefer to approach their general practitioner (especially elderly) or just to wait until the problem is over (which may lead to hospitalization) or for the next consultation. The general practitioners cannot adapt the medications themselves and therefore need to call the heart failure department in case of medication doubt.

There is a necessity for all heart failure patients to do proper and adequate self-management. Instructions and methods are repeated at every HFN consultation and transferred to the home by giving brochures and booklets. In addition, the heart failure patient receives a lot of information in a short time. The role of a remote care system can support the patient in having access to heart failure information at home and checking several parameters (i.e., weight, blood pressure, and heart rate) to provide the HFN and cardiologist with extra health status information. This could reduce exacerbations and lead to a more flexible appointment policy.

In the Netherlands the interest for eHealth is increasing to realize care delivery with higher levels of quality and efficiency. There is a steady increase in the availability of telemonitoring in heart failure care and the SmartCare pilot participant in Tilburg, The Netherlands (Tweesteden Hospital) is in a preparation phase of including telemonitoring in their heart failure care process¹⁴.

Open Data for Health (OD4H) in Eindhoven

The current Eindhoven situation for ICT deployment is the following: In an area of approximately 400.000 inhabitants, there are 4 hospitals, each with their local hospital information system and each with their own (configuration of) electronic health record. There is electronic data exchange with general practitioner information systems. There is also a regional platform, the Regional Care Communication Centre (RZCC), which tries to bridge the communication of data between all stakeholders in the region. Furthermore, various organizations are involved in apps development for cardiac patients. Then there is the creation and further development of the Open Data for Health (OD4H) security, infra-

¹⁴ http://www.hartenvaatgroep.nl/uploads/media/Samenvatting_enquete_telemonitoring.pdf

and infostructure. This will enable reuse functions of various data, mostly local or regional.

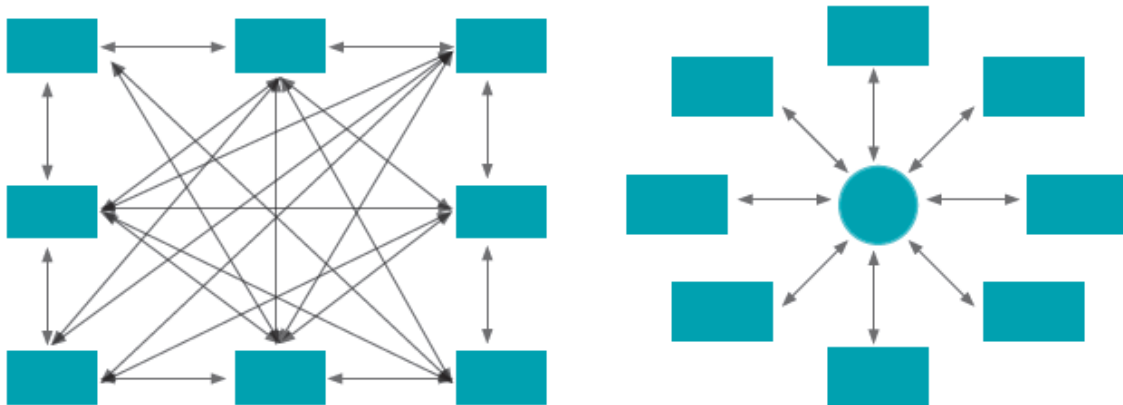
For integrated home support - for long term care or after hospital discharge - the current situation in the Eindhoven region is roughly as follows. There are variants due to the size of the four hospitals, and different EHR systems, or different implementations and configurations of similar EHR systems. Admission data are entered in all four hospital EHR systems. Admission into a hospital in the Netherlands, legally assumes consent for record keeping for internal functions. Since the failure of the national EHR data exchange system, the remaining facilities for electronic data exchange require explicit opt in consent of each individual patient. This is kept at the care facility, e.g. the hospital, the GP office, the pharmacy, the home care organisation and so on. Assessment data are usually collected into the EHR. Meaning that some assessment data e.g. from diagnostic systems are entered manually into the EHR. Most EHRs will have some kind of care plan; however, this might be a simple to-do list. Care coordination is done mostly by the transfer nurse who interacts with the CIS organisation that checks eligibility for specific care in nursing home or home care. Care coordination is usually sought with the home support organization of patient's choice. Transfer nurse and home care / nursing home nurse either get some kind of hand over documentation, which is received either via snail mail, or the patient brings it with her/him at discharge. In case of questions or specific treatment and care options, there will be a phone call. The region is experimenting with the e-transfer, which is the nursing discharge document, using Health Level 7 version 3 Clinical Document Architecture, together with an agreed basic data set for care. Interventions are usually based on institution specific guidelines that come from a professional organization. There is a tendency to create national care standards covering all aspects of care and following the integrated approach. These are in progress for cardiology and due to national legislation will likely tend to be superimposed above the SmartCare approach. However, since the SmartCare project describes the processes at a rather generic level, it can be foreseen that both materials are easily harmonized when implemented in ICT. They will probably lead to some combined overview of interventions and services, which currently is not integrated. Re-admission data are kept both in the hospital and the GP EHR systems. Review and re-assessment info is kept mostly in the same systems described here, but for some situations this might still be done on paper. Discharge and referral info are kept in all EHR systems.

