



*Competitiveness and Innovation Framework Programme (CIP)*

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# **INDEPENDENT**

## **ICT Enabled Service Integration for Independent Living**

### **Guidelines for the implementation of integrated eCare services**

WP8: Dissemination and Exploitation

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**Authors**

Ingo Meyer, Sonja Müller, Lutz Kubitschke, Wencke Höhner (empirica)

Ilse Bierhoff, Wil Rijnen (SMH)

Mark Gretton (University Hull)

**Contributing partners**

All partners

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## **Table of content**

<b>1. Overall guidelines approach.....</b>	<b>4</b>
<b>2. Clients.....</b>	<b>8</b>
<b>3. Informal carers .....</b>	<b>12</b>
<b>4. Care professionals.....</b>	<b>14</b>
<b>5. Implementation.....</b>	<b>17</b>
<b>6. Technology .....</b>	<b>20</b>
<b>7. Efficiency and effects.....</b>	<b>23</b>
<b>8. Exploitation.....</b>	<b>27</b>
<b>9. Laws and regulation .....</b>	<b>29</b>
<b>10. Integrated care .....</b>	<b>32</b>
<b>11. Conclusions &amp; important “to do’s” .....</b>	<b>34</b>

## 1. Overall guidelines approach

Within the Independent project valuable knowledge has been gained from developing, implementing, piloting and evaluating integrated eCare services. The guidelines developed based upon these experiences provide valuable insights to stakeholders for the development and implementation of integrated eCare.

In order to collect feedback from all the pilot sites a questionnaire was developed that focused on general aspects across all the pilot sites as well as site specific questions. This was done in order to learn about aspects that occur across all the pilot sites but to also take into account the diversity of the pilots carried out within INDEPENDENT due to differing national situations and preconditions. The overall themes used within this questionnaire are mainly based upon results from workshops held as part of the Independent project. Several workshops investigated the readiness/openness for innovation within the care market from the point of view of different stakeholders, for example technology providers, care organisations, health insurance companies, and educational institutions. This input was complemented by experiences gained within the CommonWell project and topics highlighted by the Action Group B3 on Integrated Care within the European Innovation Partnership on Active and Healthy Ageing (See Appendix I).

As basis for writing the INDEPENDENT guidelines the following nine main topics were identified: 1) clients, 2) informal carers, 3) care professionals, 4) implementation, 5) technology, 6) efficiency and effects, 7) exploitation, 8) laws and regulation and 9) integrated care provision. In the following, the aspects that were discussed per main topic are summarised.

### 1) Clients:

- Incorporation of the use case development (UCD) process outcomes in service development: *Before starting the pilots an intensive process of gathering user requirements takes place. It is important to see how this work has affected the design and set-up of the pilot*
- Possibilities for service personalization before the start of the trial: *Every client is different and it is therefore valuable to be able to personalize the service. This can partly be done before starting the trial by setting personal preferences.*
- Possibilities for personalization of the services during the pilot: *Once the trial has started additional requirements might be raised by actually trying services in real life. This could require additional personalization. It however needs to be carefully planned in order to not hinder the creation of reliable and robust evaluation data.*
- The active role of the client within his/her own care process: *Increasingly it is expected from clients to take on a more active role in their own care process. Integrated care might be an added value to empower clients to take on this role.*
- The role of the community aspect within the pilot: *Another trend is the rise of virtual communities and the huge effect they have on daily life. Within the care sector the benefits of using communities can be explored.*
- The use of techniques to motivate the clients: *Lifestyle change is one of the hardest things to accomplish. Motivational techniques can be of added value.*
- The access to personal data generated within the pilot: *In terms of privacy and also in relation to the trend that increasingly the focus is on the client as the owner of his/her own electronic health record it is interesting to see how the pilots dealt with this issue and what can be learned for future implementations.*

## 2) Informal carers:

- Tasks and responsibilities informal carer: *In order to align the 'work' of the informal carer with professional care it is necessary to have a clear view of the tasks that the informal carer performs and to involve them appropriately in the development process.*
- Use of services: *Service can either be targeted at providing care to the client or at supporting the informal carer.*
- Possibilities for service personalization before the start of the trial: *Every informal carer is different and it is therefore valuable to be able to personalize services. This can partly be done before starting the trial by setting personal preferences.*
- Possibilities for service personalization during the pilot: *Once the trial has started additional requirements might be raised by actually trying the service in real life. This could require additional personalisation. It however needs to be carefully planned in order to not hinder the creation of reliable and robust evaluation data.*
- Active role of the informal carer: *The trend is that increasingly the support of informal carers is needed within the care process. Therefore it is interesting to know whether or not informal carers actively increase their own role.*
- Communication with informal carer about the client: *Often the informal carers play a role in discussing the care plan of the client. Communication is important to streamline the care process.*
- Support of the informal carer: *Providing informal care is a demanding task and therefore informal carers need to be supported. Not only by guidance on how to carry out tasks but also on an emotional level.*
- Changing role of the informal carer by using the INDEPENDENT services: *By using the Independent service the relationship between client and informal carer might change. The effect of this change can be both positive (e.g. more confidence, piece of mind, better communication) and negative (too much focus on care aspect, time consuming).*

## 3) Care professionals:

- Type of care professionals that participated in the pilot: *Due to the diversity in the executed pilots it is interesting to have a view on the disciplines involved.*
- Attitude toward the use of technology in the care process: *Increasingly it becomes clear that clients and informal carers are most of the time quite willing to try new things to enhance their quality of life, care professionals are often much more reluctant to accept to use technology within the care process and sometimes are afraid to lose their job.*
- Possibilities for service personalization before the start of the pilot: *Every care process and discipline is different and it is therefore valuable to be able to personalize the service. This can partly be done before starting the trial by setting personal preferences. It however needs to be carefully planned in order to not hinder the creation of reliable and robust evaluation data.*
- Possibilities for service personalization during the pilot: *Once the trial has started additional requirements might be raised by actually trying the service in real life. This could require additional personalization.*
- Changing role of care professionals by using Independent services: *When offering integrated care additional focus is placed upon cooperation with other care*

*professionals and supporting the informal carer.*

- Cooperation between different care disciplines and willingness to cooperate: *Integrated care will only be a success if different care professionals are willing to share information and jointly develop care plans.*
- Use of data generated within the trial to adapt care plans: *Data generated within the pilot is a valuable source of information for adapting care plans to changing needs and by doing so provide better alignment of the offered care for a specific client and to detect exacerbations earlier.*

#### **4) Implementation:**

- Recruitment of participants for the pilot: *A description of how the participants were recruited including success and failure stories.*
- Preconditions for installation of INDEPENDENT services, both in homes as in care organizations: *The Independent services become part of an existing infrastructure so it is important to identify beforehand how the integration will take place.*
- Training provided to all involved stakeholders: *Explanation needs to be given on the use of the INDEPENDENT services to ensure correct use and that participants know about all the possibilities of the services and feel confident to use them.*
- Approach in case of changing needs of stakeholders/encountered problems: *Pilot site organizers have to agree upon an approach on what to do when additional requests are made and in case of problems with the Independent service.*

#### **5) Technology:**

- Preconditions for the chosen technical set-up: *Reasoning behind the chosen solution for the pilot.*
- Level of knowledge about the chosen set-up before the start of the pilot: *Due to the fact that increasingly organizations have some experiences with the use of technology in the care process it is important to know the amount of experience that is available.*
- Integration process of the components of the technical set-up: *Integration is a key factor for the success of the pilot.*
- Modularity of the technical set-up: *To be able to respond to changing demands and to be flexible in terms of people wanting to use not the whole but only parts of the system, modularity is important.*
- Procedure in case of technical failures: *In case problems occur during the pilot it must be clear who is responsible for providing a solution and within what timeframe.*
- Possible technical improvements that would have a positive effect on the pilot: *Part of the pilot evaluation is technical improvements that can make a huge difference for the persons that are part of offering or using the Independent services.*

#### **6) Efficiency and effects:**

- All pilot sites have identified expected effects in the developed use cases. In the evaluation report in-depth insight will be presented on the occurred effects. In the guidelines attention will be given to expected effects but also the possibility was presented to indicate effects that were not anticipated but did occur during the pilot.

