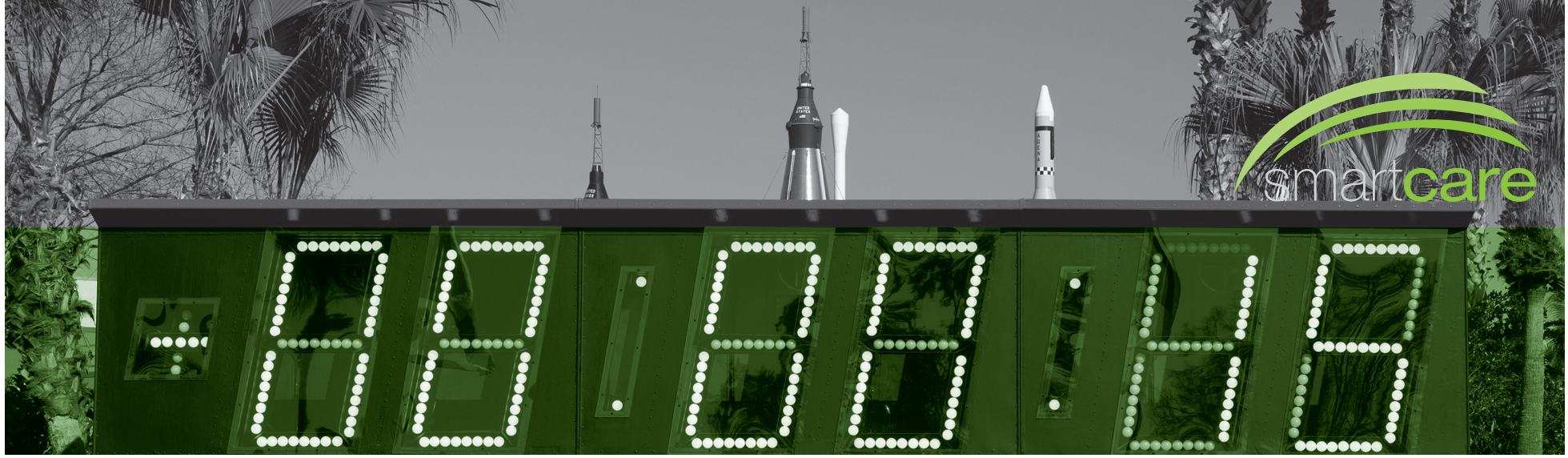
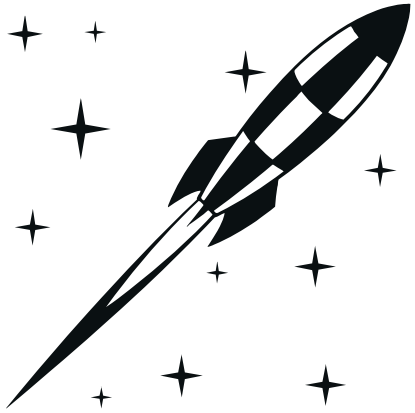


Countdown to integration

The SmartCare Guidelines for the implementation of integrated e-care service



The SmartCare project is co-funded by the European Commission within the ICT Policy Support Programme of the Competitiveness and Innovation Framework Programme (CIP) .
Grant agreement no.: 325158

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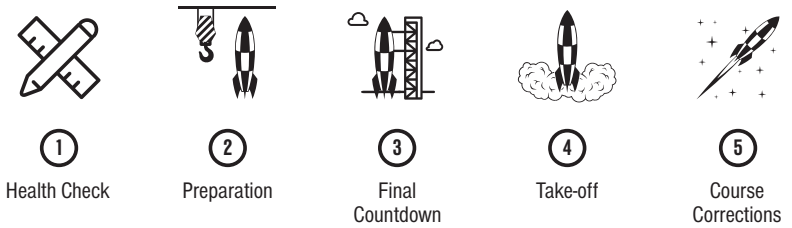
1 Executive Summary

Deploying an ICT-supported integrated care service and implementing an eHealth innovation within the usual care process represents a big challenge for most European regions. Implementing innovation in care provision has proven to be a difficult undertaking. Several causes for this challenge and difficulty can be identified, including organisational and legal aspects, weak political commitment, low level of eLiteracy and technology availability, and too little involvement of key stakeholders and end users.

With more than three years efforts and a significant number of different profiles of the organisations involved, the SmartCare project has provided a realistic picture of the complexity of deploying the regional systems, and how to deal with this. This awareness of complexity is the main feature that supported the regions to find step-by-step the local definition of a common process framework for deployment, accompanied by a comprehensive approach to achieve widespread understanding of the opportunities and risks.

With consistent cross-region information sharing happening during the whole project, these SmartCare Guidelines are based on the lessons learned from case studies in nine deployment sites around Europe: Friuli Venezia Giulia (Italy), Aragon (Spain), Scotland (UK), Southern Denmark (Denmark), South Karelia (Finland), Noord Brabant (the Netherlands), Kraljevo (Serbia), Tallinn (Estonia), and Attica (Greece). The aim of these guidelines is to help other regional and local systems to identify the key elements to make real the opportunities offered by ICTs to support integrated care services, and to analyse under what conditions these technologies are most likely to result in efficiency, sustainability and quality-of-care improvements.



During the different phases of the SmartCare project, a continuous collection has been made of the problems encountered and lessons learned. This inventory, that is accessible in specific project deliverables, has fed these Guidelines with evidence based suggestions, remarks and tips.

The SmartCare Guidelines come from the joint analysis of the project's methodological and operational elements that took into account the distinctive features of the participating regions' health and social care systems and other relevant contextual information. This information was crucial to understanding the similarities and differences in the care delivery systems, organisational approaches, and service provision.

Each section of the Guidelines aims to give a framework of actions, and has been developed as a working document providing details of the issues affecting the different phases of planning and deployment of integrated eCare supported by ICT. To achieve this aim, each Guideline section addresses the main phases detected from the SmartCare experience: Assessment and Planning (health and social check), Preparation, Introduction, Operations, Revision.

By generating answers to key questions, the SmartCare Guidelines offer policy makers, managers, practitioners, and users a systematic framework toolbox that can be used as a "deployment regional operational route map" with practical guidance in planning, developing and implementing ICT-supported integrated eCare deployment.

2 How to use these guidelines

Our Guidelines are built around a rocket launch analogy that is reflected in the title and in the names of the five phases that we have divided the process into. The analogy should help you navigate through the Guidelines, and make them easy to understand and remember. The names and symbols that we use can also help you to communicate with others, especially those who you work with when making integrated eCare a reality in your organisation or region.

Note that these Guidelines do not address why we are launching this rocket! Or rather, they do not go into the justification for implementing integrated care, supported by ICT. This has been covered by others, for example the Kings Fund in UK[1].

Are these Guidelines really for me?

The short answer to this is 'yes'. The (slightly) longer answer is that we have taken great care to make these Guidelines useful to you, no matter what your position is in the implementation of an integrated eCare service. However, you will notice very soon that you will not be able to work alone, no matter what your position. Integration means collaboration; this means that you will have to get many other stakeholders on board: patients, family carers, nurses, social care workers, doctors, call centre staff, ICT staff, middle and upper management, and policy makers, etc.

How should I start?

We recommend that you start by reading these Guidelines. Take some notes along the way, highlight those things that seem important to you, and write down any questions that come to mind. This can help you later on when working with a larger group of people, focusing the discussions and asking others what they think about the things that you had questions about.

Did that...what is next?

You have taken your first important step on the way towards an integrated eCare service. Next, you might want to start breaking down our generic Guidelines according to the situation in your organisation or region:

- **What** exactly will you have to do in each phase?
- **Who** will have to be involved in what capacity?
- **How** many and what type of resources will be needed?
- **When** should the process be completed and when does each phase have to start and end to achieve this?

In this context, we think it is important to formulate a structured set of prioritised objectives, distinguishing between primary and secondary objectives. What is to be achieved overall? What is to be achieved in each phase, and the steps that constitute it? We also recommend defining benchmarks (or performance indicators) that will help you to keep track of progress. For all of this, you should now develop a first version of a plan to be refined together with the wider group of stakeholders later on.

1) http://www.kingsfund.org.uk/audio-video/evidence-base-integrated-care

And now I have to go out there, right?

Yes, by now you have probably achieved everything that you can achieve alone, and will need to involve many other people. Call a meeting, circulate an agenda and get going: but whom should you involve? This depends on the service you want to achieve, and will differ from one case to another. But in general, it might help to use a responsibility assignment or RACI matrix[2] (Responsible, Accountable, Consulted, Informed). For each phase, think about who is going to be:

- Responsible: person doing the work to achieve the task.
- Accountable: person ultimately answerable for the correct completion of the task.
- Consulted: person(s) whose opinions or contributions are needed.
- Informed: person(s) who need to be kept up-to-date on progress.

Since this is the beginning of a large project, be inclusive. Further along the way you will be happy for all the support that you get. Also, you should become clear about who is going to drive this process and be the champion of your integrated eCare service implementation. Will that be you? Or will it be someone else?

Any help?

This is why we have prepared these Guidelines. First, the Guidelines are there for you to use and adapt as you see fit[3].

There is also by now a sizable group of organisations and regions that are already doing what you plan to do. You can go to them for help and practical advice. You can start by looking into the 26 regions that participated in the SmartCare project[4]. In addition, both the BeyondSilos[5] and CareWell[6] projects follow an approach that is very similar to SmartCare, and there are 13 more regions that will be able to support you. There is also the European Innovation Partnership on Active and Healthy Ageing (EIP on AHA) and its Action Group B3[7] that addresses integrated care and has a lot of helpful information to offer. Last but not least, there is the International Foundation on Integrated Care[8] that provides a great forum of practitioners and relevant events.