SmartCare will further build upon different aspects of ICT which is currently available / under development to support the workflow across the pathway of patients with various heart conditions. That is divided into the situation as of the end of 2013 in hospitals, rehabilitation, general practice and home care and the current development of the Open Data 4 Health (OD4H) infrastructure that will be available at the start of the deployment. OD4H is an ecosystem for exchanging patient data and multidisciplinary discussions among care professionals. The infrastructure is realized, and ready to be configured for specific patient groups or use cases. The ecosystem interconnects patients with care professionals. The patient plays an active and prominent role and stays in control over the personal data. Finally, it will capture some elements of ICT development that will be different or enhanced through the implementation of the SmartCare pathways and resultant changes in workflow.

In this ICT infrastructure and infostructure the SmartCare care pathways will be introduced and deployed in terms of cardio care. In this use case the patient will be linked with care professionals being the general practitioner and the cardiologist. Within the SmartCare project also social care providers and informal carers will take part in the integrated approach.

The ICT infrastructure, currently mainly healthcare oriented, will grow towards an open platform that combines formal and informal healthcare, social care, informal care and

self-care. The aim is an open service platform offering interactive apps for care and self-management, for e-inclusion, social participation and entertainment.



The ICT situation in the Eindhoven region, for both hospitals and home care organizations, is best characterized by the point to point connection approach of hundreds of silo applications: the “ist” situation on the left of this figure. The hospitals are moving to some integrated electronic health records, however still face various departmental, functional and diagnostic applications that need to be connected. In home care and nursing homes, there is a tendency to move away from the administrative and financial systems towards more client record oriented systems. However, it is a well known problem that they lack any form of semantic interoperability and workflow support. Both characteristics of electronic health record systems that must be available for the integrated pathways. The “soll” situation is depicted in the right figure. It represents the OD4H infrastructure, infostructure and end-2-end Trust Assurance.

From mid 2013 on, the Eindhoven medical care and social care organisations have engaged in the Open Data for Health (OD4H) project. Partners are the two main hospitals, rehabilitation centres, general practitioners, pharmacist, home care organisations and companies such as Synergetics Benelux BV). Early 2014, the existing ICT environments in the various stakeholders have been further analyzed. The outcome parameters for integrated care pathways are being determined in spring 2014. This will further be followed by definition of the ICT environment for the SmartCare pathway deployments in 2015.

The goals for the ICT environment are further broken down into three layers: the information and recording systems, the ICT infrastructure and the information communication and sharing mechanisms. The most important goal for the project however is to use a pragmatic interoperability approach. The integrated pathways shall facilitate the patient, his/her informal carers and the professionals to offer the best possible care. Hence, workflow and pathway support is crucial. However, the pathway without the relevant personal and clinical content is useless. To achieve the pragmatic interoperability and do what is right, the data that are used mutually must be well understood. Hence, the fundamental content for the integrated pathways must be semantic interoperable data. For this, in the Eindhoven region the SmartCare project will follow up with so called Detailed Clinical Models (ISO 13972: 2014).

North Brabant towards SmartCare

The region has some advantages for the SmartCare deployment of pathways. There have been earlier projects, which can be reused to a large extent, and there are ongoing projects, in particular OD4H, which offers the perfect infrastructure for SmartCare. Both will be briefly summarized below.

Earlier, the Eindhoven region has carried out the project Digitaal begrepen (Digitally Understood, DB) . DB created Health Level 7 messages for process optimization and data exchange between the care offices of municipalities and home care / nursing home organisations. The blueprint material has been piloted successfully and was available to projects, but no follow up was possible at the time of finalization. The data specification for exchange is based on semantics for health and care infrastructure and is therefore based on a format which meets 95% of the Detailed Clinical Models approach.

