The SmartCare pathways

An initial step towards implementing integrated eCare

1. A new solution to known problems

The call for better joined-up care is anything but new (Balint 1957; Goodwin and Alonso 2014). However, implementation of person-centred and integrated care at a larger scale has yet to occur in Europe. With respect to long-term care for older people in particular, Rigby (2014) has pointed out that "modern European society has created many services to help these citizens. But these services are split into organisational clusters such as health, social care, housing and others, each in most settings separately organised, delivered and recorded by organisations and their staff who are separately funded, managed, and regulated. As a result patients are surrounded by uncoordinated Islands of Excellence, when what is needed is Coordinated Care."

One of the main reasons for the missing link between the services is that historically national health and social care systems have developed in an incremental way, without a coherent vision of how both social care and healthcare systems should interact (Leichsenring, Billings et al. 2014). SmartCare aims to improve this situation by delivering integrated eCare services in the community, joining in a better way health, social and informal care service provision thanks to the support of information and communication technology (ICT); this is also expected to enhance self-care and empowerment of care recipients and their relatives.

Based on supportive informatics solutions, integrated home care services are defined, implemented and deployed in nine European regions until summer 2016. More precisely, SmartCare pursues the two main goals of:

1. successfully implementing integrated eCare services in its nine deployment regions and,

2. producing and disseminating knowledge and guidance for the future uptake of integrated eCare in other regions of Europe and elsewhere in the world.

The first objective will contribute to one of the aims of the European Innovation Partnership on Active and Healthy Ageing Initiative, and in particular the B3 Action Group on Integrated Care which is to make available integrated care programmes for chronic conditions/case management in at least 50 regions by 2015 (European Commission 2013). The second objective will hopefully support calls of the EU Member States for tools to enable system-wide changes through knowledge-synthesis, field evidence, and change management (World Health Organisation 2013).

Real-life implementation and mainstreaming of innovative care services does however never occur in a vacuum, neither organisationally nor technology-wise (Allan, Glasby et al. 2013). It is clear that the implementation of any new service is influenced by structural framework conditions, which sometimes act as strong barriers towards joint working. In many current care systems across Europe, a range of specialist health and social services tend to be delivered by organisations which are funded, managed and regulated under different rules. Existing care systems tend to be slow in adopting new ways of collaborative working and information sharing, particularly where these cut across established organisational boundaries. Likewise, the process of implementing new ICT tools has to address legacy technologies which were created to support a range of silo processes prior to the concept of better joined-up service provision (Kubitschke et al., 2014). A simplistic approach towards service innovation can easily be interpreted as the wholesale migration to new service processes and ICT tools supporting them. Such an approach, however,

poses major budgetary problems for service providers, and introduces risks in terms of system delivery and potential loss of service (and data) continuity.

The regions participating in SmartCare share many of the structural challenges mentioned above. They differ for example in terms of:

- health and care systems and their objectives,
- legal and regulatory frameworks,
- stakeholders and their role in service provision,
- health and care processes,
- existing ICT infrastructures.

SmartCare's first challenge therefore was to find a way of working within the framework of this diversity, while at the same time achieving common goals, given the agreed basic premise that integrated care, independently from ICT support, represents the best (unique) tool to address complex needs of people in need of social and healthcare. In order to reach its objectives, the project needed an instrument that would:

1. result in a common vision for integrated eCare services cutting across the many European regions with their different frameworks, settings and preconditions, and

2. support the controlled migration towards integrated eCare services by managing change within these regionally different conditions.

On the one hand, this instrument needed to be concrete enough to structure integrated care processes and to serve as a model that each deployment site could work towards. On the other hand, it also had to be flexible enough to allow for a wide-ranging consensus to be established between the regions and the stakeholders working within them.

A widely used instrument to structure processes in care delivery are pathways. The predominant use of pathways is in healthcare, where they are most commonly used as a concept associated with specific clinical conditions such as heart failure or diabetes, (e.g. (Turner, Lattimer et al. 2008). While clinical pathways are an excellent tool to regulate, prioritise and manage a sequence of events and actions assigned to different healthcare professionals in the delivery of healthcare, their granularity is for the purposes of SmartCare not suitable and productive. They are for example too detailed to achieve a common vision that works for many European regions and too bound to actors and roles that normally change from region to region and context to context. Further to this, the clinical pathways identified by a dedicated stocktaking exercise were too difficult to adapt for the purposes of SmartCare, as they are too specific to support subsequent phases of needs- and requirements-based development processes.