## **7) Exploitation:**

- To be able to consider exploitation of the developed solution and services reliability both of the technology and the delivery processes is a pre-condition. *During INDEPENDENT, the time and effort invested in the development and testing of the prototype systems as well as the experiences made during pilot operation proofed invaluable in achieving reliability.*
- In case needed the involvement of third parties to finance the services: *A possible solution to the issue of finances can be the involvement of third parties.*
- Distribution of costs and benefits among stakeholders: *It isn't always the case that the person/organization who pays also gets and equal share of the benefits.*

## **8) Laws and regulation:**

- Laws and regulation that have affected the pilot: *Laws and regulation can have a positive effect on the pilot but also a restricting.*
- Possible influence of upcoming laws and regulations: *Integrated care including the use of technology is an upcoming and highly dynamic area. Therefore laws and regulation are still being shaped.*
- Insight into laws and regulation that could offer huge advantages to the pilots: *In order to make progress laws and regulations can be restricting. Insight to the types of restricting aspects is important for policy makers.*

## **9) Integrated care:**

- A description of all involved stakeholders: *Pilots focus on different aspects and therefore involved different types of stakeholders.*
- Insight into the type of stakeholders that currently weren't involved in the pilot but that would be taken on board next time: *When setting up a pilot decisions are made on the stakeholders that are involved. When carrying out the pilot it might become apparent that stakeholders groups are missing.*
- The way the continuum of care is incorporated in the pilot: *Care is not static. Focus should therefore be on the continuum of care that consists of a focus on prevention and informal care as well as formal care and cure*

## **10) Conclusions & important “to do’s”**

## 2. Clients

Part of the INDEPENDENT project was the development of the system and services based upon a user-centred design approach. Pilot sites indicate that by using this approach before the start of the trial all the major requirements could be gathered. However, there are always some client needs that are not apparent until the actual pilot is running – in large part because as you recruit different people from the ones you tested the system on, you will find new issues. Furthermore it was also clearly stated that collecting user requirements is an iterative process.

This continuous monitoring of the use of services must take place on a technical level as well as on a content level. With respect to technology the pilot sites indicate that even though most of the issues were foreseen, others were raised during the pilot which are been dealt with thanks to the support from the helpdesk and the operational team, recording the incidences and forwarding them to the technical team which study them and provide solutions as required. In terms of content there is a need for having regular checks on the clients for future improvements. The clients can give their opinions and feedback in relation to the service, which in turn is used as an input for the design of the new updates and system on-going feedback. When this client feedback is collected and analysed, also client training and training materials can be enhanced.

The collection feedback from clients that make use of the integrated care services is vital for refinements of the services. A structure and process must be put in place to collect the feedback, incorporate the feedback in improvements of current services and the development of new services, and communication mechanism must be developed in order to give feedback to client on how their feedback is taken into account.

With an increasing number of organizations that in one way or the other have gained experience with the use of technology as part of care provision a thorough evaluation of previous pilots conducted is important. By building on previous experiences and formulating lessons learnt big steps forward can be accomplished with less effort.

Use previous experiences to get to the core of problems, the added value of services, and vital pre-conditions. By doing so long-term data on the use of services can be collected. Connecting pilots that strengthen each other makes each individual pilot much more valuable.

With respect to collected data there is often a strict division between organizations that collect non-medical information (e.g. address, contact points, history of events, habits, etc.) and organisation that collect medical data. When a service encompasses with aspects it is important that the client perceives it as being one service.

Even when different organisations jointly take care of offering a service to the client it must come across as one organisation taking care of all aspects surrounding that service.

How to adapt a service for a specific user is a question that can be approached in different ways. Firstly focus can be on the initial assessment of the needs of the client. In order to make the integrated care services individualised for each user, the assessment must be carried out by the “Home Care Coordinator”, a person who is also assessing the person’s wider needs. In this way the Home Care Coordinators can determine exactly what parts of the integrated care service would be required to assist the client.

Secondly in terms of the ability of the client to use technology there can be big differences. The

service must be offered in such a way to on the one hand not discourage the inexperienced user by making it too difficult to use a service but on the other hand to also not discourage the more experienced user by removing functionalities that they are used to have.

Thirdly in terms of disability awareness, features such as enlarged fonts, zooming possibilities, and easy screen navigation are offered.

Fourthly in terms of the service differences can occur. For example clients performing exercises do not all have the same capabilities and the service should facilitate that for each client a challenging exercise program can be offered.

Fifthly the environment that is used to offer the service can be altered. For example, an environment can be used that enables people to access the system alone, if they need privacy, but that is also spacious enough to allow someone to help them, if they need assistance. In shared-care areas for example the use of barcodes to access the system worked well to protect privacy and provide a personal service, whilst allowing the system to be multi-user friendly. Another example is that wall bars were provided for clients in the shared-care areas, as it was found that some clients had difficulty standing freely on weighing scale without losing their balance. As a result clients had to be taught how to steady themselves as they weighed themselves, so they didn't 'hang on' to the bars and distort the readings.

Personalisation needs to be taken beyond the setting perspectives to better follow the changing needs of clients. Some aspects to consider:

- 1) Integrated care services are part of a service package that assists the client. A broad context of the client's life is needed to understand how the service could fit into daily practice and provide real support.
- 2) Provide version of for example the interface for clients who have no computer experience but also more advanced versions for clients who do have computer experience.
- 3) Disability awareness
- 4) Facilitate diversity in the use of a specific service
- 5) Also take the environment where the service will be used into account

Within several pilots community/group aspects were observed. In one area people were very motivated by group factors, as at one of the sheltered homes they formed a 'lunch club' whereby they would go along and record their observations together and then go out for lunch afterwards. There did seem to be an informal competitive element here, as they teased one-another about their respective weight and blood pressure.

A change in lifestyle is complicated. Technology and care professionals can support this, but the real change should come from the clients. In the project we noticed that the social aspect (group coaching) plays an important role with the change of behaviour. In lifestyle change a lot of facets play a role, those aspects differentiate per individual. For COPD an important motivational factor turned out to be the social aspect. So the health improvement in groups.

People were motivated to use services by newsletters, support groups and forums. Group factors can play a huge role and encouraging use of services. More work could be done in group environments, not only with potential users but with family and friends to encourage the use of the system. It is known that learning any new skill is best done with lots of support to lend a hand to encourage and further teach.

The beneficial effects of group factors were highlighted during the INDEPENDENT pilots. This is an area that requires more research in order to fully benefit from its effects.

Besides group effects professionals also play an important role. Clients were motivated by creating individual exercise plans and goals to fit their needs. They got a lot of one-on-one coaching. The technology always had a supporting role. Without the active guidance of the coaches, the technology would have been used a lot less.

Clients were also motivated by the staff as they were available to manage problems and by being around for them to talk to about the service, so they were quite visible to the users. This was necessary for some people, whilst others were clearly self-motivated and were happy to access the system and use services anyway.

People with dementia and family carers did not require motivation to use the telecare. The satisfaction ratings with the telecare were high, and indications from the satisfaction questionnaire show that the majority were keen to continue to use the system, for as long as the person with dementia remained at home.

Care professionals can also have a motivational influence by being available to clients and to take on the role as coach. When services clearly contribute to being able to live independently no additional motivation is necessary.

Sometimes the client that participated in the pilot were people with dementia. This means that they do not have the capacity to take a prominent or active role in the pilot. All attempts were made to identify people who did have capacity and include them directly in the evaluation.

The clients were full and active in all stages at the pilot and were keen to let know what they like and what they did not. This should undoubtedly be built on, and will continue anyway as people increasingly (and rightly) demand more say and more choice in managing their health and social care needs.