The current ongoing OD4H project aims to implement the developed ICT ecosystem. This will facilitate the regional data exchange between medical care and social care professionals, care recipients and their informal carers. The ecosystem consists of a privacy by design end-2-end Trust Assurance, an ICT infrastructure that facilitates the data exchange between many applications and smartphone apps; and a system for data exchange based on semantics for health professionals, in particular the Detailed Clinical Models. Furthermore, it will facilitate various formats of analytics, which will help to identify and specify those data elements which will assist in determining the differences between the current situation for the use case and the situation after the SmartCare pathways have been introduced and deployed.

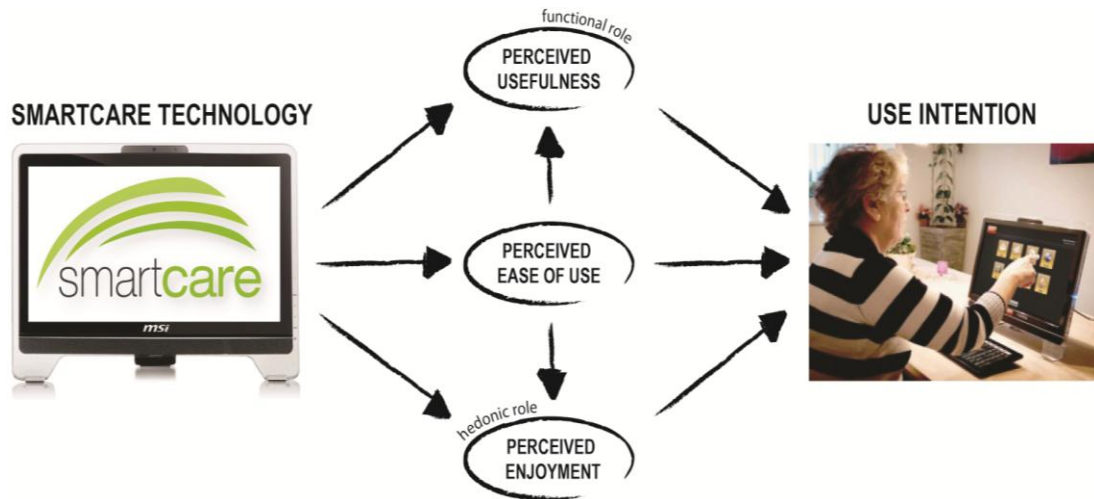
Key implementation requirements identified in the deployment region

End user requirements

Based on previous projects in the field of integrated eCare, eHealth and Independent living, we have gathered many insights and viewpoints to develop an extensive list of end user requirements, related to perceived usefulness, ease of use, ethics, age-related changes and/or heart-failure specific issues, and acceptance.

Telehealth and telecare technologies can assure the basic support for daily activities, detect health critical situations, and stimulate social and psychological engagement that fosters the emotional wellbeing enhancing dignity and quality of life. Although technology has great potential, older people and chronic patients often categorise it as meaningful when associated to the activities and needs of other groups, but superfluous and useless for themselves. Studies conducted on the usage of IT technologies, demonstrate how the reluctance of adopting communication technologies is not only due to a lack of skills but, above all, to the absence of perceived advantages and benefits. Everybody likes to grow old, but nobody likes to be old. People are not willing to admit that they are ill. Therefore, people in general are reluctant in accepting solutions that reveal their dependency. Thus, it is of immense importance to convince the end-users that taking part in SmartCare is beneficial for them. The first step towards the use of telehealth and telecare, is the perception of needing some assistance. Only when confronted with this feeling of needing help, they will be motivated to approach technologies that are able to answer their specific needs.