2) Jacka, Mike; Keller, Paulette (2009). Business Process Mapping: Improving Customer Satisfaction.
3) If you want, you can use our little rocket ship icons as long as you adhere to the requirements of the Creative Commons licence that they come under and reference the authors.
4) visit http://www.pilotsmartcare.eu/
5) http://www.beyondsilos.eu/
6) http://www.carewell-project.eu/
7) http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing&pg=documents and http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing
8) IFIC, http://www.integratedcarefoundation.org/

3 "Health check" – Ready for launch?

Every journey starts with the first step, whether it is building a rocket or implementing an integrated eCare service. Your first step is to engage in the first set of serious activities that will set you on your course. Having read these Guidelines, it is likely that you will soon be talking to other people about your idea. This means that you will be committing yourself, and potentially others. Therefore make sure to be well prepared.

In this initial phase, we think that it is very important that you develop and refine your initial ideas about what you are going to do. This phase probably requires the greatest amount of mental openness in the entire process. On the one hand, it will be important that you have solid ideas of your own that fall into the realm of the possible, and have the capacity to convince others. On the other hand, you will soon encounter people with their own ideas that can make your own plans better and bring them closer to reality. The ability to listen without prejudice will probably be your strongest asset.

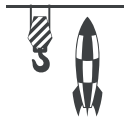
The experiences of the regions participating in the Action Group on integrated care in the EIP on AHA, as well as our own work in the SmartCare project, has shown repeatedly that a solid and methodical stocktaking exercise is a most important beginning. Where are improvements necessary? What is possible to improve things?

The principle activities in this stage cover:

- learning what needs to be done; and then
- planning what will be done.

"No passion is stronger in the breast of a man than the desire to make others believe as he believes. Nothing so cuts at the root of his happiness and fills him with rage as the sense that another rates low what he prizes high."

Virginia Woolf, Orlando



3.1 Learning what needs to be done

3.1.1 Objectives

- Taking systematic stock of your status quo with regard to health and social care concerns.
- Identify areas for improvement.
- Formulate a clear set of strategic and operational objectives to address any potential gaps/areas for improvement.
- Build partnerships to achieve your goals.

3.1.2 Task 1: Understanding your status quo

A journey towards integrated care needs to begin with an understanding of where you are coming from, and which factors have shaped the system in its current status. The Smartcare project has acknowledged throughout that health and social care systems across its deployment regions follow different organisational, financial and legal logics. In order to find the integrated care configuration that suits your particular situation best, it is important to ask a number of key questions before beginning work on integration. For further advice on stakeholder consultation in the preparation phase of a project, please see section 4.1 below.

Key questions

Q1. What are the health and social care concerns that define discussions in your region?

Q2. Is there a shared understanding and sense of urgency among key stakeholders (medical, political, managerial) about these concerns?

Q3. Are there stakeholders benefiting from the status quo?

Q4. What mechanisms are there (institutional, political) to begin discussions on a reform of health and social care structures?

Q5. Which stakeholder may possibly lose power (politically, financially or otherwise) if you pursue integration of health and social care in your region?

Tips

T1. Even though there may be a number of general concerns with health and social care, it is essential to narrow these down to a level that can realistically be managed.

T2. Bear in mind that incremental change within existing structures may yield faster and more stable returns than a complete overhaul of the status quo.

T3. Analyse existing regional health and social care policy documents and align your first ideas with their priorities, bearing in mind the way in which these documents were drafted, and that they may not have the full support of all stakeholders.

3.1.3 Task 2: Identifying gaps and general stakeholder needs/wishes

Integrated care needs to address clearly the specifiable needs and wishes of stakeholders that result from a shared sense of urgency. It is essential to create a consensus on this urgency. Otherwise your project idea has a low chance of succeeding in the long run.

Key questions

Q6. Which instruments are at your disposal to organise a focused discussion on health and social care priorities?

Q7. Are there prior experiences in your region with expert consultation processes (e.g. a Delphi Study or a World Café)?

Q8. Is there a particular political actor that has a recognised legitimacy to initiate a process on stakeholder needs and wishes?

Q9. How do you intend to document any possible results from a stakeholder consultation, and which actor(s) can initiate the next steps?

Tips

T4. You could use the B3 Maturity Model for Integrated Care as an instrument to facilitate a focused discussion to agree local health and social care priorities (i.e. stakeholders' needs and wishes), and to identify strengths and gaps.

T5. Putting integrated care on the agenda of relevant political actors is easier if you can use established political processes.

T6. Integrated care may also feature in documents and in governance levels that are outside of your immediate regional context, e.g. as part of European level initiatives or national innovation policy programmes. You should use these opportunities to kick-start the agenda setting process in your region.

T7. The collection and documentation of stakeholder needs and wishes in health and social care should not be prejudiced by a particular technological or integration vision, but should be as open as possible.

3.1.4 Task 3: Building alliances

If you have come to the conclusion that integration efforts are worth pursuing in your health and social care system, the partners helping you to reach this conclusion are your first natural allies. Further questions beyond this circle need to be asked.

Key questions

Q10. How can you sustain the momentum from the initial learning and consultation phase?

Q11. Are there any actors who have not participated in the process but may need to be involved at a later stage?

Q12. How can you begin the concrete planning process that will take you from high level ideas to a specific project with start and end points, and measurable, specific goals?

Tips

T8. Consider creating a permanent working group or steering group composed of people who have shaped the initial learning process; use this group to advance from ideas to planning stage.

T9. Raise awareness early for your idea among stakeholders that may not immediately come to mind: mayors of towns in which you intend to pilot a service, or scientific associations/foundations that research the topic of health and social care integration.

T10. Give your initial team and the policy makers in your region time to buy into and develop your ideas before you approach questions of planning and funding.

3.2 Planning what will be done

3.2.1 Objectives

- Define integrated care pathways, formal/informal stakeholders, and roles.
- Carry out a risk management analysis.
- Identify and schedule the main steps to take: legal, ethical, organisational, technical, and clinical/social.
- Ensure co-design and testing of products and services.
- Define technical responses to person-centred needs.
- Elicit stakeholders' involvement through a bottom-up/top-down approach.
- Make change management an organisational issue.
- Ensure correct handling of sensitive information.
- Develop recruitment/enrolment strategies.
- Test to learn, not to confirm.
- Identify assessment, evaluation, and monitoring tools.
- Ensure up-scaling flexibility.

The planning stage of an ICT-supported integrated care intervention paves the way for the official launch of a project. At this stage, usable information must be collected and finalised: target population; tasks, pathways and organisations need to be clearly identified; resources need to be accounted for; and risk management tools as well assessment instruments and goals need to be put in place. This is the stage where legal and ethical aspects need to be thoroughly examined and effectively tackled. The planning phase will set the stage for successful implementation, and requires experience and vision.

3.2.2 Task 1: Priority setting process: general aspects

Planning is a multidimensional and multiple-step process where stages need to be prioritised, executed and closely monitored. The main goal is to cover a greater amount of needs, and users and health/social care demands, in a more timely and cost-effective way.

Key questions

Q13. What kind of activities need to be performed?

Q14. Who will carry out the planning?

Q15. What is the planning time frame?

Q16. What methodology will you be using to evaluate the integrated care service vs usual care service?

Q17. How much will the service cost and how will funds be secured?

Tips

T11. Identify existing pathways for health/social care interventions which may benefit the targeted population groups.

T12. Identify service needs, existing instruments/devices, interoperability features.

T13. Identify roles and responsibilities.

T14. Establish a risk management plan.

T15. Check budget resources, and have a financial person monitor this area closely.

3.2.3 Task 2: Priority setting process: aspects specific to your site

Planning at site level requires correct identification of socio-demographic, clinical, social, organisational, legal and ethical aspects relevant to the site/region. Knowing your community and the societal/cultural environment within which your intervention will take place is likely to lead to better results and greater sustainability.

Key questions

Q18. Are there existing integrated care pathways in place?

Q19. What kind of technology is presently available (broadband, fast mobile internet)?

Q20. How long will the procurement process take?

Q21. Who are your formal/informal stakeholders?

Q22. What are the integrated care needs specific to your patient population?

Q23. What kind of legal/ethical aspects and processes will need to be activated?

Q24. How will help desk/contact centre services be provided?

Q25. Will integrated care services be developed internally or subcontracted?

Q26. How will you handle data protection and who will be ultimately responsible for this?

Tips

T16. Check workforce resources and see whether additional resources may be needed and/or sustainable.

T17. Consult experts and draw up a legal and ethical step-by-step protocol in line with your national/regional legislation. Keep in mind that ethical committees may take several months to provide approval.

T18. If public procurement is required, start early, since it may be a lengthy process. But note that as a prerequisite, procurement needs a clear definition of your requirement, which may take time to develop and agree.

T19. Decide where data will be held and who will be responsible for handling it.

T20. Set up subcontract service level agreements.

T21. Set up help desk/contact centre and relevant protocols for services to be provided (training, technical support, alarm handling, etc.).

T22. Use lean management tools to monitor different steps of the process, from beginning to end.

3.2.4 Task 3: Working today for future up-scaling

ICT-supported integrated care is the way of the future. With this in mind, it is important to allow for up-scaling of services while maintaining high standards of clinical and technical excellence. Paving the way for future up-scaling of services requires multi-level efforts; up-scaling does not happen overnight. It needs planning, and it requires a good operational service. In order for a service to be up-scaled, guarantees need to be provided on the smooth running of the service regardless of who the service provider/contractor/sub-contractor may be.