For this reason, SmartCare introduced pathways as a high-level view of a typical service flow involving health, social and informal care. The pathways present a service flow on a more schematic level, i.e. the logical sequence of structured actions along types of activities or groups of tasks, and do not specify actor roles for a clearly defined set of tasks within a specified time. A further differentiation to clinical pathways is that the SmartCare pathways do not specify detailed processes for specific interventions, but instead span the entire integrated home care service provision from enrolment to leaving the service.

2. Achieving a solid basis for strategic planning and concrete implementation

The SmartCare high-level pathways were developed through an iterative collaboration approach. An initial version of the pathways was created in the kick-off phase of the project, on the basis of a review of existing integrated services and literature research. Members of the project team then visited the SmartCare regions, speaking with both front-line staff and decision makers about how health and social care are organised in the region, how different work processes are structured, and how both types of services currently co-operate. They brought with them large-scale print-outs of the pathways that were presented and discussed, passed around and written upon. The results of each visit were fed back into the project and discussed with a wide range of stakeholders, resulting in ever more developed versions of the pathways. Ultimately, a final version of the pathways was agreed between all partners, and used as a tool for the development and implementation of the SmartCare services.

In the course of this work, the pathways fulfilled a number of functions. They served as an instrument for strategic planning on the decision maker-level. They helped the various stakeholders in the regions to join forces and formulate objectives and concrete work tasks to achieve them. They also proved to be an invaluable dissemination tool, both for the regions and SmartCare as a whole, to communicate what the project is about to both ex-pert and non-expert audiences.
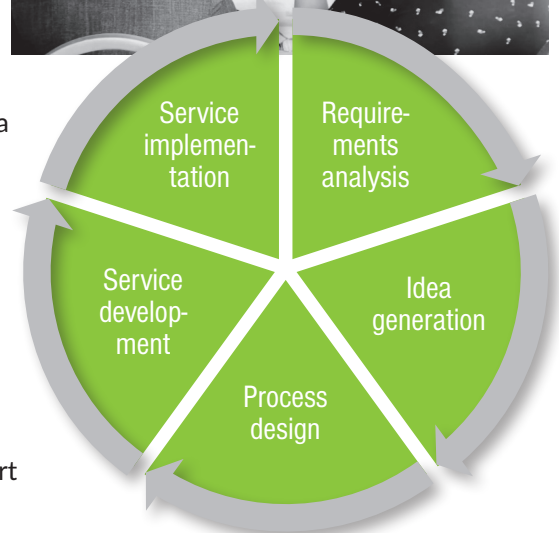
The pathways also fulfilled a success-critical function in SmartCare's service development and implementation process. SmartCare follows a deployment cycle consisting of five steps leading from initial requirements analysis to service deployment (Meyer, Müller et al. 2011). The SmartCare regions went through this cycle in two iterations in order to arrive at the services that were ultimately being piloted. The pathways were developed and refined on the basis of the requirements

analysis, and from there on served as a structuring and guiding instrument in the design of detailed service processes, the specification of the IT systems and the SmartCare architecture, as well as the development and testing of service prototypes.

During requirements analysis, the initial pathway versions helped people in the regions to identify gaps in their own service provision that would have to be filled. The design of pathways also helped to point out gaps in the SmartCare service concept that had up to that point been missed.

▶ Learn more about the SmartCare requirements analysis online by visiting
http://www.pilotsmartcare.eu/norm/topics/service-requirements/.

The *service processes* – detailed flowcharts of action sequences – were developed as an expansion of the pathways into a more detailed definition of the activities and roles in the service.

▶ See an example of a SmartCare service process by visiting
http://www.pilotsmartcare.eu/topics/integrated-ecare-pathways/service-processes-based-on-pathways/.

The *IT specifications* define information recording systems, ICT infrastructure components and information sharing mechanisms for each step of the pathway.

▶ See an example of the SmartCare technical service specifications by visiting
http://www.pilotsmartcare.eu/topics/integrated-ecare-pathways/it-specifications-based-on-pathways/.

3. The SmartCare pathways

The SmartCare pathways have been designed around two major service scenarios:

- Integrated long term care support at home (ICP-LTCare pathway).
- Integrated care following hospital discharge (ICP Discharge pathway).

Both scenarios respond to a recognised need for improved integration at crucial junctions in health and social care service delivery.