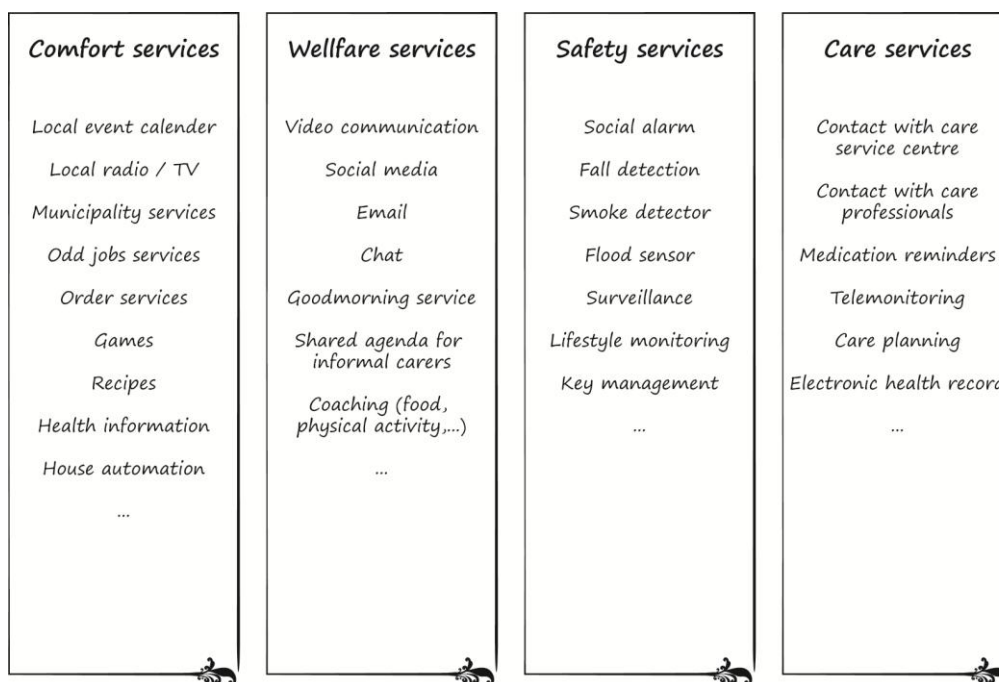
Both the system itself and the offered services are developed in the light of the needs and wishes of the target population. If the system indeed does grant the patients' wishes in a less effort or less money consuming way, they will experience a feeling of perceived usefulness. In order to realize a use intention, this usefulness perception should be combined with both enjoyment and perceived ease of use. Since (older) patients are often shivery in accepting and using new technologies, an attractive and user-friendly interface is indispensable. The end-user interface should lower the threshold to start using new technologies, by making it easy, familiar, and enjoyable. Therefore - besides the requirement to fit disease-specific needs - it is important to take into consideration more general age-related changes in perceptual, motor and cognitive abilities to guarantee the required accessibility.



The system should not only grant the users' wishes, but should also do this in a less effort or less money consuming way in comparison with standard solutions. In this way the users will experience a feeling of perceived usefulness. In order to realize a use intention, this usefulness perception should be combined with both enjoyment and perceived ease of use. Enjoyment refers to the extent to which the activity of using the system is perceived to be enjoyable in its own right, apart from any performance consequences that may be anticipated. Perceived ease of use is related to the impression of how much effort is needed to learn and use the system. Here, factors like system quality, coherence, familiarity, complexity and support come into play.

Besides quality and usability requirements, the key requirements have to do with perceived usefulness. By offering the right set of services, people will be convinced that SmartCare is not only useful for their health situation, but that it will also positively impact their independency and their social and emotional quality of life. Therefore, these kind of services are important:

- **Comfort services:** services for practical maintenance and housekeeping, not specifically targeted at people in need of care. These are the typical services that make a platform attractive, and empowers people to do things themselves and to participate actively in society.
- **Welfare services:** services that contribute to the physical and mental wellbeing of people. This category of services is about improving either the physical condition (e.g. nutrition or sports coaching) or the mental state (e.g. making social contacts).
- **Safety services:** services to increase the level of perceived safety, like the possibility to automatically or manually contact someone in case of emergency (fall, burglary...).
- **Care services:** all services related to medical treatment or increasing the level of self- management, like telemonitoring.



Whereas some services (video communication, social alarm and games) will target an older population in general, others (telemonitoring, care planning and medication reminders) will focus on chronic disease management. Besides tele-consults with the case manager, also video services and self-training modules will be developed for physiotherapy, psychological support and dietary coaching.

Focus groups will better help to identify, clarify and integrate specific needs from cardiac patients arising from the implementation of the SmartCare platform.