Key questions

Q27. Is the present service operational structure open to up-scaling?

Q28. Should the present contractor/subcontractor change, would the service still be able to run as usual?

Q29. Will you have an integrated care core team who can support stakeholders in a future up-scaling of service?

Tips

T23. Evaluate every decision against the possibility of future up-scaling.

4 Preparation phase

Now is the time to make sure that you have all the components available to assemble them in the right way. A lot rides on this phase, and fundamental mistakes now may lead to fundamental consequences later on. At the same time, you can now lay a solid foundation for later success. Above all, make sure to build flexibility into your system, because from here on there will be new challenges and unforeseen developments with every step you take.

In the preparation phase, you finalise your initial plans, making them concrete in order to then translate them into action. More than ever, it is important for you to realise that you are not (and cannot be) working alone. In any integrated care service, many people come together, and each one of them will have their own expectations, aspirations, requirements and objectives. You are looking at a twofold goal: on the one hand, you will want to achieve as much buy-in from relevant stakeholders as you can, to avoid people turning into veto players working against you. On the other hand, if you manage to achieve a broad network now, you will be able to distribute the workload much wider, avoiding overburdening yourself or others later on.

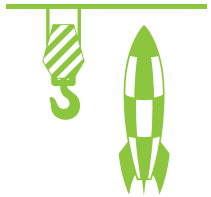
While you may well be breaking ground when it comes to your own organisation or region, you may not be the first one trying to do what you are trying to do. Others may have gone this way before, and have information and advice to offer. Therefore we recommend spending some time searching for similar initiatives. You can start from the sources that we mention in the introduction; a literature or web search might yield even more results.

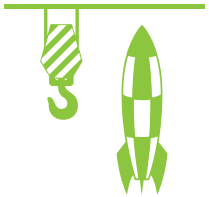
The principle activities in this stage cover:

- Consulting with stakeholders.
- Specifying the service.
- Procuring the ICT.
- Setting up the evaluation.

"A beginning is the time for taking the most delicate care that the balances are correct."

Frank Herbert, Dune





4.1 Consulting with stakeholders

4.1.1 Objectives

- Achieve consensus through co-design.
- Help older persons, their informal carers and health and social care professionals understand the added value of integrated care.
- Build public understanding.
- Cultivate trust.
- Promote change management within organisations and communities.
- Make integrated care a social learning process within a person-centred approach.

Stakeholder engagement as a concept goes beyond consulting and participation, because co-design and co-decision ensures that consensus must be achieved. Engagement in policy design and implementation, such as developing integrated care, creates space to build public understanding of a value-driven policy.

Engagement can provide opportunities to: improve the substance of policy input; cultivate trust between government and the public; and increase the legitimacy of policy action and implementation.

Recent research provides evidence that the absence of an effective stakeholder engagement approach to designing health system reforms and new policies leads to a lower level of acceptance of the change.

An important element of the consultation is getting to know the existing skills of professionals, and the services that each organisation could deliver better, and could benefit more from, with the integration of care.

4.1.2 Task 1: Mapping stakeholders

Stakeholders include health and social care professionals, older people and informal carers, top management and political leadership.

Effective stakeholder engagement implies mapping the formal/informal stakeholders' roles during the design and implementation process, including their interests and their patterns of interaction and influence alongside their potential to reach the objectives. Only then can stakeholder engagement lead to successful outcomes.

Key questions

Q30. Who are the formal/informal stakeholders in your region/community?

Q31. Why are they important to the successful outcome of the project?

Q32. Will different stakeholders come into play at a later stage of the project?

Q33. How can each stakeholder contribute meaningfully to the design of the service?

Q34. What are specific stakeholders' skills/roles?

Q35. Are stakeholders already used to working together? If so, within which organisational structure(s)?

Tips

T24. Collect as much information as possible on the present structure/ roles of stakeholders in your region/community.

T25. Check and see whether changes in the present stakeholders' structure and/or organisation are expected to take place within the medium-long term.

T26. Whenever a target group is not organised formally, e.g. older persons and their informal carers, they should still be recruited via other stakeholders or directly through a public call.

T27. Find out what is the present level of integration within and among stakeholders' groups.

4.1.3 Task 2: Mapping stakeholders' needs: Provider organisations

When involving health and social care organisations, is it essential to take all their needs on board: the design and implementation of integrated care is most successful when it adopts a bottom-up approach, meaning that all elements in the service, i.e. ICT elements, distribution of roles, criteria for inclusion of patients, etc., match the real needs of people.

Key questions

Q36. Are formal/informal stakeholders' needs already known?

Q37. How can integrated care better meet stakeholders' needs?

Q38. Do we have a system to monitor stakeholders' satisfaction?

Q39. What are the health and psychological needs of those who provide care?

Q40. How can integrated care better meet these needs?

Tips

T28. Organise focus groups with different stakeholders.

T29. Identify the emerging needs and how they can be supported by integrated care.

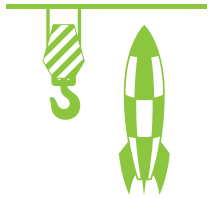
T30. Keep monitoring emerging needs and involve stakeholders' groups in providing feedback.

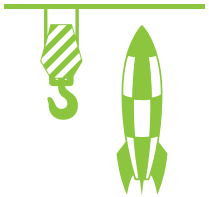
T31. Make every person feel important.

T32. Identify your formal stakeholders and collect information on if and how their needs are presently met in your region/community.

T33. Identify your informal stakeholders and collect information on if and how their needs are presently met in your region/community.

T34. Promote healthcare and social integration and inclusiveness through interventions supported by ICT platforms and technology, not led by technology alone.





4.1.4 Task 3: Mapping stakeholders' needs: Care recipients

Providing quality care for care recipients entails respecting their dignity and their rights, and ensuring that the principles of person-centeredness, prevention, availability, accessibility, affordability, comprehensiveness, continuity, outcome-orientation, transparency and gender/culture sensitiveness are respected[9]. The consultation should help learn more about the concrete expectations of care recipients and how all these principles can be ensured in the implementation and delivery of ICT-supported integrated care. Integrated care means putting the care recipient (both clients and families) at the core; the results of this consultation therefore need to orientate the development of the service.

Key questions

Q41. How can integrated care fully respect the dignity and real needs and expectations of care recipients? Which principles in terms of quality of care and dignity of older persons need to be enforced throughout the implementation?

Q42. Who are the recipients of our integrated care?

Q43. What are their health and social/psychological needs?

Q44. How can integrated care better meet these needs?

Q45. How can integrated care empower the care recipients and make them feel a real change in their quality of life?

Q46. How can integrated care support person-centredness, health and wellbeing?

Q47. How will the service involve and support informal carers?

Tips

T35. Identify your client population and collect information on if and how their needs are presently met in your region/community.

T36. Adopt a rights-based approach when assessing the needs of older persons in need of care. I.e. meet their needs and views, and treat them in a dignified way as autonomous individuals willing to express their preferences regarding the care they receive.

9) These principles are part of WeDO – the European Quality Framework for long-term care services.

4.2 Specifying the service

4.2.1 Objectives

- Produce a specification of the service, detailing the activities and roles of stakeholders.
- Overlay the service specification with a view of the ICT systems to be used and the functionalities they are to deliver.
- Understand the legal and regulatory requirements and how they are to be met.
- Gain an understanding of the costs and benefits that the service will bring to all stakeholders.

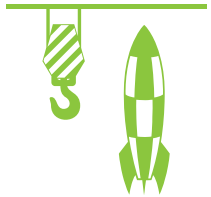
Description

With all stakeholders on board, the service now needs to be defined in detail. This means that you need to map the steps of the service flow as well as the tasks and responsibilities of patients, carers and providers at each step. The service specification should be a kind of recipe for service delivery: following it, everyone should know what to do at any given time. Furthermore, it should detail the ICT components, i.e. what systems and functionalities support service delivery in what way.

The biggest pitfall in this exercise would probably be to disregard all the different framework conditions and influencing factors that impact on how a service is developed. Therefore you should be systematic about understanding how far you are changing existing organisational practice, what legal and regulatory requirements you have to meet, and in particular what the new service means to every single stakeholder in terms of costs and benefits.

4.2.2 Task 1: Care pathways

There are many ways to develop a service specification. In SmartCare we have used a care pathway, mapping the steps that a patient or client (along with professionals and informal carers) follows from referral into the service to disenrollment. We went from rather coarse-grained, high-level pathways to detailed service process models, distinguishing between long-term and short-term care.



You can visit http://pilotsmartcare.eu/topics/integrated-ecare-pathways/ to see examples of our pathways and how we developed them.

Key questions

Q48. What do you want to achieve through your provision of new services?

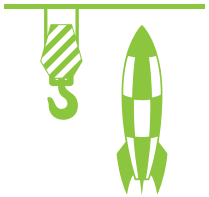
Q49. Any specific aspects for:
- Care recipients?
- Professional users (both health and social care)?
- Informal carers?
- Empowerment?
- Quality of life?

Q50. Who are your care recipients and what defines them as relevant in your setting?

Q51. Who are your professional users in healthcare and/or social care, and what define them as relevant in your setting?

Q52. Who are the informal carers, if any, and what define them as relevant in your setting?

Q53. What safety concerns might be relevant in your setting?



Q54. What entry points does the service have, and who will be able to refer patients/clients into the service?

Q55. Will patient/client assessment, as well as initial care planning, be done jointly or by different professionals?

Q56. What are the enrolment criteria for the service?

Q57. What elements of care provision will be available from healthcare, social care, and informal or third-sector care?

Q58. How will joint care service provision be co-ordinated and documented?

Q59. Is there going to be a case manager?