Within the INDEPENDENT pilot the participants took an active role in being involved in the pilot and by expressing their experiences. This is however one step before people taking an active part in their care process. In order to explore this aspect the service should function without flaws and can incorporate aspects that would make the client interested in data generated.

In terms of access to data generated within the INDEPENDENT pilots a group of clients that requires a different approach are persons with dementia. Not all of these clients have the capacity to make decisions regarding access to the data generated by the telecare system or the web portal. Informed consent was obtained from family carers regarding care professionals accessing telecare data.

In anticipation of the mental health capacity act, a process of determining the capacity of the person with dementia has been implemented – the functional test of capacity. This was also used in the evaluation of the INDEPENDENT project. If the person with dementia has capacity, then he or she gives informed consent to a decision about care. If the person with dementia does not have capacity, then the family carer is the person who gives consent.

It should be noted that, due to the nature of dementia, care plans are adapted and changed on an on-going basis as a matter of course. The INDEPENDENT project did not initiate adaptations to the care plan as an innovation, rather the idea was to use the information generated by the telecare system to provide further information that could be useful in care planning; an integration that did not exist before.

When other target groups were involved they were very interested in the measurements, and wanted to know what the results meant, whether they were 'doing well', whether any of their results were problematic. From the focus groups some of them undoubtedly made use of the information when visiting their GPs and in managing their own weight.

In one pilot site using a questionnaire to collect information on the health of a client was more popular than expected. The focus groups indicated that a number of clients used this facility, and liked filling in the questionnaire, and found it reassuring and took notice of the advice it offered them on diet and exercise.

When informing the client about the collected data it means the client is aware of an issue first and can give their view. This sharing of information and providing people insight into their health condition is an important aspect to allow clients to take on an active role in their own care process.

In some pilots the focus was on enhancing the existing relationship between the carer and their assisted person(s) by means of video conferencing. Overall goal is that the informal carer sees an improvement in coping and managing their caring role. In detail this meant that if presented with a carer and assisted person to whom physical visits were infrequent this was a useful mechanism for supplying a method of daily contact, without infringing on the assisted person(s) independence. It also worked well for anxious working carers who wanted confirmation that they were ok whilst they were out at work.

The video conferencing was in no way designed to reduce face-to-face contact. In case an informal care organisation is not adequately funded for individual home visits so the video conferencing increased visual contact with individual carers.

Focus is on reducing the impact that responsibilities of informal carers have on their lives; for example allows video conference calls between carers and their assisted person allowing the informal carer to maintain contact even when they are not able to visit and in some cases reducing the number of unnecessary visits that carers make on demand.

The physical and emotional demands placed on an informal carer are many and can impact the relationship they have with the assisted person(s). The ability to manage information about the assisted person(s), to include medication history, history of well-being gives the informal carer capability to evidence or recall information when in the presence of formal care professionals, giving them greater control of the situation.

Services to support the informal carer benefit the relationship between client and informal carer. Video contact makes it possible to have visual contact even when there is no possibility to make a visit. Better insight in the 'status' of the client provides piece of mind and control, leading to more quality time with the client.

### **3. Informal carers**

The informal carer was involved on a case-by-case basis. Some carers had little input, although the clients often enjoyed talking to them about using the system. Some had more input, in assisting them using the service, or walking them to it, or encouraging them to use it.

In the early stages informal carers assisted with exploring the planned functionality and layout of the software development. Later as pilot users they were quick to identify usability issues, however most of this was reported through their trusted network, for example an informal care organisation.

When moving from pilot to large scale roll-out it is important to think of a channel that can be used to collect and share user experiences, not only from older clients but also from informal carers.

Currently a lot of informal caregivers are feeling isolated and left alone to deal with their relative's condition. No professional guidance and psychological support is given to them concerning their everyday care burden and feelings of depression and helplessness. Within INDEPENDENT several services are developed to assist informal carers.

One area where informal carers can receive assistance is providing a comprehensive overview of all relevant information concerning the client. In one pilot the developed portal offers an opportunity to record information in one place. It also allows informal carers to extract that information plus information visible from the assisted person which is useful for planned review meetings with formal care provision. In some pilots the possibility for informal carers to gain access and view telecare data is dependent on ethical issues and data protection guidelines that have to be investigated before this could be implemented. In some pilots because of privacy rules the informal carer cannot access the health record directly.

Tele-sessions were used that gave the relative the ability to realize his/her frustration and feelings, deal with everyday stress and build a better relationship with the assisted person. The psychologists did not only offer psychological support but also helped the caregiver realize the assisted person's symptoms and deal with these symptoms in a more satisfying way.

After a couple of months the first signs of relief for the informal carers were noticeable because the exercising had a positive effect on the independence of the participants. It did seem to give some informal carers a sense of increased importance if they were involved, and a sense of reassurance.

Support of informal carers is an increasingly important aspect of offering services. Within INDEPENDENT positive experiences have been gained with giving informal carers access to data about the client. This can lead to a sense of reassurance. When clients make use of services that enhance their well-being they have more possibilities to be independent without the assistance of an informal carer. The informal carer can also be supported in dealing with the disease of a client; by learning about a disease but also by sharing frustration and feelings.

In terms of use of services, frequent usage was found in accessing information about up and coming events and booking on to the events, recording medication and accessing links to other organisations. It took longer for informal carers to understand and use the forums. This is not a familiar method of communication in this age range and it does not really have a non-technical equivalent so here training and support was needed to increase interactivity. In another pilot all of the informal carers made use of the offered services. Most of them were quite content. Some of them had a problem understanding the usage of the electronic health file.

Informal carers do use the services offered but need additional training to use services with a higher degree of ICT aspects like an electronic health record. This is mainly the case for informal carers that are about the same age as the clients but this is often the case.

Same as was the case for the client it is not possible to take into account all of anyone's requirements during service development, for the simple reason that in this sort of pilot not everyone involved in testing and early use case iterations will be involved in the final pilot, and the pilot recruited people who for various reasons had not been involved in earlier testing. But informal carers were present at all stages of the proposal and their views were always taken into account.

One pilot site indicated an important additional aspect for the personalization of service. They indicated that Tele-session is a service characterized by the ability to adapt to the needs of each case whereas the health files have a specific form that is considered to be adequate for all cases.

Additional aspect personalization:

6) Take into account the level of personalization that is of added value. Sometimes consistency is key to a good service, like for example the way an Electronic Health Record is set-up.

When changes are made to the care plan of the client it is normally orchestrated or heavily supported by the informal carer. In home care, informal carers are usually the person who reports such changes in health conditions to the professionals, such as GP's and occupational therapists. Where they are not, it would be dependent on the relationship between the informal carer and the assisted person.

The informal carer is responsible for the assisted person's care and needs. During the sessions he/she can discuss with the health professional the problems that he/she faces and with the psychologist's guidance make any necessary changes.

In the UK as in many other countries there is very little joint up between informal and formal care. In so far as the remit of the informal care organisation as a commissioned service provider allow we have ensure that communication methods within the portal accommodate these methods. However, as previously determined this project was too early in an infrastructure change to allow a system link between this and formal care systems. Also the informal care organisation is only responsible for the support of informal carers and not the assisted person.

Initial experiences have been gained on how ICT services can enhance the communication between formal and informal carers. However, the task division between formal and informal care is still quite conservative. Different types of services need to be developed when the goal is to have an equal interaction.

## **4. Care professionals**

A variety of care professionals have been involved in the INDEPENDENT pilots. Some examples are psychologists, social care workers, health care staff, physiotherapist, tele-operators, nurses, and managers. In order to cooperate they had meetings and discussed what would be the best way to collaborate.

In general the attitude towards the use of technology as part of care provision was rather positive. In some cases the attitude became even more positive during INDEPENDENT because as the possibilities were being presented throughout the pilot the National Agenda was also changing bringing the partnerships supporting carers to a high level of importance.