Organisational, staff and business related requirements

Healthcare and social care services are still often delivered independently. The Dutch healthcare system is based on the Bismarck model. Care is not provided nor financed by the government, but it uses an insurance system and many independent private sector providers. The lack of a centrally organised healthcare system has resulted in a fragmented care market, and in the development of different systems for health and social care, that are not interoperable. In the fragmented Dutch care market, many initiatives exist next to each other, and the care organisations only look from their own narrow perspective. In the North-Brabant region various initiatives in the care sector have come to a success, focussing on EHR’s, telemonitoring, independent living... Despite the success of various independent projects, there seems to be problems with integration, scalability and interoperability: Due to the current manner of how healthcare is organised in the Netherlands, the Dutch care sector lacks ownership, costs and benefits do not belong to the same chain partners, and the financing models do not reflect the current way of paying for care. Therefore, it is difficult to increase the care efficiency by innovative ICT solutions.

As learned from central care management in the UK, we can learn that in such a setting rigorous care innovations with eHealth are possible. Integrated care could offer a lot of added value for patients, care professionals and service providers. By involving all chain partners, and starting from the overall care picture, blockades from individual stakeholders are raised. Therefore, it is important to follow the example of the UK, and focus on a more centrally organized and integrated care delivery. Within the SmartCare project independent social and health care providers will join forces, to establish integrated care pathways for arthrosis patients. By including health insurance companies in

the SmartCare project, and adapting the financial models for care delivery, also cost-benefit shifts can be resolved.

The integration of SmartCare in North-Brabant will benefit from the realisations of earlier projects on integrated care and eHealth in the region, supporting social care, telemonitoring and video-based physical exercise programs. The combination and integration of an ICT-system for patient management and the patient portal MiBida, an open service platform for communication and secure information exchange, offers a wide variety of new opportunities for integrated care and self management, including screen-to-screen communication, data exchange, and information provision.

From the guidelines for integrated care service delivery, developed by Smart Homes in the Independent project, we can extract requirements with regards to organisational, staff and business issues.

- Since staff members are the ambassadors for integrated eCare, it is important that they are convinced themselves about the benefits of sharing information and working together. Involving care professionals as experts in their field increases their motivation and willingness to participate. Additionally, they are interested in ways to increase care quality, patient satisfaction and workload reduction.
- In order to realize SmartCare acceptance by staff, it is of great importance to seamlessly integrate innovations in existing infrastructure and procedures.
- Motivated staff members that face restrictions on a technical, organisational and legal level, could break barriers on a higher level to align organisational, technical and regulatory aspects needed for optimal cooperation between disciplines.
- From a business point of view, real integration into current practice - and not as an experiment on the side - makes it easier to continue the service after the project has ended. Only then, it is possible to attune care processes to the new way of working.

Legal / regulatory / contractual requirements

The first phase of the SmartCare project will include an investigation of legislation and regulation, both on European, national and regional governance levels, which is likely to have a bearing on the design and implementation of the SmartCare pathway in the Noord-Brabant pilot.

In view of the immature nature of the integrated care domain as a self-standing field, it may not come as a surprise that no dedicated legal and regulatory framework has emerged in this domain as of today. Nevertheless, a number of policy/regulatory fields have relevance for ICT-enabled services directed towards the health, well being and independent living of older people in general. Together they provide a rather dispersed and patchy frame of reference for legal and regulatory guidance of the various actors involved, in particular when it comes to developing services that cut across existing domain boundaries such as social care and medical care. Based on previous experience in similar projects, the list below is developed as a starting point for possible legal and regulatory requirements. During the SmartCare pathway development and implementation, the list will be refined accordingly.

- Data protection, data privacy and EHR
 - EU: Directive 95/46/EC: protection of individuals with regards to processing and free movement of personal data.
 - EU: Directive 2002/58/EC: processing of personal data and the protection of privacy in the electronic communications sector.
 - EU: Directive 2011/24/EU: patients' rights in cross-border healthcare.