Q60. When and on what basis will care plans be revisited?

Q61. What is the exit point at which patients/clients leave the service?

Tips

T37. We had good experiences with producing a first version of a pathway, printing it on a poster, and taking that into a group discussion with all stakeholders, talking through every single step.

T38. You will probably need several iterations to refine the service specification, asking for new feedback from stakeholders at each iteration.

T39. It might be useful to write a document that goes with the pathway schematic which contains additional information for each step.

T40. Read existing literature, and have joint meetings among formal/informal stakeholders to identify potential issues.

4.2.3 Task 2: Technical system overlay

The care pathways also provide a good starting point for the development of the technical specification. In SmartCare, this was produced as an overlay to the original pathway, listing the ICT infrastructure components (e.g. LAN, wireless networks, databases), ICT systems (e.g. electronic health records, telehealth devices), and functionalities needed for each step.

You can visit http://pilotsmartcare.eu/topics/integrated-ecare-pathways/it-specifications-based-on-pathways/ to see examples of the technical system overview.

Key questions

Q62. What ICT systems will have to be implemented from scratch?

Q63. What ICT systems are already in place and will have to be integrated into the new solution?

Q64. How open are existing systems when it comes to exchanging data?

Q65. Which users will have access to which parts of the systems, and with what user rights (e.g. browsing, editing, uploading, requesting, distributing)?

Tips

T41. Similar to the care pathways, expect several iterations for the development of the technical overlay.

T42. If you have not done so already, make sure to involve ICT experts from the involved organisations, in particular to consult about existing technology.

T43. Feedback from ICT suppliers on the technical overlay should be sought as early as possible, to avoid a mismatch between what you want and what suppliers are able to offer. An open market consultation as part of a procurement procedure is one way to achieve this.

T44. If the service calls for components or entire systems that are currently not provided by suppliers, a pre-commercial procurement (e.g. joint development of a solution by suppliers and clients, sharing the investment risk) might provide a way forward. More details on procurement issues can be found in section 4.3.

4.2.4 Task 3: Legal and regulatory requirements

There are likely to be numerous legal and regulatory requirements that you will have to take into account, from professional codes of conduct, to reimbursement regulation, data protection law and beyond. Although it may seem like an unrewarding task, invest the time now for a systematic stocktaking of all applicable laws and regulations: these can become major roadblocks if not addressed early in the process.

Key questions

Q66. What areas of legislation and regulation will be relevant?

Q67. What are the exact laws and regulations that apply?

Q68. What are the specific requirements and how can they be met?

Q69. What activities are not covered by current legislation and regulation, or fall into “grey areas”? How to deal with these?

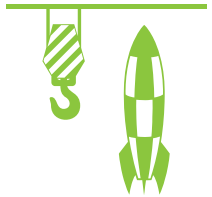
Q70. Are there any changes to current legislation and regulations expected during the lifetime of the project?

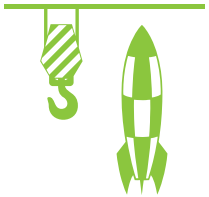
Tips

T45. Involving a legal expert might be useful, as well as asking other people about their experiences. Maybe specialised rights organisations exist that are willing to support you.

T46. Be systematic and comprehensive in your collection of applicable laws and regulations. You can always discard something later on if it turns out to be irrelevant

T47. These elements should be addressed: clinician accreditation, device certification, information governance, professional liability.





4.3 Procuring the ICT

4.3.1 Objectives

- Match the ICT capabilities to the requirements of the service.
- Understand the limitations of the ICT capabilities at the different points of the service.
- Understand what ICT can be provided by modifying existing legacy systems, as well as what needs to be newly procured.
- Ensure that the integration of the different functional aspects of the service can be done as seamlessly as possible.
- Procure the necessary works and services in line with EC procurement law.

The SmartCare project developed two care pathways that used similar functional blocks: enrolment and consent, care plan, on-site provision of care, remote provision of care, documentation of care, assessment and re-assessment of care, and exit from the service. Each deployment site used different ICT to support these functional blocks for the two care pathways. The ICT procured was based on a combination of the capabilities of their existing legacy systems, and any new requirements to meet the care pathway service requirements.

Due to the nature of the expansive set of requirements to provide an integrated platform for the provision of clinical and social care services, all kinds of ICT were procured and used by all of the deployment sites.

4.3.2 Task 1: ICT requirements

Questions to be answered in relation to ICT requirements/issues:

Q71. Which aspects of the problem with the integrated service are targeted by the ICT solution, i.e. are expected to be improved by its use?

Q72. How is the ICT solution used to provide (better) integrated care?

Q73. At which level(s) of healthcare and social care and by which type(s) of professionals, informal carers and care recipient is the service used?

Q74. What are the technical characteristics of the service tested?

Q75. Is the technology fully developed or in its early stages?

Q76. How is the solution integrated with other applications and the ICT-infrastructure?

Q77. Is there previous evidence or experience in the use of the ICT solution and the integrated care application in the target health problem, or in other clinical conditions?

Q78. What kind of special premises are needed to use the ICT system?

Q79. What equipment and supplies are needed to use the ICT system?

Q80. What kind of data needs to be collected to monitor the use of the application?

Q81. What are your local, regional and national laws with regard to data privacy?

Q82. At what interfaces will there be data security risks?

Q83. Plan scenarios of possible problems, and try to design the problems out.

Tips

T48. Integration is usually enhanced by promoting interoperability between systems. For ICT, Integrating the Healthcare Enterprise (IHE – www.ihe.net/) offers profiles based on clinical/social workflows that specify standards to be used at the interfaces in the workflows. The Continua Health Alliance (http://www.continua-alliance.org) has design guidelines available for procurers and vendors to provide standards based systems for health and wellness. Adding these to procurement specifications will encourage vendors to provide systems which are standards compliant and will ease integration and interoperability for your service.

T49. Ensure that data privacy and security requirements are adequately identified and can be tested/validated at every system interface.

4.3.3 Task 2: Scanning the market

Investigating what the market can provide in your region will be of paramount importance to determine how your service can be built and supported. There are a myriad of ways in which ICT systems can be deployed to support functional requirements. However, you will probably find that your legacy systems will dictate to a large extent what needs to be procured to support the service. You will also need to decide which aspects to develop in-house versus outsource.

Key questions

Q84. If the service is to be integrated into an existing system or systems, what are the interface requirements?

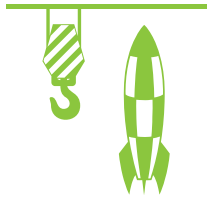
Q85. Is there a complete system technical specification that defines the performance and interface requirements?

Q86. What bandwidth requirements are driven by the service requirements at the different points of care? If there are limitations, how will that modify the service?

Q87. What end devices or platforms will be used by the different stakeholders, and how can the ICT requirements support them?

Q88. Are there some new technologies on the horizon that can be adopted and/or incorporated into the integrated system?

Q89. Is there access to a lab to test the ICT systems against the specifications, as well as to simulate the integration?



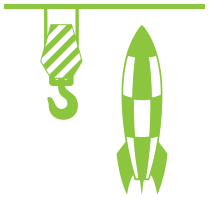
Tips

T50. The range or distance required for data transmission to a hub will usually determine the network protocol.

T51. Several of the deployment sites had a 'bring your own' device policy, so manual data entry was used to minimise many disparate interface requirements. Having a mechanism to ensure the correctness of this clinical and social data will be important for trust and service acceptance by the different stakeholders.

T52. As the integrated platform will need to meet many different stakeholder requirements, in SmartCare the deployment sites relied on mobile and internet technologies (web portals and service oriented designs) to be able to scale across the disparate hardware and software platforms used by the different stakeholders.

T53. Aim for simplicity at the care recipient and informal carer interfaces.



4.3.4 Task 3: Publish a call for tender in line with EC procurement law

It is crucial to be aware of the procurement law governing public purchases in the European Union. The corresponding legislation is formalised in directive 2014/24/EU. In a SmartCare type situation, the procurement of software, hardware and consulting services is to be expected as part of the technical deployment of the service.

Key questions

Q90. Will you be reaching the EC threshold of 207.000€ that currently applies to services and works in a public procurement situation? Do you have lower thresholds in your region?

Q91. Do you have a legal team in place that can help you document any market scan activities and prepare, if necessary, a European-wide call for tender?

Q92. Are you aware of the different ways in which a procurement process can be organised, and the rules that apply to the formulation of award criteria?

Q93. What will be the implications of a lengthy procurement process on the further planning and implementation of your project?

Tips

T54. Your legal team can only help you to prepare sound legal documentation if they receive the technical information from ICT experts; you should bring these two groups together as early as possible

T55. If you find that the market for integrated care solutions does not have a "ready-made" solution to offer that suits your needs, consult with your legal team about the implications of this market failure for the procurement process.

4.3.5 Task 4: Successfully manage and conclude negotiations

Throughout the procurement and negotiation process, whether it will be a European or a national one, transparency of documentation and clarity of requirements and award criteria is essential.

Key questions

Q94. Do you have both legal and technical expertise available in the negotiation process to ensure minimising the risks of misunderstandings and delays?

Q95. Have you planned a contingency in your project plan in case the procurement negotiations take longer than allotted?

Tips

T56. Be prepared to consult quickly with the person or entity that guarantees the funding for your project, should the negotiations with ICT or other service providers show the need for additional investments.

T57. Assemble a negotiation team that understands the technical, legal and possibly medical implications of the procurement.