Each pathway consists of three major phases, which are again separated into different steps:

- Entering into the SmartCare pathway.
- Receiving continuous personalised (health and social) care.
- Leaving the SmartCare pathway.

3.1 Entry phase: Service user identification, needs assessment and planning

"You can't integrate all of the services for all of the people all of the time." (Leutz 1999) This fundamental dilemma of integrated care points to the need to clearly identify individuals who may benefit most from the integrated delivery of health and social care. In general, these are care recipients who require a whole-life approach, in order to be supported both in the health and social domain ("complex needs").

Care recipient story

/Jose Antonio is a 72 year old with long standing chronic obstructive pulmonary disease (COPD). He is living alone in his house, but needs support from his daughter Anna from time to time since his wife Maria died a few years ago. After a recent fall in his home, Antonio had to undergo hip surgery. As discharge from hospital is pending, Jose is approached by the general care nurse working at the hospital. She tells him of a new support scheme that the regional health services in Aragon now offer to people like him.

Jose is a clinically stable patient with social care support needs at home; and with his COPD condition, he is likely to benefit from regular monitoring, possibly through a telehealth monitoring and telecare application and from receiving social care services such as meals on wheels for a certain time. He also fulfils the age related inclusion criteria and may have problems coping with daily household duties./

This situation is typical for a SmartCare service configuration in the deployment sites that are implementing the hospital discharge pathway. Before actual service delivery begins, a potential SmartCare service user needs to be referred by either a healthcare or a social care provider.

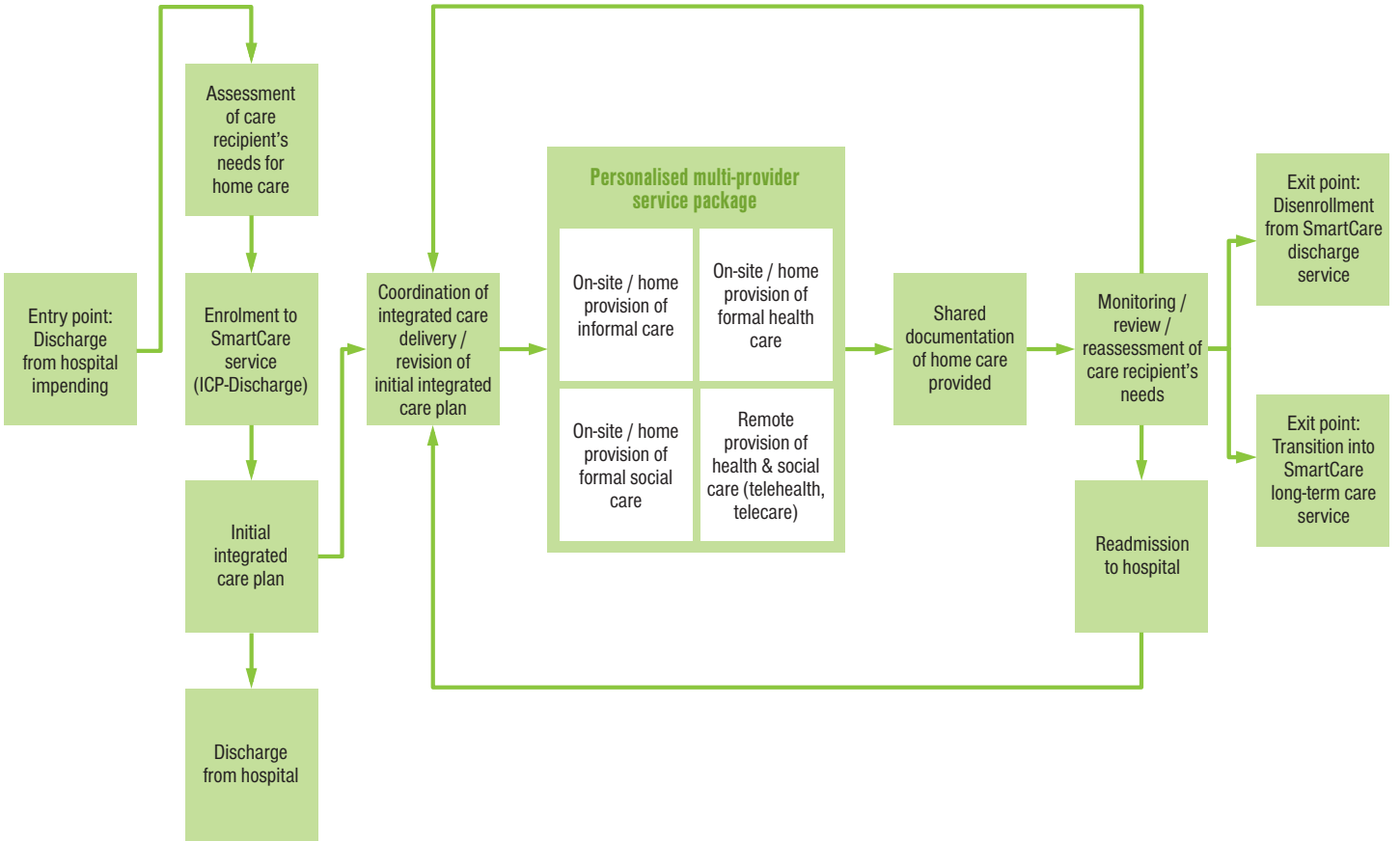Depending on the characteristics of the health and social care system, direct subscription by a service user themselves or a family member is also possible. When it comes to hospital discharge in particular, the entry point is usually defined by a pending discharge event.