- NL: Law on protection of personal data (WBP - Wet Bescherming Persoonsgegevens).
- NL: Legislation on the use of the Citizen Service Number (BSN) in healthcare.
- NL: Medical Treatment Act (WGBO - Wet Behandelingsovereenkomst).
- In the Netherlands, the current situation about legislation on EHRs (EPD-wetgeving) is vague and unstable. Different bills and law amendments are currently discussed.
- Liability
 - EU: Directive 2000/31/EC: e-commerce.
 - EU: Directive 85/374/EEC: product liability.
 - EU: Directive 93/42/EEC: medical devices.
 - EU: Directive 98/79/EC: in vitro devices.
- Licensing and quality control
 - EU: Directive 2005/36/EC: recognition of professional qualifications.
 - NL: Law Occupations in Individual Healthcare (BIG - wet Beroepen in de Individuele Gezondheidszorg).
 - NL: Quality on Healthcare institutions act (Kwaliteitswet zorginstellingen).
 - NL: Medical Treatment act (wet Geneeskundige Behandeloovereenkomst).
- Patient rights
 - EU: the European Charter of Fundamental Human Rights.
 - EU: the European Convention on Human Rights and Biomedicine.
 - EU: Directive 2011/24/EU: patients' rights in cross-border healthcare.
- Ethics approval
 - EU: Directive 2001/20/EC: clinical trials.
 - NL: Medical Research Involving Human Subjects act (WMO - Wet Maatschappelijke Ondersteuning).

In cross-border use cases of integrated care, health data storage in an EHR and patient data exchange, the additional issue of legal interoperability arises. Different countries may have diverging legal requirements for the content or usage of electronic health records, which can require radical changes of the technical makeup of care pathways and EHR implementation in question. (in particular, when fundamental legal incompatibilities are involved) Exploring these issues is therefore often necessary when implementing cross-border solutions. To fulfil all legal and regulatory requirements a well thought plan have to be designed including electronic identification and authentication procedures for patients and carers, roll-based access categories, and data security measures like encryption.

Technology / functionality related requirements

In the fragmented Dutch care market, many systems exist next to each other, and the care organisations only look from their own narrow perspective.

So far, Dutch health insurance companies have invested money in various small scale pilot projects on ICT-supported care. Since all stakeholders in chain care are now confronted with the limitations of systems that are not interoperable, the focus is slowly shifting towards large scale integrated eCare and interoperable systems.

For the SmartCare pilot in North Brabant, interoperable systems with open communication protocols will be used to offer integrated care services to cardiac patients.

Any other requirements

Ethics

Because in the SmartCare project at this site, a randomized controlled trial will be performed (RCT-design), the project will be subject to the standard procedure of approval by an EU-certified Medical Ethical Review Board (METC). This procedure takes normally 3 months.

Besides legal issues with respect to ethics, also non-legal issues have to be taken into account. Namely:

- Should the patient pass away, protocol to shut down platform access should be drafted.
- Should the evaluation phase end or the project, then there should be an exit strategy ready, also to provide care recipients the possibility to buy/rent the equipment apart from project dependencies.
- Timing of access to lab data on the platform should be carefully assessed so as to allow sensitive information to be appropriately delivered to the patient/caregiver by the healthcare provider.

The sharing of patient information between health care organizations and IT systems is changing from a "point to point" model to a "many to many" one. The European Commission is supporting moves to facilitate cross-border interoperability of e-health systems and to remove potential legal hurdles, as in the project www.epsos.eu/. The biggest challenges will relate to interoperability and legal clarity.

Expected pilot service impacts on local / regional actors

| Type of actor | Positive impacts | Negative impacts |
|---------------|--|---|
| CR | <p>Thanks to the care coordinator, the care recipient has only 1 point of access for both health and welfare-related issues. In this way, care recipients feel more confident to contact the care coordinator, rather than having to figure out which care professional is responsible for what.</p> <p>Communication among professionals and organisations, improves the level of care quality and efficiency. Besides benefits for the professional sector, this also decreases the chance for double or adverse treatments, improving the patients' quality of life.</p> <p>Through the portal of the SmartCare ICT platform (OD4H) care recipients perform telemonitoring tasks themselves and they have access to their EHR in a user-friendly manner. For the care recipient, this leads to a higher level of involvement and better insight in their health condition. Through the care recipients portal they also have access to a wide variety of other services to enhance their independency, their level of physical activity and social inclusion.</p> | <p>Due to the greying society, care recipients are forced to take more responsibility themselves. Instead of being a passive care consumer, care recipients have to take a more active role. Since they are empowered to do things themselves, face-to-face contact with carers will be reduced.</p> <p>Although new technologies can offer many opportunities, older people have to learn how to cope with it.</p> |