4.4 Setting up the operational protocol/process

4.4.1 Objectives

- Produce the operational protocol (description of new programme of care interventions), sharing all contents with all local stakeholders, all participants, and all "care actors".
- Agree at the start on a glossary of terms (definition of concepts) used in the document and in practice.
- Finalise the text of the operational protocol, and collect the sign off of all actors involved.
- Make clear the outcomes of the care interventions ("what the new care interventions add to usual care") and be explicit about the expected results ("what will you achieve and how you will measure it").

Description

As observed and learned in SmartCare, the operational protocol is a unique opportunity to explain the added value of the new ICT enabled integrated care aimed to better meet the needs of the person and to provide benefits to the organisation.

The protocol should provide highlights on integrated care; this is a difficult task and a real challenge. It is necessary to recognise that integration is the fundamental basis for integrated care. Be aware that integration is unavoidably linked to human relationships; attention has to be devoted to persons, both care recipients and care practitioners.

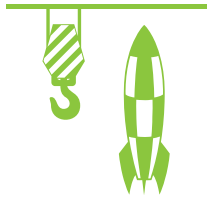
In preparing the protocol, remember that:

a) Integration is a tool and not a scope: integrated care is to be used in the presence of ascertained complex needs, when a multi-dimensional, multi-professional and multi-disciplinary action is required to approach complex needs or situations: in general, health plus social needs, which need to be set out in the inclusion criteria.

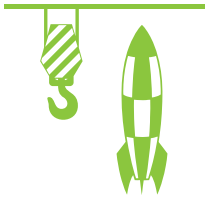
b) Integration is a process, subject to continuous changes and, possibly, improvements. It could occur with or without ICT facilities.

c) It has been demonstrated that, when appropriately employed, ICT may facilitate integration and integrated care: its value is to improve circulation of information, to share data of care/clinical relevance, to reduce time scales for decisions, to enhance remote control of risk situations, to minimise geographical constraints to deliver care, and to monitor efficiency and efficacy.

d) ICT has to be introduced in the organisation to reach as many stakeholders as possible.



One possible frequent risk in the preliminary phase of ICT use in integrated care is to put more attention on the technologies and technical aspects rather than on users' aspects, particularly when users are frail elderly persons with a low level of ICT literacy. It is important to remember that the technical user interface should not totally replace human interaction. In addition, do not forget that the introduction of ICT has a deep impact on the service. It must be emphasised that the learning curve of adopting ICT is often longer than expected, and the process may be more time and resource consuming than planned.



4.4.2 Task 1: The operational processes

In SmartCare, we initially prepared a generalised protocol; then each deployment site defined local rules, derived from the general ones ("think global, act local").

In the generalised protocol, the order of the various issues was assembled in a logical order: background and rationale; description of participants; enrolment strategy; selection, eligibility, inclusion and exclusion criteria; selection of stakeholders and care actors; settings and care interventions; primary and secondary outcomes (including unintended outcomes); expected effectiveness and efficiency of the new care model; project coordination and responsibilities; field actions and time schedule; data security and archiving; ethics; quality control; and dissemination.

Your own operation protocol/process could usefully also take the SmartCare generalised protocol as a starting point. Finally, detail the issues of communication and dissemination.

Key questions

Q96. Does the protocol provide appropriate answers to the fundamental questions: Why (are you acting)? What (are the main topics)? Where (will you act)? Who (will be involved)? When (will you start and end)? How (will you deliver care interventions)?

Q97. Have you really shared and agreed with all participants/end users (care recipients and care practitioners) the spirit, the aims, the methods, the outcomes and the expected results of the programme/project?

Q98. How are the health and social situations currently being managed? In accordance with what (if any) practice guidelines/recommendations?

Q99. What integrated service, if any, is currently offered to care recipients?

Q100. Why are you expecting better results from this new type of care organisation and care practice, in comparison with usual care?

Q101. Have you comprehensively described all the procedures and care processes, so that everyone understands and acts on them?

Q102. Are the expected gains in effectiveness and efficiency clear?

Q103. Have you really tailored the programme and the interventions to the local context?

Q104. What social and health assistance is being offered to the care recipients?

Q105. How are informal carers being involved in the provision of care, if appropriate to the local context?

Q106. Have you accurately identified the levels of responsibilities of each stakeholder?

Tips

T58. Describe the local context (starting point) and why you are driving changes in the organisation of services and care pathways (aims, scopes).

T59. Define in detail the target group of people to be enrolled: the target diseases they are suffering from (e.g. heart and/or respiratory insufficiency; diabetes; etc.); the extent of comorbidities accepted; the target social needs; etc.

T60. It is strongly recommended to provide evidence of changes and differences occurring during the follow up of implementing the new integrated care processes: one of the most important findings is to identify the delta, rather than recording if/how the new care pathway/processes works.

T61. Describe how the multidisciplinary assessment works across the clinical and social domains, together with the consequent definition of the personal care plan.

T62. Describe the type of care pathways you will employ: duration, type and intensity of care interventions, etc.

T63. Plan introductory tests to demonstrate that all staff engaged in the field are really able to understand the sense of the protocol.

T64. Define the level of social support utilised by enrolled people at start and end, e.g. detailed as technical, logistic, personal and/or loan services support.

T65. Make all efforts to ensure the greatest participation of all end-users in the preparation of the protocol. Although it might seem a waste of time, you will get a positive return in subsequent phases of the programme.

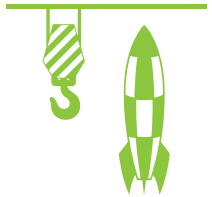
4.4.3 Task 2: Ethical issues

Key questions during the follow-up period:

Q107. Are we acting in the primary interest of the care recipient?

Q108. Are we producing some adverse events or unfavourable effects?

Q109. Are we able to see trends of positive and negative effects and make a cost/benefit balance?



Tips

T66. The ethical issues report should begin with a detailed review of any submission made to ethical committees, setting out the outcomes of such submission, and any changes which were required.

T67. Note that these elements should be addressed: care recipient autonomy, access and equity, normative codes, assessment of risk and benefit.

5 Final countdown phase

In the countdown phase you attend to all the things that need to be done before your service goes live for the first time. Fine tuning service processes, putting technology in place, and training end-users in the use of the full integrated care system. A lot of details now require your attention, and the attention of the people you work with. The final rush before the launch may make small problems appear larger than they really are. Having default options is likely to make your work a lot easier. If you anticipated major challenges and developed plans for how to address them, you can now simply pull those plans out of your hat if and when a problem arises.

As you are rushing headlong towards your start date, keep your eyes and ears open. Do not stop listening to the people around you. New and good ideas may still come up, and should not be discarded without being assessed. You may be able to implement them right away, or at least file them away for later. Our experience when launching the SmartCare services was that people came up with ever better ideas the closer the start date came. The imminent prospect of actually having to operate the service led many people to involve themselves much more intensively than before.

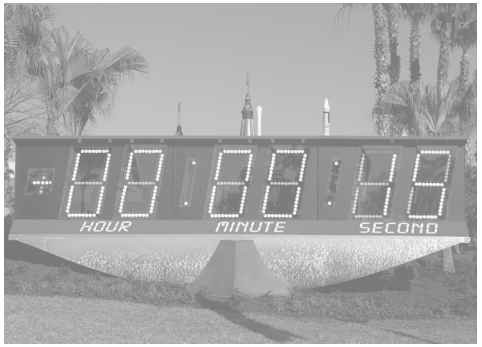
Finally, think beyond the start date even now. Soon, your service will be confronted with real-life conditions, real people doing real things. Are you prepared for that? And are you ready to tell the world that something interesting is about to happen?

The principle activities in this stage cover:

- Reviewing systems and processes.
- Training staff and informal carers.

"Don't ever become a pessimist...
a pessimist is correct oftener
than an optimist,
but an optimist has more fun,
and neither can stop the march of events."

Robert A. Heinlein, Time Enough for Love



5.1 Reviewing systems and processes

5.1.1 Objectives

- Review the original service specification, activities and roles of stakeholders against what is now about to be implemented.
- Ensure that the ICT systems deliver all the functionalities needed.
- Ensure that the relevant legal and regulatory requirements are being fulfilled.
- Check the expected costs and benefits for each stakeholder against the current service specification.

Description

With the service concept nearing completion, it is important to go back to your original planning and see what has changed. This means revisiting all the items from the service specification stage (section 4.2).

Deviations may have occurred in relation to the service specification, the ICT specification, the legal and regulatory requirements, and the business model. Some of these deviations will be necessary, simply because your thinking has advanced over the last period. Other changes may have crept in inadvertently. Now is the time to make sure that these deviations are well in hand, so as not to cause any problems later on.

Make an effort to systematically revisit:

- The care pathways.
- The technical system supporting delivery of the pathways.
- The legal and regulatory requirements.

Also make sure that everyone is on board, i.e. that all teams have been informed about the changes and adaptations (including last-minute ones).

Key questions

Q110. Are all planning documents, including the care pathways and the technical system overlay, up-to-date, reflecting what will actually be implemented?

Q111. Can you put a checkmark beside every legal and regulatory requirement that you have to fulfil? Is last-minute legal advice needed?

Tips

T68. The pathways and the technical system overlay are more than internal planning documents; they are also great communication tools when talking to decision makers, journalists or the public.

5.2 Training staff and informal carers

5.2.1 Objectives

- Training of all formal/informal stakeholders (including care recipients and their family members).
- Identify different levels of eLiteracy and provide accordingly.
- Make training a social learning experience.
- Provide support to stakeholders throughout the whole course of the project.
- Make feedback and outcome monitoring part of any integrated care intervention.

There is widespread recognition of the importance of continuous professional development (CPD) and life-long learning (LLL) of health professionals. When designing and implementing new systems of care to strengthen continuity of care, the CPD structures need to engage all stakeholders involved, including competent authorities and employers, to recognise the importance of CPD and to enable all health professionals to undertake CPD suited to their needs and interests.