The referral is followed by a needs assessment which targets both health and social care needs. It is a first junction for collaborative work of health and social care service providers, and focuses on assessing the individual service user in relation to any home care needs they may have. It should enable the identification of health-related needs as well as needs for other forms of home support. Upon completion of the assessment, the service user is enrolled into the services, and an integrated care plan is agreed jointly by health and social care providers. The integrated care plan is a formal document that also feeds on input by the service user to describe the care interventions to be provided and the appropriate intervals. The focus is on achieving the highest level of empowerment of the care recipient and her/his family. The care plan guides the care team by establishing a course of client care, priorities, and selecting a course of action from identified alternatives. It is regularly revised according to the (changing) social and healthcare needs of the service user and his or her preferences (e.g. they are consulted on organisational matters such as the preferred day of the week and time for nurse or social care worker visits or follow-up phone calls, and on any other relevant matter related to his or her care).

| Entering into service | Receiving continuous personalised care | Leaving service |

Entry point (1): Referral by health care provider

Entry point (2): Referral by social care provider

Assessment of care recipient's needs for long term home care

Enrolment to SmartCare service (ICP-LTCare)

Initial integrated care plan

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

Personalised multi-provider service package

On-site / home provision of informal care

On-site / home provision of formal health care

On-site / home provision of formal social care

Remote provision of health & social care (telehealth, telecare)

Shared documentation of home care provided

Monitoring / review / reassessment of care recipient's needs

Temporary admission to institution (e.g. hospital, care home)

Exit point: Disenrollment from SmartCare service (ICP-LTCare)

Generic SmartCare pathway for integrated long-term home care support (ICP-LTCare)

Entering into service

Receiving continuous personalised care

Leaving service

Entry point: Discharge from hospital impending

Assessment of care recipient's needs for home care

Enrolment to SmartCare service (ICP-Discharge)

Initial integrated care plan

Discharge from hospital

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

Personalised multi-provider service package

On-site / home provision of informal care

On-site / home provision of formal health care

On-site / home provision of formal social care

Remote provision of health & social care (telehealth, telecare)

Shared documentation of home care provided

Monitoring / review / reassessment of care recipient's needs

Readmission to hospital

Exit point: Disenrollment from SmartCare discharge service

Exit point: Transition into SmartCare long-term care service

Generic SmartCare pathway for integrated hospital discharge (ICP-Discharge)

The hospital discharge pathway is designed to meet the needs of individuals who face discharge from hospital and transfer to their home setting. The important difference to the long-term care pathway is the elaboration of an initial integrated care plan prior to discharge from hospital. In both service scenarios, regular monitoring of the service user's health status and needs allows for temporary (re)admissions to hospital or residential care, if needed.

3.2 Continuous personalised care

Service users in the SmartCare deployment regions benefit from different service configurations that are augmented by technology and backed up by the cooperation of service providers and the joint documentation of care. This is crucial for the effective coordination of care delivery. The personalised care delivery package at the centre of the SmartCare pathways combines both informal and formal care delivery, as well as remote support delivered via telecare and/or telehealth services.