| Type of actor | Positive impacts | Negative impacts |
|---------------|---|---|
| I/FC | <p>Via the SmartCare platform informal carers have a better view on the situation of the care recipient. Via telemonitoring and alarm functionality the informal carer can feel more at ease, because professional carers keep an eye on their beloved ones. Via the ICT platform, also informal carers can have extra support.</p> <p>Thanks to the portal the care recipient is empowered to do many things themselves, reducing the need for informal care. This could lead to more quality time. Also when the informal carer lives far away, or has only little time, videocall functionality enables the informal carer to stay in touch frequently.</p> | <p>Due to the greying society, more tasks and responsibility will be allocated to informal carers. In the beginning, some extra time and effort from the informal carer could be needed to help the care recipient to get used to the platform. But the extra functionalities would definitely counterbalance the investment.</p> |
| SCP | <p>Thanks to the SmartCare ICT platform - and in particular to the portal for care recipients - various social services can be delivered online. In this way social care providers can save on time and travel expenditures.</p> <p>Since communication between health care and social care professionals is improved, social carers are informed when a care recipient is suffering from health-related issues.</p> <p>The platform empowers care recipients to form small communities, and to be social and physical active. Consequently, social care providers might offer social care to groups in district houses, increasing efficiency. More time is left to support people who need it most.</p> | <p>Due to people becoming more active and self-supportive, care recipients need less formal social care services, meaning less work for the social care provider.</p> |
| HCP | <p>Via telemonitoring services, healthcare professionals have more and accurate vital signs data. This enables them to react properly on (and maybe even avoid) exacerbations and admissions to the hospital.</p> <p>Because of the continuous vital signs monitoring, health care professionals can decide whether care recipients need a face-to-face check-up or a tele-consult is sufficient. This way, the professional carer can use his time more efficiently.</p> <p>Since communication between health care, social care and informal care is improved, health carers are informed about social circumstances that could affect a patient's health status.</p> | <p>Since not all care recipients need a regular check-up, the care professional will have fewer patients.</p> |
| TSCP | n.a. | n.a. |



| Type of actor | Positive impacts | Negative impacts |
|---------------|--|--|
| Other | <p>Technology providers: In integrated care, formal healthcare professionals, social workers, informal carers and volunteers work together to realize joined-up service delivery for a wide variety of care recipients. Providing the technology for offering integrated care is a way to collaborate with all parties involved in chain care. These contacts could improve a company’s market share.</p> <p>Health insurance companies: Since the collaboration between carers is improved, background information, medical data and treatment plans are exchanged; efficiency and quality of care will increase.</p> | <p>In order to be able to cooperate with a wide variety of parties, it is important for technology to be interoperable. So, it is important to work with open protocols.</p> |

Annex 9 - Kraljevo Serbia

The current service landscape in the deployment region

Kraljevo is a municipality located 180 km from the capital city of Serbia. It is one of the cities which the old and the majority of the population is between the age of 50-59 years, it their 10.585 inhabitants. Also large population occurs at the following age ranges from 60 to 64 years (8.673 inhabitants), from 65 to 69 years (5.837 inhabitants) and with over 70 is around 17.000 inhabitants. That city going old is the fact that the average age is 42.3 years, the number of pensioners in the city is 22,689.

In Kraljevo city the basic unit of social protection is Centre for Social Work, established in 1960, and the Gerontology Centre to accommodate elderly. Within the Health Centre Studenica, PHC operates as a separate organizational unit for Home care. As a part of the Health Centre, operates Emergency Services as well as all the hospital wards and the admissions department for admission of patients to hospital. All these services are connected and share information in writing. In the general medicine there are 26 ambulances with 54 teams in the municipality, which is considered a significant resource in the implementation of this program.

According to the data available to the Centre for Social Work, in 2012 services of the social security system is used by 1.865 persons of older population, out of them 1072 were from the urban areas. Looking at the structures of clients, and their household, majority of them are elderly households (1567), singles (145 persons) and 151 persons are chronically ill.

As for social vulnerable elderly clients, 830 persons received some kind of financial aid in 2012. During this year, 32 elderly clients received foster accommodation, and 185 were accommodated in social protection institutions. 578 elderly clients were entitled to receive social care and support services, of which 279 had a degree of physical disability of more than 70%.

According to data of PHC (Primary Health Care Information system) the Home care service currently provides for 1750 chronically ill persons. Home care services are also provided by five remote peripheral ambulances which enables accessibility to the patients in remote areas of the city of Kraljevo.

Bearing in mind the population and territorial characteristics, the Centre for social work Kraljevo (SCP) together with local self-government is keen to promote active care and to provide elderly clients longer stay in their homes and extend independent life.