Older persons and their informal carers also need training and support in order to learn how the service works and become fully operational. As end-users, they will be confronted by the use of ICT; their involvement in the training phase is therefore essential.

5.2.2 Task 1: Identify skills and targets of training

Learning may be defined as a relatively permanent change in behaviour that occurs as a result of practical experience. It is a multifaceted process that needs to be carefully planned by the organisation and skilfully mastered by the facilitator; a first step is the identification of barriers and needs within a person-centred perspective.

Key questions

Q112. What are the specific targets of integrated care training? Who needs to be trained on what?

Q113. Have all stakeholders' eLiteracy levels been clearly identified?

Q114. Have all stakeholders' needs and expectations been shared?

Q115. Have all stakeholders been involved in the definition, monitoring and evaluation of training objectives?

Tips

T69. Have a kick-off meeting to share training objectives.

T70. Perform needs' assessment.

T71. Have a check list ready for participants for an assessment of eLiteracy and specific needs.

T72. Make training a social learning and peer-to-peer learning process.

T73. Make it a point not to have anyone left behind. Have a toll free number to call should any question arise.

5.2.3 Task 2: Design training programme

The scope and depth of training depends on the role of each individual participating in the project. A successful training strategy should provide the level of depth that is required for each role and responsibility. Particular attention should be given to identifying critical skills and knowledge areas that should be covered in training programmes for the common roles.

Key questions

Q116. Do the stakeholders involved actually understand the new ICT enabled care processes?

Q117. Has information been collected on stakeholders' age, education, health status, computer literacy, role within the organisation, perception of individual / organisational benefits?

Q118. What kind of training material and training approach will be used according to the above information?

Q119. Is training material accessible to all?

Q120. Are training materials user-friendly and easy to use and understood, even by those with lower eLiteracy levels?

Tips

T74. Make training a priority of your integrated care intervention.

T75. Adjust the training experience according to your training target. Have written, oral and visual material ready.

T76. Prepare cheat-sheets to summarise main issues and provide quick reference guides to users.

T77. Ensure that the atmosphere encourages respect, acceptance and trust as well as openness and curiosity.

T78. Do not take anything for granted: integrated care can sound technical and complex, especially when training older persons and informal carers. Make sure you explain adequately what integrated care means, and why it can improve the quality of the care and the quality of life of end-users.

T79. Make training fun!

5.2.4 Task 3: Assess learning and evaluate training outcomes

Training is a continuous process and careful, ongoing evaluation of learning outcomes and programme effectiveness needs to take place. Monitoring training and its outcomes will foster self accountability and empowerment.

Key questions

Q121. How will we know that training has been effective?

Q122. Are we prepared to evaluate immediate reactions/actual participants' learning/job performance outcomes/organisational performance and change?

Q123. Are we prepared for participants' learning/job performance outcomes/organisational performance and change?

Q124. Are we prepared to evaluate job performance outcomes/ organisational performance and change?

Q125. Who will monitor training outcomes?

Q126. Has a training assessment protocol been drafted?

Tips

T80. Define critical skills and knowledge areas to be covered by the training programme.

T81. Prepare specific training for specific target groups: older persons/ patients and informal carers, health and social care professionals.

T82. Test the training courses with smaller groups of persons from the target groups before training in larger groups.

T83. Train the trainer(s) to adapt to the specific training environment.

T84. Prepare training and evaluation check lists and keep them updated.

T85. Ask for feedback from trainees.

T86. Be flexible. Training is not a one trick pony!

6 Take-off phase

The take-off phase is literally the “proof of the pudding”, the time to see whether all the careful planning and preparation will pay off. It involves more activity by the system operators and users; the role of planners and other stakeholders reduces to one of problem solving and assessment.

Whereas the countdown phase was characterised by its pace and by frantic activity, now is a probably a good time to reduce the speed of your work a bit. The service has its own momentum now, which will carry it for some time.

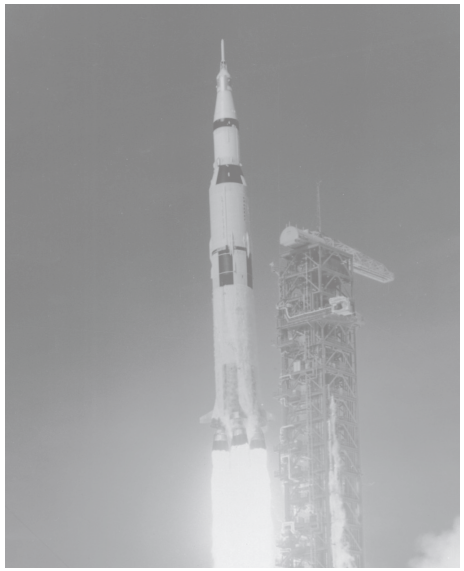
Of course, it is not a time for idleness. Patients or clients need to be recruited. Devices have to be installed in their homes. A thousand people will come up with a thousand questions, ranging from nitty-gritty to major concerns. Your services confrontation with real life is likely to reveal design flaws that could not be foreseen during the planning phase. Some of them you might be able to fix right away, others will require more thought and reflection... later on.

The principle activities in this stage cover:

- Introducing the service to clients/patients.
- Operating the service.
- Monitoring and evaluating systems and processes.
- Refining systems and processes.

“The only thing that makes life possible
is permanent, intolerable uncertainty;
not knowing what comes next.”

Ursula K. Le Guin, Domestication of Hunch



6.1 Introducing the service to clients/patients

6.1.1 Objectives

- Ensure smooth recruitment at organisational and legal level.
- Closely monitor the early phase of introduction to reinforce trust and motivation.
- Communicate clearly the innovative character of the service.

The introduction of the service in an operational environment begins with recruitment and installation work, but should also be accompanied by clear communication.

6.1.2 Task 1: Introducing the service: recruitment and consent procedure, communication strategy

The long-term success of your integrated care service depends on a smooth recruitment procedure, both of health and social care professionals, as well as patients/care-recipients and informal carers. If prior work in the planning and preparation phase was carefully executed, the recruitment of health and social care professionals should not be an issue. However, various ways exist to approach patients/care recipients that meet the service's inclusion criteria. Where it is necessary, a critical element is a legally sound document for patient consent, including consent to having data used for evaluation purposes.

Key questions

Q127. Are all relevant health and social care professionals aware of the inclusion criteria and therefore available to recruit new patients?

Q128. Will you need to schedule specific appointments with patients to install the technology at their home or for a training session?

Q129. Have older persons/patients and their informal carers fully understood the commitment that getting involved implies?

Q130. Is there a permanently available back office/help desk that can answer questions during the recruitment and installation phase?

Tips

T87. Train those professionals who will be responsible for recruiting other professionals and/or clients on how to best present the service.

T88. Always be ready to answer the "What's in it for me?" question. Pros and cons need to be clear.

T89. Always be open to questions and to explaining the added value of integrated care; always be ready to listen and to adapt the service to the needs of older persons/patients.

6.1.3 Task 2: Building trust and motivation

Clear information needs to be provided to all stakeholders, notably to end-users and their families, on the safety and security of eCare integrated services. Staff members who are known and trusted by end users can and should present the new service opportunity to them, and be ready to answer their questions and clearly inform them on roles, responsibilities and benefits of the service. Trust building is a crucial element of any integrated service. Through trust and clear communication, professionals, as well as clients, can feel empowered. An important aspect of trust building for patients is the involvement in a supporting role of their relatives and possibly informal carers. However, trust building cannot be seen as a one-way process: for older persons to trust staff members, they need to be listened to, and their dignity and capacity to decide on the type of care they want to receive needs to be respected at all times. Trust cannot be an act of faith, but is the result of two-way communication where the preferences and needs of older persons are fully respected and applied.

Key questions

Q131. Who should the stakeholder contact should a problem arise?

Q132. How will potential patients be made aware of the new service?

Q133. How will relatives and informal carers be activated to help the patient?

Q134. How will staff establish a two-way dialogue with older patients/persons that ensures they listen to older persons' needs and take them into account in the service delivery?

Q135. How will stakeholders know that what they are doing is actually producing benefits to them and to the whole community?

Tips

T90. Prepare a clear recruitment and technology installation protocol.

T91. Pick one reference person/team, and make their names and faces known to stakeholders.

T92. Consider evaluation meetings with patients and healthcare/social care professionals shortly after introducing the service to reinforce trust.

T93. Also consider an active role for relatives and informal carers of the patients; this is especially valuable when introducing new technology into the patient's home.

T94. Make every person count and feel accountable. Hold team meetings. Talk to clients and families.

T95. Organise regular open discussions where people can express their views; these should be incorporated into a plan to improve service delivery on the basis of their needs and preferences.

6.2 Operating the service

6.2.1 Objectives

- Activate and operate multidisciplinary ICT-supported integrated interventions.
- Maintain excellence of clinical/organisational/technical standards over time.
- Ensure problem-solving readiness.
- Run an efficient monitoring and feedback system.
- Ensure that users' enrolment continues as planned.
- Implement actions/interventions to minimise drop outs.
- Pursue dissemination on integrated care at leadership level and among the general population.
- Elicit formal/informal stakeholders' active involvement.
- Guarantee system's flexibility and ensure compliance with legal/ethical standards.

Operating an integrated care service goes far beyond the simple implementation of technical instruments by a multidisciplinary team. It requires competence, adaptability, skilled team work as well as the right amount of flexibility to adjust to evolving needs and requirements of our citizens, systems, and organisations.