Care recipient story

/Solidea is a 89 year old lady with diabetes and is a long term smoker. Monitoring her blood pressure and blood sugar levels has become an everyday habit that she masters without any help. A short beeping sound of the telehealth box confirms the successful transmission of the clinical values to the SmartCare call centre in Trieste. Once in a while, Solidea's neighbour visits her small apartment to help with grocery shopping and assist with household work. Together, they have built a relationship of trust with the nurse working in the local district who also regularly visits Solidea. The alert level configuration of the SmartCare call-centre guarantees that all deviations from pre-defined blood sugar or blood pressure levels trigger an SMS alert on the nurse's mobile phone.

A few kilometres away, another effect of real-time monitoring makes all the difference for a 74 year old person suffering from COPD, heart failure and diabetes. "Last year, I was in hospital seven times. This year, not once!" His wife nods approvingly. Coping with this complex condition has become much easier thanks to the technology, the training given by Agostino, the nurse working in primary health care, and his regular visits. "We now have time to focus on those patients who really need our presence most."

Every single visit, the medication prescription and care process step is documented, allowing for free text commentary where necessary. Nurses are the most active users of this information, showing clearly that there is a benefit to their everyday care practice. Moreover, patients as well as family members / caregivers and the GP may also access the platform to write notes and actively contribute to self-care./

The story of these two users is taken from the Italian deployment region of Trieste. Field visits by the SmartCare User Advisory Board have identified the particularity of this personalised service delivery model. It builds on the traditionally strong role of nurses and a strong collaboration of

health and social care professionals. The shared care record is predominantly used by nurses, but is also accessible to other care professionals, as well as the service user and informal carers. The clinical adjustment to medication and alert levels is done by a GP in close consultation with the nurses. For service users in remote areas living in isolation, a social care worker is also available. Information from the encounters is also integrated into the shared care record system.

The service user story clearly shows the pathway steps concerned with the care delivery, the joint documentation, and the continuous re-assessment of the service user's needs. Joint coordination of integrated care service delivery focuses on the continuous tracking of SmartCare service users when they receive professional home care, remote care in the form of telehealth and telecare and/or informal support from different parties as identified in the initial care plan. It enables carers to coordinate delivery of required care interventions, and to effectively utilise available resources. As a consequence, the right mix of clinical, social and informal care in line with the care plan is delivered. The documentation of any care provided to the service user needs to be available in an integrated manner, and serves as a basis for ongoing decision making within the overall care process between all involved caregivers.

Integrated care provision following the SmartCare pathways also includes regular monitoring and re-assessment of the needs of the service user and adaptation of the care plan accordingly. Should a service user no longer require care in one of the two pathways, the transfer to usual care is initiated.

3.3 Leaving the SmartCare service and entering usual care

Care recipient story

/Miguel is a 92 year old heart failure patient who has been receiving the SmartCare service for several months. He was and still is quite happy with the support he gets at home, including meals on wheels and a nurse visiting him every day to help him get dressed and taking his medication. His daughter Lupe lives a few hundred kilometres away with her own family, and unfortunately cannot visit him very often. However, since Miguel is enrolled in the SmartCare service, Lupe can better follow-up what is going on with her father, as he has granted her access to his integrated care record.

Two weeks ago though, Miguel experienced a serious fall in his house and was admitted to hospital. Although he feels a bit better now than last week, it seems that it would be best for him to try to find, together with Lupe and nurse responsible for the discharge of course, an apartment in a sheltered housing estate as he feels not really comfortable and safe anymore to live alone in his house. His view is strongly supported by the nurse responsible for the discharge and last but not least by Lupe, who promised to support him in his new life situation as well and often as she can. The nurse responsible for the discharge, in cooperation with Miguel's social care provider and nurse working in the community, initiates the necessary actions, in close cooperation with Miguel and Lupe./

The decision to transfer a user from the SmartCare pathway to usual care can be triggered by two scenarios:

- Changed needs requiring adapting the services provided to the client.
- Voluntarily leaving the service.

Under the first scenario, it is possible that patients develop a clinical condition under which it can no longer be considered safe for them to stay in their home environment. If institutionalisation is temporary, a re-admission to the SmartCare pathway is possible. It can also happen that the patient's overall condition improves so that they no longer need integrated eCare services.

However, there may also be transitions into irreversible clinical conditions or severe cognitive impairment that effectively prevent the patient from using certain tools such as the blood pressure, blood sugar or body weight telemonitoring device.

If consent for participation becomes invalid, the SmartCare user leaves the service, but the follow-up and usual care will continue, in order to protect the person. This may relate to changing personal circumstances or challenges with using the technology.