Thus, services for elder clients were developed on the local level: Help in home service (30 users), Social housing with supportive condition (35 users), a Day care centre for elderly citizens (160 users). During 2012 there were 8 elderly persons in high risk condition and it was necessary to respond with urgent intervention/separation and emergency accommodation. For that purpose on city level there is an urgent accommodation facility in a Gerontology centre and urgent accommodation in foster families is available.

Currently no electronic communication channels exist that would connect:

- the Studenica Health Centre Studenica (HCP) and the Centre for social work Kraljevo (SCP).
- Primary health care department/GP information system (PHC) and the module for admission/discharge inside the Health information system.

- Care Recipient (CR) and/or I/FC (Informal/Family Carer) and SCP/HCP information systems.

An example of the current negative consequences of this lack of communication when providing health/social care is:

- Unnecessary home visits from HCP or SCP due to non-existence of information exchange between the two institutions. This disturbs the planned work of institutions, waste resources and started a procedure of finding CR.
- Unnecessary home visits from SCP not knowing that CR is hospitalised.
- Not timely or delayed alert for SCP when the patient (CR) is discharged from hospital. This causes an extended number of bed days in the hospital and social care services are not ready to plan and provide best care.

Given the national strategy on aging, as well as the national strategy for the development of social and health care and the local strategic plan for social policy of Kraljevo for the next seven years, the SmartCare model is a challenge and opportunity to provide even more users to extend independent life. The wider deployment of ICT is considered beneficial in order to reduce the effects of the above poor practice allowing efficient operation HCP and SCP and therefore better care for CR. In the project, we attach great importance not only to appeal to local authorities, but to the ability to provide older people with a much broader range of services in the field of social and health care through a coordinated approach to the two systems, which can provide integrated care in an optimal and sustainable manner, ultimately leading to improved quality of life for the elderly.

Key implementation requirements identified in the deployment region

End user requirements:

- The majority of the envisaged users will most likely be unable to use advanced technology without any help or advice. Targeted capacity building measures need to be carefully planned and conducted against this background.

Organisational, staff and business related requirements:

- Adaptation of current workflow will be required, mainly targeted towards healthcare providers and social care providers in using integrated data of the CR and creating an integrated care plan.
- This task will require careful training of all actors (social, health, informal carer and care recipient), with a view to enabling them to effectively exchange information, data, reminders, alerts and using ICT solutions more generally.

Legal/ regulatory / contractual requirements:

- In particular the integrated database needs to be designed in a way that should be designed, to define what set of data are legally available to exchange.

Technology / functionality related requirements:

- Secure connection for exchange of data between HC and SC will need to be established.
- Existing solutions already in operation at the part of the health care provider organisations, i.e. a web based solution, will need to be adopted for Social Care Professionals in receiving/viewing selected data.

- A call centre does not exist in both Institution and that is a chance to implement integrated call centre and Message Dispatch System for alarm, alerts, reminders, notifications.
- At the part of the social care provider organisations, some legacy system are in place as well (database and social care record of clients) and these will need to be integrated into the SmartCare solution as well.
- Access to the integrated infrastructure will need to be enabled by desktop devices (e.g. PCs located in an office environment) and mobile devices (e.g. mobile phones) used by health and social care staff and for some remote delivery of care.

Expected pilot service impacts on local / regional actors

| Type of actor | Positive impacts | Negative impacts |
|---------------|---|--|
| CR | <p>Since the SmartCare record will hold selected data of both social and health aspects so actors will be able to adjust their actions to the CR situation.</p> <p>Shorter hospital stay.</p> <p>Timely reaction of health or social professionals.</p> | <p>Some CR might be reluctant to share their social or medical information or to understand the idea of mixed social-health provision of the service.</p> <p>Due to the poor background of the majority of social care recipients and the lack of their technical knowledge it might be difficult for them to accept new services.</p> <p>Patients may have access to an amount of technical data which they do not understand and which may potentially make them feel even more unsecure, increasing anxiety and misconception about their health condition.</p> |
| I/FC | <p>Relatives or friends... will be able to give better home care to the CR.</p> | <p>overwhelmed by IT technology.</p> |
| SCP | <p>Social care workers will have easier and updated access to their CR environmental and social needs, and better communication about CR with Hospital</p> | <p>overwhelmed by IT technology.</p> |
| HCP | <p>ICR - real timesharing information with GP and SC</p> | <p>overwhelmed by IT technology.</p> |