Some care professionals were already using the technology as part of their daily work in the call centres and INDEPENDENT has been an improvement of the system without any change in the attitude to the use of the technology itself. They see the technology as part of their work when contacting the users, and the improvement in the efficiency and also the communication between service providers has been evaluated positively. A local authority indicates that technology has played a significant role in its delivery and performance for some time. However, system link and data sharing is still an extremely important issue. A pulmonologist had a very positive attitude towards the service. In the future he wants to inform clients digitally more often than face-to-face. A pulmonary nurse noticed improvements in the condition of her clients and that made her enthusiastic.

After using INDEPENDENT services, clients are able to be serviced remotely, most of the time with the help of a formal care giver of their own, in real time. This leads to a better management of professional staff, as they are able to service milder cases remotely, reducing the number of cases where their presence is necessary and thus involve travelling. This way, the clients don't have to visit an institute or nursing home physically which is more convenient for doctors/medical staff and enable them to be more effective in performing their job. Finally, the fact that an electronic client record is used with access not only to professional medical staff but also to the clients' relatives, significantly reduces the consumption of time that is used by medical staff to inform any interested relatives about the client's status. Thus, the positive attitude doctors and social workers have mainly depends on the reduction of their workload.

Monitoring nurses were comfortable with the technology and merely had to be schooled in systems that they had not previously encountered. They sometimes preferred one system to another, but were comfortable with both. The community nurses were more likely to be sceptical at the outset, due to less familiarity with this type of system, but appeared to trust it more by the end. Social carers were quite enthusiastic about it from the start and generally remained so, though they sometimes became critical if there were failings caused by equipment or technology.

The attitude of care professionals who participated in the INDEPENDENT pilots was already rather positive due to previous experiences or willingness to participate. During the pilot reduction of workload appeared and a positive effect for the clients are important motivational factors. This willingness to participate is a vital aspect to be able to carry out the pilot. Care professionals who already have gained experiences with the use of ICT can act as ambassadors for other care professionals. They can educate less experienced care professionals.

Sharing the health file with others then care professionals is not always easily realized due to data protection regulations. For example the issue of data sharing with non-formal organisations has been subject to years of national debate in the United Kingdom and is only now being attempted in small ways, always ensuring that it complies with Government data protection and associated ethical issues.

Even when it is attempted the cost implications of such systems are extremely high as you are not dealing with linking one organisation to another but one to many. When dealing with informal care organisations each will have their own specific systems.

Other constraints that were experienced are related to the costs of implementation. Pulmonary nurse mostly sees added value in the sharing of data through the EHR. Because of expensive technical implementation this has not been fully realised. Furthermore all requirements expressed by care professionals have been taken in account. The requirements that were not met had to do with technological limitations or costs that the adaptation of the technology would require.

Care professionals sometimes also face restrictions on a technical, organizational and legal level in their enthusiasm to try out new possibilities. It is vital that those barriers are taken away for integrated care to be a success.

Within pilots often the services are compiled based upon the general feedback from the different groups of actors, but once implemented the service itself is standard. Small changes can however be made. For example the coaching website Activ8 has been adjusted to the requirements of coaches and users. Also several form/tabs in the Electronic Health Record were adjusted to enable the treatment registration properly.

Sometimes request for changes come from the client. Changes are made based upon client needs and health care professionals are informed accordingly. This was partly due to system constraints – once we had developed systems based on everyone's input, including care professionals, it was difficult and not appropriate to change them too markedly – and partly due to the fact that this was not generally asked for once the pilot was operational.

Care professionals are also inspired by the implemented services. Physiotherapists and sport coaches are for example exploring new ways of smart exercising. They recognize opportunities for the future.

Additional aspect personalization:

7) Use the creativity of care professionals to optimize services and develop new services.

Cooperation between disciplines was enhanced within the INDEPENDENT pilot. For example in the past, the pulmonologist and the pulmonary nurse only felt responsible for the clinical treatment. Because of the good aftercare and communication the pulmonologist and the nurse can make better agreements with the patient about aftercare and guidance in it.

Communication is the most important aspect for the cooperation. For example the integrated care records that were created build an immediate communication bridge for all involved care professionals (psychologists, social workers, relatives even private doctors) creating a very useful inter-communication tool. Furthermore the exchange of information and points of view helped to understand each other's service.

The willingness to cooperate was sometimes prohibited by current internal and external data protection governance. A further integration of ICT services is desirable. The requirements of the involved parties vs. the available budget in short term is of importance. Even though long term health benefits are achievable, the financial business case has to fit as well. At this moment this was a difficult situation. Further, financing models are sometimes obstacles for cooperation as well. Some institutions were not willing to refer patients for the project. They were afraid to lose patients and therefore the funding from insurance companies and governmental authorities.

In the future more work should be done with other professionals as early as possible, though the experiences of other telehealth and telecare projects suggests this is always difficult, as such people are hard to engage until they see a system in action.

Cooperation between disciplines increased during the INDEPENDENT pilots. It however sometimes got to the point where regulations, financing models and technology prevented further cooperation. Therefore more emphasis should be placed on aligning organizational, technical and regulatory aspect needed for optimal cooperation between disciplines. Some issues can be dealt with beforehand others will occur during the pilot. A clear decision process needs to be in place on how to deal with those issues.

In terms of practicalities of the cooperation between disciplines difference occurred between the pilot sites. Some had a detailed procedure for the cooperation others cooperated based upon the professional experience. For example the monitoring nurses assessed the data and, where appropriate, involved other professionals. This is the value of having clinical monitoring triage done by clinical specialist nurses. In another case a medical professional visited the centres on a weekly basis conducting basic medical procedures such as prescriptions etc. This doctor also has limited access to the EHR which enables them to be informed for any major change on the elderly as well as the caregiver's status and vice versa.

Depending on your own organization a procedure on how to share and interpret data needs to be in place. This procedure should be in line with current practice and level of cooperation required. Don't overdo because of technical possibilities. It must have added value.

## 5. Implementation

Important part of the implementation of a pilot is the recruitment of participants. The Independent partners prefer to recruit via persons who know their clients and can highlight the potential for increased support to their clients. When recruiting participants for a pilot a clear description must be made about the type of participants that can have added value in the early stages of development of a service. This could very well be a slightly different target group than would be selected for a 'market product'. Having a clear view on what type of participants to involve avoids the investment of a lot of resources in filtering participants from a large group of potential candidates. This clear view also leads to a clear message towards potential participants on what is expected from them.

A risk when narrowing down the type of participants that can be part of the pilot is that the inclusion and exclusion criteria are so detailed that a lot of potential participants cannot join the pilot. For example in one of the Independent pilot sites it was specified that the person with dementia must have an identified main family carer, and that the person with dementia must live either at home or in a supported independent living facility. A significant number of people did not have an identified main family carer (n=13), and therefore could not be included in the evaluation.

When setting recruitment criteria make sure that the criteria are in line with the goal of the pilot. Be aware that setting a lot of criteria might make the group of potential candidates very small whereas setting very broad criteria might lead to on large group of potential candidates that needs to be filtered.

Another aspect is that for pilots often a fragile user group is targeted. So for example in one pilot attrition was high due to the fact that the majority of clients had moderate or severe dementia, and entered residential care. These could not be evaluated. A number of clients also died during the course of the project. It is hard to think of another way to enhance recruitment for evaluation under these circumstances. One option would be to identify and recruit people who have mild dementia, however telecare is not really applicable to this group. Another would be to change the longitudinal nature of the research to one that is more flexible, such as action research or process evaluation. None of these options solve the challenges inherent in researching community-dwelling people with dementia in the context of telecare.

Within integrated eCare projects that include fragile target groups there is a trade-off between testing a service in practice and learning from it and sound scientific research. A balance must be found between being able to offer real support to participants and being able to deliver scientific data on the effect of using the services. There are some known risks when testing with fragile user but that shouldn't prevent somebody to try out services with this target group.