The planning stage may lay the foundations for operational work; however, the latter must take into consideration that today's societies and the healthcare/social care systems within them are progressively changing, as is the concept of implementation of integrated care services.

6.2.2 Task 1: Formal and informal care teamwork

An integrated service is made up of a (large) number of individuals each with their own role, responsibilities and accountability. A well functioning team is a prerequisite for any ICT-supported intervention to work effectively and efficiently. This is the core of person-centred care, i.e. each person counts, and each person needs to know his/her own role, protocols, and service structure. The operating stage sees every individual working as a beehive structure with a common goal: support the frail portion of the population to allow for clinically, socially and technically supported integrated care.

Key questions

Q136. Has the team leader (case manager) been clearly identified?

Q137. Does every stakeholder (including the case manager) clearly know his/her own responsibilities?

Q138. Who will formal/informal stakeholders turn to should any integrated care-related problem or need arise? E.g. legal or ethical issues, training, equipment malfunction, alarms handling, etc.

Q139. Who is responsible for monitoring that technical issues are dealt with in a timely manner?

Q140. How do you plan to promote team cohesion?

Q141. Are you pursuing a change management plan within your organisation?

Q142. Are informal stakeholders (e.g. Third Sector) a part of the team, and/or are their views and experiences going to contribute to guiding the service?

Tips

T96. Make a list of names and responsibilities of integrated-care reference persons. Keep it updated (e.g. work turnover, vacation times, etc.).

T97. Use the integrated platform to collect suggestions and/or emerging issues.

T98. Hold regular meetings to discuss emerging issues and suggestions, and monitor subjective perception of service.

T99. Ensure the help desk/call centre appoints a manager responsible for monitoring quality and efficiency of service.

T100. Make change management an ongoing measurable goal.

T101. Have more experienced integrated care staff support and mentor newcomers.

T102. Be ready to redesign pathways or system's features should specific, unforeseen needs arise. Be flexible!

6.2.3 Task 2: User's satisfaction and adherence

Empowerment in healthcare is based on the idea that giving citizens skills, resources, authority, opportunity, motivation, as well as holding them responsible and accountable for the outcomes of their actions, will contribute to the quality and effectiveness of self-care, competence and ultimately satisfaction.

Adherence is a multifaceted issue, and is linked to a number of physical, social, organisational, and environmental factors. An empowered user is more likely to take charge of his/her own health, and implement self-care behaviours. ICT-supported integrated care may promote and enhance both empowerment and adherence.

Key questions

Q143. Does the user know who he/she should contact should a technical need arise?

Q144. Is supporting and enhancing computer and eCare literacy still on your agenda?

Q145. How do you deal with cultural/gender issues?

Q146. How do you plan to monitor adherence?

Q147. How do you plan reinforce user's positive adherence behaviour?

Q148. How do you plan to monitor user's satisfaction?

Q149. Is caregiver's satisfaction also being monitored?

Q150. Is your system flexible enough to adjust to older users' specific needs? E.g. special arm cuffs for blood pressure, easy-to-use electronic scales for users with poor balance, etc.

Tips

T103. Learn who your users are, not only from a clinical, but also from a social and cultural viewpoint. Make a thorough initial assessment.

T104. Provide each user with a written sheet with names and phone numbers of reference person(s), or toll-free number to call should a (technical) need arise.

T105. Reinforce knowledge and awareness on how alarms are going to be handled, and on the benefits that the service provides.

T106. If something does not function properly, make sure action is taken as quickly as possible. Talk to the user and his/her caregiver, and keep them updated on actions and timeline.

T107. Make sure that the platform contains a feedback form to collect issues that arise during the service; these can be discussed during team meetings, and pave the way for further improvements.

T108. Encourage users and families to provide feedback through the platform. Make them feel (as they actually are) a pivotal part of the service.

T109. Plan social contacts (either from call centre or third sector) to make the individual feel cared for and to promote a sense of belonging and self-acknowledgement.

T110. Be on the watch for improvements and innovation. Listen to what users and caregivers say.

6.3 Monitoring and evaluating systems and processes

6.3.1 Objectives

- Ensure the implemented service is meeting its planned objectives.

6.3.2 Task 1: Essential elements to monitor and evaluate systems and processes

- Description of the methodology to monitor activities and results achieved.

Key questions

Q151. Is service performance being monitored and assessed?

Q152. Can you identify the chain of contacts and responsibilities of professionals devoted to capturing evaluation data?

Q153. Can you identify a data manager and the person responsible for the final evaluation (preparation of the final report)?

Q154. Have you planned to test through some experiments/exercises the real capacities of the staff, the correct functioning of the system, the definition of the responsibilities, and the global efficiency of the system?

Q155. Are leaders/top executives kept informed of how the service is performing?

Tips

T111. Define the evaluation criteria and parameters/processes to be monitored/measured with the variables in order to adjust the course of the whole programme.

T112. Share results, challenges and knowledge, using department/district meetings, conferences, workshops, etc.

T113. Make a list of guidelines to be updated throughout the service according to new experiences, challenges and lessons learned.

6.3.3 Task 2: ICT support and solutions

Key questions

Q156. Can you describe how the technical solution supports the integrated care, before and after the introduction of the new ICT-supported integrated care pathways?

Q157. What does the new ICT supported integrated care add to usual care?

Q158. How is the end user experiencing the new integrated health and social care when ICT is being used?

Q159. How are the professionals experiencing the delivery of integrated health and social care when ICT is being used?

Tips

T114. In general, remember that in order to assess if participants met the inclusion criteria, the data should preferably be collected from electronic records.

6.3.4 Task 3: Context description and analysis

In line with the contents of the operating protocol/processes, be prepared to provide adequate answers to some crucial questions during the whole follow-up period (monitoring consistency of care actions).

Key questions

Q160. How is the health and social situation being managed?

Q161. What social and health assistance is being offered to the care recipients?

Q162. Which integrated service, if any, is offered to the care recipients?

Q163. How are informal carers being involved in the provision of care?

6.3.5 Task 4: ethical and legal issues

Return to chapter 4.4.3 and verify if recommendations on these issues are respected.

6.4 Refining systems and processes

6.4.1 Objectives

- Observe the service in operation, with a special view to service processes and the way they are supported by ICT.
- Collect feedback on service performance and satisfaction from stakeholders involved in the service.
- Based on observation and feedback, again review the service specification, activities and roles of stakeholders against what is now being done.
- Update your cost-benefit model.

Description

After the service has been in operation for several months, and after initial problems and glitches have been resolved, it is time to take stock and check the operational practice against the plan. This is similar to what you have done already in step 4.2 and 5.1, but may now include the first changes to how the service is being provided.

The operation of the service under day-to-day conditions may have led to deviations in relation to the service specification, the ICT specification, the legal and regulatory requirements, and the business model. Again, some of these deviations will be necessary, either as necessary adaptations to real-life conditions, or because your thinking about what the service is and does has once more advanced. But other changes may have crept in inadvertently, especially since there are now many people involved, all with their own ideas.

Once more, make an effort to systematically revisit:

- The care pathways.
- The technical system supporting delivery of the pathways.
- The legal and regulatory requirements.
- The service costs & benefits.

All deviations should now be checked, not only against the original plans, but against key performance measures and the feedback of staff, patients/clients and other stakeholders.

Key questions

Q164. Is the service running more or less as planned/expected, or are their major deviations? What are stakeholders saying?
Q165. What is your assessment of the deviations? Are they OK, or can they at least stand for now, or do they need to be remedied immediately?
Q166. Are all planning documents, including the care pathways and the technical system overlay, up-to-date, reflecting what is actually being delivered?
Q167. Did you take the time to revise your initial model of what the impacts of your service on the different stakeholders (in terms of costs and benefits) are likely to be?

Tips

T115. Listen to rumours as well as to “official” feedback that you hear. Some problems may take a long time to surface.

T116. Make a list of all deviations that you observe and do a SWOT analysis (Strength, Weaknesses, Opportunities, Threats) for each of them to find out how you should react.

T117. Reserve another half-day for a cost-benefit workshop with all major stakeholders. Based on the cost-benefit model from the last workshop, ask stakeholders to confirm or revise their initial expectations.

7 Course corrections

Your rocket is out of sight now, only a column of smoke remains showing its course from the surface into space. You are back in the control centre for the first crucial after-launch activity: correcting the pre-programmed trajectory to ensure that your rocket stays on a true course towards its final objective.

By now you, and all those working with you, have come really far and achieved a lot.

This is now the time to take stock of what has happened so far, and draw conclusions from it. Did the initial operation of the service go well? What went wrong? What was good? What is the feedback from the users? Now is the time when the definition of performance indicators, the data collection and the evaluation really pay off. There is a lot that you can learn from such data. As much as possible, you should now try and analyse every part of the service: work processes, technical systems, staff performance, outcomes, what patients/clients think, etc. Beyond a (more or less) formal evaluation, there is more "data" to be gleaned from what people have said in passing in the last few weeks or months. Front line staff, informal carers and other people who are actively involved may have experiences that do not show up on any spreadsheet. In SmartCare, we had a dedicated online tool to collect the experiences of front line staff; we included these in our final analysis.

And while your evaluation data may well be useful for academic purposes, its main purpose is somewhere else: to help you improve your service, and prioritise the measures that you need to put into place now. For your rocket has not yet reached its final objective and will require constant tending.

The principle activities in this stage cover:

- Addressing immediate problems.
- Reviewing service performance.
- Taking key decisions on future operation.

"So the universe is not quite as you thought it was. You'd better rearrange your beliefs, then. Because you certainly can't rearrange the universe."