3.4 Joint documentation and coordination of care provided

Service provider story

/John is a district medical doctor with responsibility for about 1,500 inhabitants. He has recently volunteered to monitor 10 of his patients who have enrolled into an integrated care programme focussing on COPD, heart failure and diabetes monitoring. The new responsibility means that a different documentation system is now available to him. Every morning, John logs into the SmartCare central documentation hub. With his read/write privileges, he is able to see the full record of interactions that have taken place between the nurses working in primary care, social carers and physiotherapists who visit his patients. A few additional clicks bring up the history of vital clinical parameters such as blood pressure values, body weight and blood sugar.

This morning, an alert message pops up immediately after log-in: the nurse working in primary care has escalated the case of Ms. Thompson. For the second time in a week, Ms. Thompson has complained about early morning dizziness and nausea. The nurse suspects that this may be related to the new medication that Ms. Thompson received ten days ago after being discharged from hospital. Ms. Thompson's timeline allows John to navigate back to the discharge record produced by the hospital. Indeed, pain medication was prescribed to alleviate the effects of hip replacement surgery. John puts the "dispense" button for the medication on "hold/review." This triggers an automatic appointment request sent out to the nurse. She will now ask Ms. Thompson to see John personally to discuss the medication plan. As soon as Ms. Thompson agrees to the appointment proposal, John's calendar will be blocked for the meeting./

None of the above interactions are possible without a joint documentation system. Below is an example of the different record systems that usually interact in a SmartCare type scenario, depending on regional context and legacy systems of course:

- **Hospital Health Care Record System:** generates the admission, readmission and discharge summaries, the health home care plan; accepts information from the SmartCare system into Care Recipient healthcare record; prepares and documents CR consent for participation in SmartCare System.

- **Community Health and Social Care System:** generates health and social care plan; documents health and social care provided along with review and assessment of care provided; provides health and social care discharge summary for SmartCare service exit and/or admission to the hospital.

- **Health professionals system:** prepares and documents consent for participation in SmartCare system; receives information from the nurses, GPs, specialists, social workers, and other professionals involved in the care pathway; receives discharge summary information from Hospital Healthcare Record System; generates and/or receives hospital re-admission information for home care recipient; generates and/or receives SmartCare discharge and/or referral (for ICPLT Care) information for home care recipient.

- **Caseload management and appointment system:** generates interventions and services for formal health, social and informal care workers for care delivered in home; this may be separate systems providing a similar function for the different SmartCare users.

- **Telehealth and telecare system:** measures vital parameters prescribed by home healthcare plan; measures environmental and social parameters prescribed by home social care plan; provides automated alerts of critical situations, handled in different ways locally by health or social authorities; provides virtual access to formal health, social care and informal care providers for home care recipient.

- **Care Recipient record:** information under the control of the care recipient that documents individual aspects of the care they receive, perhaps personal comments on well-being or reminders.

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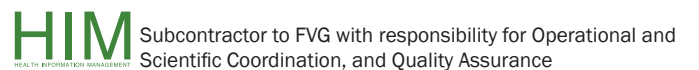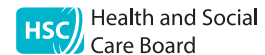
6. Useful... also for you!

The SmartCare pathways have proven to be a useful tool to guide the implementation of integrated eCare services in the nine deployment regions, setting them on a course towards viable and sustainable mainstream operation. They are care system neutral and therefore need to be translated into the local setting(s) in which the services are being deployed. The clear articulation of the three phases have helped the stakeholders involved to identify current gaps in service provision as well as fitting integrated eCare services into the existing roles and responsibilities of health and social care workers. Furthermore, the pathways guided work beyond the initial needs and requirements elicitation phase and helped in the development of detailed service processes and of specifications for IT systems supporting service delivery. The pathways also served as a common vision of what integrated eCare can be and how it can be achieved, facilitating communication between project partners and with the outside world, and providing knowledge and guidance for the future uptake of integrated eCare in other regions of Europe and elsewhere in the world.

Following the work done in SmartCare, a further 13 European regions have taken up the pathways for their own service development in the framework of the projects CareWell (http://www.carewell-project.eu/) and BeyondSilos (http://www.beyondsilos.eu/).

We would like to invite you to follow the example of SmartCare, CareWell and BeyondSilos. The pathways are available from the SmartCare website for you to use (and improve) in your implementation of integrated eCare.

Contact us and discuss

For more information please contact us at PilotSmartCare@empirica.com or visit the website at www.pilotsmartcare.eu.

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