In some cases no recruitment was needed, for example when the innovation was carried out in the organization leading to any user of the telecare service being part of the pilot when requesting a medical appointment of medical advice.

In order to keep participants motivated constant, consistent communication about the project progress is vital. Organisational preconditions to carry out a pilot are partly related to motivation of participants. For example continual encouragement by the informal care organisation and other family members to use the system and get PC literacy support can be given. Organisational requirements can also include the availability of care personnel. In one pilot site for example the availability of home care co-ordination staff was mandatory to monitor the use of the telecare packages, assess for new telecare packages and to recycle old packages.

Organisational preconditions indicated by the pilot sites are increasingly the availability of care personnel to monitor the use of services, to assess if additional services or changes are required and to motivate the participants in the pilot.

Technical preconditions are related to the need for a stable broadband service and a consistent level of PC software maintenance to ensure that all version updates are carried out to allow full system functionality. Increasingly participants have equipment at home that can be used as part of the pilot. When in place people also expect that they are able to use their own equipment. It is however difficult to predict the extreme variants in the age and software compatibility of each users machines.

Technical preconditions in the home environment are a stable broadband connection and (PC) maintenance to keep the system up-to-date. A thorough review of existing equipment is needed due to variety in age and software compatibility of home equipment.

Maintenance can be approached in different ways. The ICT infrastructure can be delivered and supported by a third party IT company not involved in the project. When this is the case all communications has to go through a pilot partner and then they would communicate them to the company, which can delay and blur the issues. The pilot partner in this case for example manages contacts between all other parties and the end users. Also when procuring the hardware/software technologies from the manufacturers, it can be negotiated and contractually agreed that installing (if applicable) and maintenance is included.

Another possibility is that the pilot partner has a technical team that is involved in the pilot. For example a team that is responsible for making the ADSL lines installation as well any internet lines where needed. That team is also responsible for the training of the users in using the equipment, maintaining the services and solving any technical problems.

In terms of installation and maintenance of the technical equipment roughly there is a distinction between outsourcing to a third party and having a technical team within the own organization. When outsourcing it is important to have a good communication channel and agreement on used terminology to describe possible problems. When providing maintenance within the own organization this needs to be incorporated into the organizational structure of the entire organization and not as a separate activity.

The offered training was a mix between face-to-face contact and supporting material. The duration of the training needed varied to a large degree and training took place repeatedly. For example at least once a month for carers and assisted persons and at the time of relevant document releases or government changes for care professionals.

A help desk operated by project partners was in place and for example provided support to the end-users in case of questions concerning the service delivery process. Users who are enrolled to the pilot service can call or sometimes even physically visit the helpdesk. In some cases the help desk also provided technology related support, which initially may include remote instructions (by phone) and if required a home visit by a technician.

Training also took place between professionals, for example staff from the telecare call centre has received special training by psychologists and the technical personnel in interacting with the pilot users. In addition technicians have trained the psychologists and the social caregivers to use the Independent system. The latter have been shown the functionality of the IP video phone devices and part of the Telehealth Electronic Health Record platform. Furthermore, they provide instant instructions to end users immediately after they have installed any equipment at the users' premises. Furthermore, technicians and psychologists together train the pilot users if possible in group sessions

whereby the number of 10 participants is not exceeded. Both technology related issues and service process related aspects regarding the tele-counselling are addressed. Finally, specialised technicians from manufacturers have trained technical staff at the pilot site in the use of the Electronic Health Record platform, in dedicated face-to-face sessions according to a "train the trainer" approach.

Training can not only function as a tool to explain the use of services but can also play a role in the cooperation between the different stakeholders involved in the pilot. By jointly explaining both technical as well as care related aspects there is also a joint learning process on the use of services. Professionals with different backgrounds can also train each other, the "train the trainer" approach to broaden knowledge within the organization.

When the pilot has started the majority of the changes that were made to the system where ones that affected operability. When there was a request for a different type of change some pilot sites used a decision process, for example such a process consists of the following steps: 1) Evaluation level of importance; 2) Technical Implications and implications on evaluation; 3) Development and Implementation Costs and resources required and 4) Final evaluation of justifiable benefit. In some cases satisfaction questionnaires are issued to clients on a regular basis which assess the need for change to existing services and potential need for new service provision. However not all functionality was possible as it was deemed outside of the project. For example issues like linking some of the functionality to similar functions on the informal care organisations website weren't possible.

When a pilot has started a clear strategy needs to be in place on what to do in case somebody requests a change. On the one hand it is important to guarantee the reliability of the system but on the other hand it is important to take into consideration feedback of users and act upon their suggestions to show that their input is valued.

## 6. Technology

Technical reliability is one of the most important aspects of conducting a pilot. Technical flaws can sometimes lead to not using specific functions, for example in one of the pilots delay in video communication led to people only searching for information and not calling the service provider.

Even when a pilot is concerned and not a market product reliability of the technical system remains one of the most important aspects to even be able to carry out the pilot.

The selection of most suitable software and hardware is based on technical analysis and includes:

- Current infrastructure
- Required functionality
- Security and data protection (walled garden)

Increasingly equipment from previous pilots is used so the main objective would be to improve the service without increasing the costs to the users. This can be done by building upon an existing architecture, a software upgrade or to reuse equipment.

Increasingly there is already some sort of technical infrastructure in place, not only in homes but also in organisations, therefore integration into current infrastructure is an increasingly important aspect. Furthermore data protection, especially in relation to the electronic health record, is an important aspect of the technical set-up.

Partly due to the fact that already equipment is in place within the organization it is possible to build upon previous experience. For example in a pilot site the first version of the Electronic Health Record (EHR) was developed before the INDEPENDENT pilots but in a less advanced and operational form. The EHR included only some demographic data while the integrated Independent version contains a more enhanced form having medical data and medical history of the patient as well as some more advanced features.

Integration of different components is one of the most difficult technical tasks. Within one of the pilot sites for example video software was delayed due to development and integration issues. A further delay was caused by an issue with technical infrastructure at the current data centre which impacted performance. Additional/improved infrastructure was then carried out to remove performance issues. For some pilot sites the integration process has been easier in Independent because of the knowledge gained in previous projects.

In another pilot site all the separate components like the activity monitor, health kiosk and oximeters should have been integrated with the Electronic Health Record so that data would automatically be saved in it. Because of high costs this was not achieved, therefore the measured data had to be logged into the EHR manually.

Involving a partner with previous experience on the integration of the components of the set-up is a huge advantage for the pilot. The Independent pilots again showed that a lack of integration can cause serious issues for the added value of the services offered in the pilot.

Modularity adds the possibility to the solution for easy expansion of the solution and for better fitting to the requests of the user. One of the pilot sites reported that there were no specific requests, but if clients chose to use only parts of a system – e.g. not using the messaging, or not accessing the choose and book system, but using the monitoring and interview system – they were able to do so due to the modularity of the device. The modularity's were less well developed in monitoring – for

example, the systems are still most comfortable with daily monitoring, rather than weekly – but solutions were found by creating different care plans for different user needs.

Modularity can assist in aligning the services with the wishes of a client. When the requested level of modularity isn't possible in the technical set-up sometimes it is also possible to solve the problem from a care providing perspective.

Technical failures can be detected automatically within the system. For example in one pilot the technical failures were discovered through the monitoring component of the IP video phones.

Technical failures are not always related to the system but can also occur in the supporting infrastructure, for example, broadband or data centre issues. However this is considered to be one system and the reliability of the entire system, including supporting infrastructure, needs to be taken into account.

Within the pilot it is important to have a procedure in place on how to react in case of a technical failure. For example 1) Confirm fault, 2) Diagnose cause, 3) Alert relevant party to problem, and 4) Internal procedures relating to each relevant party to resolve issues.

Helpdesk solutions were established to pick up problems, but sometimes people preferred the personal touch of contacting one of the project team who, if they couldn't solve the problem, would contact the technical support of the technology providers.