Isaac Asimov, Gods Themselves

7.1 Addressing immediate problems

7.1.1 Objectives

- Identify incoming issues.
- Define sensitive areas and define protocols for intervention.
- Set up corrective actions.
- Measure effectiveness of interventions and prevent reoccurrence of problems.

Even though careful planning may minimise the occurrence of problems, it is inevitable that some issues come up with the risk of disrupting the service. Among others, problems may be related to platform malfunctioning, device malfunctioning, organisational glitches, change management issues, inadequate knowledge, low computer literacy, and lack of an adequate understanding of individual and team responsibilities.

7.1.2 Task 1: Alert system and communication

Each system needs to design and effectively implement a good communication system. Such an integrated communication system is at the heart of the ICT platform and of the whole concept of integrated care.

Key questions

Q168. Have you planned the technical features that will allow alarms to be triggered in case of system malfunctioning, or even pre-emptively detect system malfunctioning?

Q169. Have you provided adequate training to all stakeholders concerning alarms response?

Q170. Have you set up a shared protocol/process for activating the problem solving line?

Q171. Are you keeping a log of events/problems and solutions?

Tips

T118. Train all stakeholders so that they become aware of problems and solutions.

T119. Define clear actions and make communication a shared business.

7.1.3 Task 2: Who, what, where and when

No system, no matter how highly developed, can function without a clearly defined chain of control and a person-centred accountability system. The main risk of integration is that each person along the line may think that someone else is responsible for the issue and is already fixing it!

Key questions

Q172. Have sensitive areas been identified?

Q173. Have preventive/corrective actions already been defined and specified in relevant protocols?

Q174. Who is responsible for monitoring and supervising sensitive areas? E.g. technical, management, organisation, etc.

Q175. What is the problem related to? If it is a technical problem, is there an automatic alert?

Q176. Who is responsible for taking action in case of specific alerts (technical, healthcare, social, etc.)?

Q177. How will you know the problem has been solved?

Q178. How will you prevent the problem from reoccurring?

Tips

T120. Write a protocol that is structured into different sections according to the number and type of problems that might arise.

T121. Identify who is responsible for supervising these areas.

T122. Organise meetings to share knowledge of such a protocol/process, and update it if necessary through regular contributions from stakeholders.

T123. Make sure that new professionals coming on board are adequately trained, not only in the use of platform and devices, but also in personal accountability and actions to be taken should problems arise.

T124. Supervise and provide regular feedback to stakeholders, to keep attention and motivation high, while reinforcing positive behaviours/outcomes

7.1.4 Task 3: Prevention is better than cure

Some problems cannot be avoided; some others can and should be avoided with good knowledge, adequate planning and sense of collaboration.

Key questions

Q179. Does every member of your team (both formal and informal stakeholders) feel accountable?

Q180. Is your team cohesive?

Q181. Have you and your team carried out change management brainstorming exercises?

Q182. Do you have regular debriefing meetings in place to check status of the issue and set up preventative measures?

Tips

T125. Build a trusting environment.

T126. Stay open to change. If something does not work, be ready to change it.

T127. Make everybody's voice heard. Accountability starts with acknowledgment of each and everyone's role

7.2 Reviewing service performance

7.2.1 Objectives

- Collect all data that you have available about the performance of the service.
- Based on these data, again review the service specification, activities and roles of stakeholders against what was done.
- Update your cost-benefit model.
- Develop a roadmap for the further development of the service.

Description

After the service has been in operation for maybe a year or more, and can be observed under smooth day-to-day conditions, it is time to take stock again and check the operational practice against the plans. This is similar to what you have done already in step 6.4, but may now include further (and more wide-ranging) adaptations of the service, as well as planning the steps that will make the service future proof. This step lays the groundwork for the next step that is about making decisions regarding future service operation.

On the one hand, this step is again about the deviations that occurred as necessary adaptations to real-life conditions, or because your thinking about what the service is and does has once more advanced. Still further changes may have crept in inadvertently. On the other hand, and using the comprehensive data that you should have available by now, you can now also identify those elements of your original plan that worked well and those that did not.

Once more, make an effort to systematically revisit:

- The care pathways.
- The technical system supporting delivery of the pathways.
- The legal and regulatory requirements.
- The service costs & benefits.

Make an effort to establish causal links between certain performance measures and the different elements of the service. Following consultations with your stakeholders, you should keep favourable elements, and change or remove unfavourable ones. All changes should be documented in a roadmap for future improvements.

Key questions

Q183. Does the service produce benefits for all stakeholders? Who is losing out, and why?

Q184. What are the strong and the innovative elements of the service?

Q185. What are the weak and the unsustainable elements of the service?

Q186. What are the elements of the service that require improvement?

Q187. Are all planning documents, including the care pathways and the technical system overlay, up-to-date, reflecting what is actually being delivered?

Tips

T128. You could use the B3 Maturity Model for Integrated Care again to assess all elements of the service (planned and unplanned), and identify those areas that have changed (from the first baseline assessment) and, in particular, those areas that still require improvement. This would be, in effect, a SWOT analysis (Strength, Weaknesses, Opportunities, and Threats).

T129. Reserve another half-day for a cost-benefit workshop with all major stakeholders. Based on the cost-benefit model from the last workshop, ask stakeholders to confirm or revise their initial expectations.

T130. The final care pathways, results of the cost-benefit analysis, and the roadmap, make an excellent presentation package, especially for decision makers.

7.3 Taking key decisions on future operation

7.3.1 Objectives

- Lay proper evidence-based foundations for the future of integrated care.
- Help organisations be ready for sustainable up-scaling.
- Identify roles and responsibilities of key actors.
- Help decision-makers to make informed and sustainable decisions.

While there is widespread agreement that ICT can be highly beneficial to citizens from a healthcare and a social care standpoint, the challenge still exists to implement real, effective integrated care, supported where-ever relevant by ICT. It is mandatory to address the issue of long-term decision making so as to propel integration of health and social care from a pilot and/or academic exercise to a cultural, economic and social structure.

7.3.2 Task 1: Gathering evidence

At this point, clear-cut evidence of the economic benefits of integrated care may still be inadequate, mainly because of the paucity of randomised trials. It is important to bear in mind that indicators should be multidimensional so as to measure both direct and indirect costs to the individuals and their communities.

Key questions

Q188. What kind of evidence of efficiency/effectiveness of interventions have we gathered thus far?

Q189. What are the areas which show greater evidence of benefits?

Q190. Can your regional experience be compared to any other one? If so, how?

Q191. Have you carried out a cost-benefit analysis?

Q192. Do you know how savings in one area of your health/social care system may positively or negatively affect any other area?

Tips

T131. Review literature with particular focus on the comparability of experiences in different regions. Cultural, economic, structural, political differences may affect the meaning of the outcome, besides the outcome itself.

T132. If you're planning for a widespread deployment of integrated care interventions, organise it in a way to provide evidence-based results which may be used by management and political leaders to make future decisions.

T133. Use a cost-benefit analysis and/or predictive modelling tool to help you plan and build reliable scenarios.

7.3.3 Task 2: Understanding the present while envisioning the future

Each intervention is carried out on a day-to-day basis. However, just as careful planning is a must, so is a realistic and yet visionary approach for the future.

Key questions

Q193. What is your community/region/national understanding of integrated care?

Q194. What is your vision for the future of integrated care in your region?

Q195. Is integrated care an intervention only implemented because of its cost-effectiveness, or because is it viewed as a strategy aimed at activating multi-layered health and social care changes?

Q196. Who makes decisions on implementation and scalability of integrated care services?

Q197. What are the stakeholders' opinions on the benefits/pitfalls of integrated care?

Tips

T134. Start planning for future scenarios and implementation at an early stage.

T135. Collect stakeholders' opinions, notably in focus groups.

T136. Identify the most viable solution and pursue it through small building blocks.

7.3.4 Task 3: Wake up leaders and communities through effective dissemination and communication

No decision can be made or elicited without a very clear picture of the background against which this decision stands and of the economic/clinical/cultural/social impact that such a decision may have on our communities. Only deep knowledge and good vision may help communities navigate through change.

Key questions

Q198. Who is actually making decisions for the healthcare and social care future in your region?

Q199. How much do top managers/leaders know about the meaning/costs/economic and social sustainability of integrated care?

Q200. Have they been included in the initial decision-making and planning process?

Q201. Do you have a clear plan of how to disseminate information, communicate results, talk to formal and informal stakeholders, and let their opinions be heard by the top management?

Q202. Do you use multimedia forms of communication, sharing both qualitative and quantitative data?

Tips

T137. Identify key stakeholders in the decision-making process (top managers, leaders, politicians).

T138. Hold early meetings and keep them updated on each and any progress and step in the process.

T139. Have them hear what front line stakeholders and end users have to say.

T140. Bring them both qualitative and quantitative cost-benefit analysis and, if really you believe it, never give up!

Acknowledgements

This work arises from the SmartCare project ("Joining up ICT and service processes for quality integrated care in Europe") which is co-funded by the European Commission within the ICT Policy Support Programme of the Competitiveness and Innovation Framework Programme (CIP).
Grant Agreement No.: 325158.

The authors would like to give thanks to all deployment sites (Friuli Venezia Giulia, Aragón, Region Syddanmark, Scotland, Kraljevo, South Karelia, Attiki, Nord Brabant, and Tallinn), including all health and social care professionals in the field, work package leaders, SmartCare service users as well as the members of the four Project Advisory Boards (User Advisory Board, Industrial Board, Committed Regions Board and Scientific Board), for their contribution to the success of the SmartCare project and therefore to the production of this deliverable.

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The SmartCare project is co-funded by the European Commission within the ICT Policy Support Programme of the Competitiveness and Innovation Framework Programme (CIP) : Grant agreement no.: 325158

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