In relation to technical issues the entire system including supporting architecture must be considered. The use of automatic detection within the system is recommended for early detection of problems so that they might even be solved before the user even notices the problem. Furthermore in case problems do occur a procedure must be in place that also includes reporting procedures and feedback to the party that reported the problem. When critical services are offered sometimes other rules can apply for example in relation to response time.

In one of the pilot sites there have been a number of technical issues which centred on integration into existing software and the requests for change to various elements of the service from care personnel. The biggest challenge centred around the extraction of the data from the live call centre system and how this was presented in the web portal. There are still some difficulties in relation to care personnel not understanding some technical language which is embedded in the call centre system that cannot be amended for the system.

It can happen that even after solving a lot of issues that some still remain. In some cases additional training might help.

Another aspect that was addressed in a pilot site was the risk management aspect. Due to the fact that the used system was a standalone facility it was difficult to provide a disaster recovery facility. However after extensive research and an upgrade to the latest version of the call centre system it is possible to back up on a daily basis all the information provided in the portal. As a second step the possibility to provide a separate access facility which will be engaged over a separate network in the event of a systems failure will be investigated.

In terms of risk management first thing to take into account is a back-up facility to not lose any information. Second step is to make it possible to still retain some of the functionality in case of system failure.

Small alterations can make a huge difference when using services. For example in one pilot site the forums were altered to reflect those used on another website that was often used to harmonise user

experience. Furthermore it is possible to incorporate features to prevent problems in the design of the system. For example a video install process has been changed to better accommodate low performance broadband widths at end users homes. Another example is that several issues have been corrected in way in which the system notifies that calls has been hung up, and has established a double security protocol that calls not accidentally remain established.

Small changes in the design and the incorporation of features to prevent problems can make a huge difference in the user experience and acceptance of the system.

After taking part in the pilot for some time also suggestions for further improvement arise. For example one pilot site indicated that a further enhancement of the service could be the update of the videoconferencing sessions in order for more than 2 people to participate in the session. For the time being this could be changed in terms of audio conferencing and not video conferencing.

Improvement could be focuses on adding components but also on replacing components. For example in one pilot site the activity monitor was replaced. The initial one was very accurate but also unnecessarily complicated, it is meant for a more precise clinical measurement. The new one is also an accurate activity monitor, but much more user friendly and accessible to inexperienced users.

Even when the pilot is running it remains important to critically watch if the chosen components still are the best solution for the services offered.

## 7. Efficiency and effects

In the evaluation report all the pilot sites present their results. In this section a short summary of the main achievements will be given that serves as a reference for the type of effects can be witnessed when implementing eCare services.

### Early detection

*"The use of the well-being prompt alerts the informal carer to differences in the assisted person(s) state of mind/health. In situations where the client usually completes the well-being prompt every day the lack of use can also alert the informal carer to differences in the assisted persons pattern of behaviour."*

*"Thanks to the Independent project, the user can directly access to Salud Responde to obtain health advice just by pressing the button. In the event that during the advice, the nurse detects that the user is at risk, this is derived directly to the emergency services. Currently, users at risk are detected in 17% of health advice."*

*"Care professionals have had earlier updates about their clients enabling them to respond and re-plan care more rapidly. This has, in certain circumstances, improved quality of care. It does not seem at any point to reduce the quality of care."*

### Increased efficiency

*"The changes have introduced an improved management and efficiency, while providing better services to users."*

*"They have reduced the number of calls per case, which has reduced the time of case management. This in addition to impact directly on reducing service costs by providing better attention, so that the effect is twofold."*

*"Reduction in data entry effort has not really been achieved in this project, due to the lack of universally used electronic patient records."*

### Quality of the interaction

*"The support worker at Carers Milton Keynes has access on screen to all historic notes relating to the client, which improves the quality of any interaction."*

### Support of informal carers

*"Enables an informal carer to better manage the time and coping demands placed upon them in this role. Decisions or directions with regard to the clients care are now taken with recorded supporting information easily exported from the system."*

*"A carer who feels in control shows slight decrease in stress management and coping strategies under the CAMI CADI CASI measure."*

*"The informal carers are more relaxed now that the clients health care needs are being monitored."*

*"The social well-being of the Informal Carer is paramount in the longevity of Informal Care. If the Carer is unable to cope it logically reduces the length of time they are capable of delivering informal care."*

## **Avoiding unnecessary steps**

*"Through the sharing of information automatically, users receive a more personalized and faster attendance, avoiding unnecessary steps."*

## **Tasks management**

*"The team can now manage their tasks relating to one or many clients (informal carers) or place actions on other members of the team to carry out actions."*

## **Less fragmented information**

*"In transferring to a system based process for almost every element of client support the information supplied to informal carers was less fragmented, offering all services in a timely fashion."*

*"All measurements performed by different professionals were presented in a clear overview, this shows the progress and process."*

## **Tailored support to a specific person**

*"The additional information provided to carers is tailored to the conditions that the carer deals giving more clarity to the support given."*

*"The MyClinic system was useful in generating information that the monitoring nurses could pass on to community nurses in order to respond quickly to the needs of patients."*

*"The Motiva system proved useful in altering the care of the managed patients, such as the medication regime. Information for this came from examination of patient care plans on Motiva and from focus groups, Up titration of medication for heart failure patients seems to have worked particularly well in this regard, which is generally a weakness of post MI community management of heart failure."*

## **Accuracy of response**

*"Collation of all services, support history and contact information within one secure system facilitates greater accuracy in situational responses. This is supported by the reporting framework which shows a small month on month increase of informal carers contacted, further supported by increased level in the number of carers attending events, therapy and counselling sessions."*

## **Less isolation**

*"The client is reassured by the knowledge that they have been enabled to maintain communication with their carer at times when face to face contact is not possible even with the understanding that the response is not an instant one they feel less alone. This is also true in situations where formal care provision is present but they still feel the need to make contact with their "true" carer."*

## **Enhanced quality of care by better background information**

*"The improvement made by placing all client interactions on one system combined with client action management ensures that clients at higher risk are contacted for the purpose of support more frequently."*

*"The psychologists could understand better the caregivers situation and support*

*him/her in a more efficient way. What is more no proper psychological support can be offered if the professional is not aware of the persons living conditions and family relations."*

*"The KAPIs social worker were able to understand better the caregivers and the assisted persons needs and offer them more suitable activities (KAPI centres have a variety of services that a person can choose from depending on his/her age, health and likes)."*

*"It enabled the professional to track the whole treatment plan in one clear overview."*

### **Electronic Health Record as communication bridge**

*"Time has to be spent to determine the categorisation of data to be uploaded to the information of the portal."*

*"Electronic health records created an efficient, immediate and easy to use communication bridge among different care professionals (psychologists and KAPIs social workers)."*

### **Support from home**

*"Whereas the tele-sessions via IP- phones or Skype between psychologists and caregivers offered to latter psychological support, professional guidance, stress management training and a communication bridge that could take place even from inside their home."*

*"There were cases of assisted persons (mostly suffering from cognitive impairment and therefore experiencing symptoms of dilutions of persecution or conspiracy) that had outbursts of anger every time the caregiver had to be isolated and have a tele-sessions. In these cases the session had to take place in a time that the assisted person was not at home."*

### **Social aspects**

*"Video calls made the communication among employees (social workers and psychologists) more personal and efficient."*

*"The social benefit of the MyClinic device, as being a sort of 'water cooler' device, around which people could gather and talk, and then plan the rest of the day together, was unexpected, but beneficial and from the focus group information, often highly valued."*

*"Exercising was continued at TopSupport for the social aspect. Now the plan is to start group training per suburb. Here people, not only COPD patients, come together and get online exercise guidance."*

### **Additional training**

*"The team needed a low level of knowledge to deal with carers who have little or no PC literacy skills. A voluntary member of staff has been supporting this additional need by running beginners classes in Internet and PC use."*

*"It was easy for the care providers to learn how to operate the system but a bit time consuming to help all the users to operate the services. At the beginning some users had to go through a second training due to their lack of any technical knowledge."*

## **Encourage the use of technology**

*"Care professionals – ASI staff have been challenged to begin shifting from a paper-led care service to a technology assisted service. This required a large jump on their part many of whom had worked for years without any technology experience. It has proved a very slow process to encourage use of the technology."*

## **Active role of the client**

*"The clients have become more accustomed to having an involvement in their own care."*

## **Suggested improvements**

*"A better messaging system would have added more value, and informal carers being able to message the system, as originally planned, but then abandoned as not being technically feasible for the units used, would have added more value."*

*"Use of book facility: The use of this, according to examination of the use on the systems and by focus groups, was patchy. Some people used this widely, some hardly at all. This seemed to be based upon previous familiarity with the internet."*

*"Part of the issue appeared to be the set-up of MyClinic, which requires the user to effectively 'come out' of the system they have used to monitor and answer questions, and then go through a different process. Improved internal navigation in future iterations of the device would help here."*

*"Future linking of Motiva to a medication management system, though requiring extra funding, would be useful here."*

## 8. Exploitation

To be able to consider exploitation of the developed solution and services reliability both of the technology and the delivery processes is a pre-condition. During INDEPENDENT, the time and effort invested in the development and testing of the prototype systems as well as the experiences made during pilot operation proved invaluable in achieving reliability.

Reliability is a pre-condition for exploitation and scaling of the pilot. Furthermore when the service isn't running fluently people find it hard to indicate how much they are willing to pay for the service.

It isn't necessary that the entire local pilot team will be involved in the exploitation of the developed solution. For example in one of the pilots the technical developer will take over sole responsibility for the provision and support of the Independent service. Other partners continue to have a vested interest in its future operation and the prospect of more (informal) care organisations adopting the system as its benefits the long term strategy for formal care provision and commissioned services but are not part of commercializing the solution.

When talking about exploitation the organizations that take on the exploitation can be a different team than the team involved in the pilot. Clear agreements need to be made about the envisioned role of each of the pilot partners after the pilot has ended.

The chance of being able to continue offering services after the pilot has ended can be increased by developing and running the new services as part of regular service provision to the greatest extent possible and from the beginning of the pilot on, e.g. by involving the same staff members, addressing the same population group etc. but also by ensuring that participants do not see the pilot as something not essential.

Real integration into current care practice, and not as an experiment on the side, makes it easier to continue the services after the project has ended.

In many cases, financing an integrated service will require more or less complex mix calculations, drawing revenue from different sources including reimbursement schemes, equipment sales, efficiency improvements and client-payable fees. Due to this, sustainable service operation is often dependent on a number of different stakeholders, also those outside the immediate group of users and providers.

As far as client-payable fees are concerned, the INDEPENDENT pilots showed quite a mixed picture. In some countries persons are not used to pay for the services. In some pilot sites, clients and carers would prefer the service to be paid through existing schemes, such as taxes, insurance fees or rents. In other cases, different levels of directly payable fees were considered acceptable or even normal (the latter for example in the Irish pilot site).

Attracting new stakeholders to be able to have a good business case is not easy. Interested stakeholders are typically trailing behind in terms of their current ICT infrastructure and also keen to improve the quality and efficiency of the support they deliver. Health insurance and municipalities might have money available for this, if proven to be efficient and effective. This requires more research. In the Netherlands it is still generally accepted that social resources are not used for preventive means by insurance companies. Municipalities do have tasks and responsibilities but are stuck with old structures (organisational and financial).

Another solution to be able to have a exploitation plan is to include only a sub-set of the tested services. One pilot site indicated that if there isn't sufficient funding to target on this service, then the

terms of the service will be reviewed, for instance looking at offering the service that has been most popular – the health monitoring – and perhaps removing the less widely-used directory of services that is funded separately.

In one of the pilot sites the pilot was so successful that it was decided that all users would benefit from it. Therefore during the project, the pilot has been extended to all users. The system architecture allowed to scale it up smoothly.

Other providers are still facing challenges. One pilot site indicated that for a better result they need commitment from financiers and care providers, which could be either a municipality or an insurance company. Commitment is not only financially but also taking responsibility of management. Customers are willing to pay their own part. But in between care authorities there is not enough support for cooperation.

The problem for future result is sometimes caused by the opposite interests of care providers. The system reasons from treatment of illness, not prevention of it. Next to this the market operation of "battle for the patient" has emerged, this causes unwillingness to share knowledge and information between care providers.

The creation of viable business models for integrated eCare may require setting-up complex mix calculations of different revenue streams, streamlining of service provision, the adaptation of framework conditions and overcoming traditional service boundaries. The project's analyses of socio-economic return clearly suggest that such initial efforts will usually pay off in terms of better and more efficient services.

## 9. Laws and regulation

Laws and regulation can have an impact on the pilot and service design. The pilot sites reported the following aspects that had an impact on their pilot.

In **Andalusia** the service could be improved if it could be accessed from both institutions to a common database of medical records. So far this is more a problem of responsibility and political security of the data than a technical problem.

Furthermore the only change from the original planning was the dropping off the third use case "hospital discharge" due to ethical and technical problems, since certain medical information was legally sensitive and the technical system for sharing information between hospitals-Salud Responde and the Tele care service was not mature enough.

Regulation that has been taken into account:

- Directive 95/46/EC (Data Protection Directive): on the protection of individuals with the regard to the processing of personal data and the free movement of such data.
- Directive 2002/58/EC concerning the processing of personal data and the protection of privacy in the electronic communications sector.
- Directive 2005/36/EC on the recognition of professional qualifications
- The European Charter of Fundamental Human Rights
- The European Convention on Human Rights and Biomedicine

In general, both institutions taking part in the pilot would fulfill current regulations prior to the project, so they have not encountered obstacles.

In **Milton Keynes** no person(s) were recruited who were not competent, as defined under the Mental Capacity Act 2005. This resulted in a reduction in the level of Assisted Persons recruited as many conditions would define the user as Not Competent.

The INDEPENDENT service development and use of the system were strictly guided by The Data Protection Act and the operational controls of the Local Authority IT Telecommunications and User Security Policy and the operational controls for carers Milton Keynes. Access to the INDEPENDENT Service Connecti requires that all actors, Support Staff, Carers, Assisted Persons to have Username and Password authentication. Development of a self-reset of password was necessary to assist Carers and Assisted Persons failing to recall the password.

UK Government Policy changes for supporting Informal Carers. Caring about carers: a national strategy for carers was published in 1999. This was then reviewed in 2010 after consultation. The document recognised, valued and supported: next steps for the Carers Strategy sets out the Government's priorities for carers and identifies the actions we will take to ensure the best possible outcomes for carers and those they support, including:

- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- enabling those with caring responsibilities to fulfil their educational and employment potential
- personalised support both for carers and those they support, enabling them to have a family and community life
- supporting carers to remain mentally and physically well.

In **Trikala** the EHR system incorporates a proper security mechanism. There are three main organisations that create standards related to EHR- HL7, CEN TC 215 and ASTM E31. HL7, operating in the United States, develops the most widely used health care-related electronic data exchange standards in North America, while CEN TC 215, operating in 19 European member states, is the preeminent healthcare information technology standards developing organization in Europe. There is a memorandum to intensify collaboration between the two groups and move toward the development of technically identical and interchangeable U.S. and European standards. Both HL7 and CEN collaborate with the ASTM that operates in the United States and is mainly used by commercial laboratory vendors.

All data used is available only on the professional participants of the pilot. It was made clear to the participants that only the involved professionals have access to their personal data and only when they are needed. These professionals include doctors, psychologists, technicians and operators. This means that there are involved health professionals who already are compliant with bio-ethical rules and the rest of the professionals are employees of the enterprises running the pilot.

No third parties have access to personal data, as declared in the Hellenic Data Protection Authority (HDP, [www.dpa.gr](http://www.dpa.gr)). The processing of the data complies with "Law 2472/1997", regarding the protection of individuals with regard to the processing of their personal data. As far as the use of the Electronic Health Record is concerned, it also complies with "Law 3471/2006", regarding protection of personal data and privacy in the electronic telecommunications sector, as amendment of Law 2472/1997.

Consent of clients is also asked for the use of the EHR (Electronic Health Record) and they were reassured that no third party outside the pilot will have access to any of their personal data.

In **Ireland** The Data Protection (Amendment) Act 2003 is in place. The primary purpose of the Data Protection (Amendment) Act 2003 is to give effect to the provisions of Directive 95/46/EC. The most significant change is the broadening of the definition of data to include manual data in structured filing systems. Being a service provider means that project participants fall into the category of Data Controllers which brings significant legal responsibilities in relation to protection of data.

The main purposes of the Mental Capacity Bill is to provide for supported decision-making for persons lacking capacity; to reform and replace the adult ward of court scheme with a new statutory framework governing decision-making on behalf of persons who lack capacity; to change existing law on capacity, shifting from the current all-or-nothing approach to a flexible, functional one whereby capacity is assessed on an issue and time-specific basis; to provide that where it is not possible to support a person in exercising capacity, the court or a personal guardian appointed by the court will act as a substitute decision-maker; to clarify the law for carers who take on the responsibility for persons who lack capacity; to establish an office of the public guardian responsible for the supervision of personal guardians and people conferred with enduring powers of attorney; and to repeal and subsume the provisions of the Powers of Attorney Act 1996 so that its provisions are brought into line with the general principles and best interests of the provisions of the Bill. The provisions of this Bill, although not yet enacted (due to the current economic crisis it has been de-prioritised), were operationalised during the INDEPENDENT project in Ireland.

In **Geldrop** privacy laws and sharing of patient information have limited the options of the EHR. The Activ8 physical activity monitor is not medically certified because of these laws. Online therapy is not funded yet by insurance companies.

In **Hull** CE marking on health care devices had a most deleterious effect, as one manufacturer was particularly reluctant to do work (initially agreed) when they received a legal opinion that this might alter the classification of their system. This caused delays and a need for a different technological solution that was less fit for purpose than what was originally intended.

The NHS bill enacted into law in the UK this year will have an effect, placing as it does much more of the responsibility of commissioning services into the hands of general practitioners. It is too early to say how this will affect the Independent pilot in Hull, but it is likely that local GPs will have to be convinced of its value if they are to retain it beyond this year.

## **10. Integrated care**

Within the INDEPENDENT pilot different organisations cooperated and each had their own role and responsibilities. Some of the tasks that had to be carried out by the different stakeholders were more or less the same as before, some were enhanced and some were completely new.

In some cases tasks, like for example for the informal care organization to use the system to communicate with carers and report commissioned service outcomes to formal care at local authority were already the responsibility of the organisation but were delivered to significant lesser degree.

Tasks like using commissioned service outcome reports to increase capacity of support to carers and assisted people under their care and the development of services for the purpose of commissioning to informal care are a natural progression as formal care is focused on UK government policy changes to increase the support to individual carers and the people they care for.

Tasks for informal carers like using the system to monitor and communicate with the assisted person(s) they care for were generated as a result of the INDEPENDENT Service and although by definition their role is to communicate and support the needs of the assisted person(s) they care. Never before had they been in a situation whereby they could communicate and monitor remotely. Also it was the first time they had a dedicated place where patterns in the Assisted Person(s) health and state could be recorded and used for review. This effect was also shown in another pilot where the psychologists updated the EHR when a session was finished making several special remarks. This procedure was really important in order to keep a history of the sessions and track the progress of the each case.

In a few cases there were changes to the current work processes. For example the usage of the new system was in one pilot site the main obstacle since it required a change in work practices for the home care co-ordinators. This issue was addressed via extra training and enhanced encouragement from the regional managers and practice development officer. In another pilot the monitoring centre staff had to undergo training from a use-case perspective and in relation to the portal and how their interpretation of a call affected the outcome and the care plan for the person with dementia.

Tasks like to supply small amounts of PC literacy support through voluntary staff are new tasks. Offering PC literacy skill events has enabled clients to better access information not just from the Independent Service but information and interaction from a whole host of avenues.

Some partners became an intermediary between technical partners and the end users of the system because they had the knowledge and experience from supporting end users in their daily operation and the fact that the technical partners lacked that knowledge.

The majority of changes in tasks that were a result of the INDEPENDENT pilot were related to an enhanced way to carry out current tasks. Some additional tasks occurred like training in PC skills and being an intermediary between technical partners and end-users. When work processes needed to be changed additional training and encouragement was given.

Including a wide variety of stakeholders is important to have their support when carrying out the pilot and afterwards to roll-out the pilot when it is successful. This wide variety includes national policy makers, organisation that run health care and social care services, user associations and local/regional government.

Pilot sites also indicated stakeholders that weren't included in the pilot but that would have been beneficial when they were included. For example a pilot site would like to have seen other formal care aspects to be involved in the INDEPENDENT service. For example the ability for GP's to refer through

the used system would be of tremendous benefit. Their involvement was missing as a result of the connection of this system to the local authorities formal care system being marked as out of scope. It is envisaged that the involvement of the GP's would enable formal provision to provide more information about the levels of support required by the individual care. This would improve the initial needs assessment carried out by the support workers at the informal care organisation to be tailored to a greater degree.

Another pilot site also mentioned that more GP involvement would probably have helped and their involvement was sought, but they were reluctant to be involved. This would seem to be due to widespread concerns within the medical community over the value of telehealth generally from published trials, and concerns over the new roles and responsibilities after the NHS Bill as service commissioners. GPs would have been able to encourage more people to recruit and could have treated more clients more rapidly with the information available.

One pilot site clearly missed the support of the public health care services and stated that the most important stakeholder that was missing in the project was the HSE (health service executive). Telecare is not mainstreamed in the HSE, and at the time that the project started, there was very little awareness of telecare in the HSE. This situation was compounded by on-going severe budgetary restrictions and cuts to services. HSE community care staff, such as occupational therapists and public health nurses, could potentially contribute significantly to both the delivery of telecare and the use of the web portal. These staff could be involved in initial assessments, referral, and responding to data via the web portal.

There are also pilot sites where no other stakeholders should be involved in the pilot. However current stakeholders could take a more active role, for example physicians could have a more active role within the platform.

Stakeholders that are often missing due to differing reasons in pilots but should be involved are General Practitioners.

The care continuum does not refer to social versus medical care, rather it looks at care as a journey, from referral, and assessment, to delivery and outcomes. In this model, the care continuum involves a range of stakeholders who input at various points along the care pathway. Key stakeholders can include: the client, the family and informal carers, the community, social care professionals such as social workers and formal care assistants, as well as care co-ordinators and service managers, and health care professionals such as GPs, nursing staff, geriatricians and psychiatrists of old age.

The care continuum does not refer to social versus medical care, rather it looks at care as a journey.

## **11. Conclusions & important “to do’s”**

Within the INDEPENDENT project lessons have been learned on the various aspects surrounding the development and piloting of integrated eCare services. The guidelines provide a summary of the lessons learned. Previous experiences can be used to get to the core of problems, the added value of services, and vital pre-conditions. By doing so long-term experiences and lessons on the use of services can be collected. Connecting pilots that strengthen each other makes each individual pilot much more valuable.

The collection feedback from clients that make use of the integrated care services is vital for refinements of the services. A structure must be put in place to collect the feedback, incorporate the feedback in improvements of current services and the development of new services, and communication mechanism must be developed in order to give feedback to client on how their feedback is taken into account.

Personalisation needs to be taken beyond the setting perspectives to better follow the changing needs of clients. Some aspects to consider:

- Integrated care services are part of a service package that assists the client. A broad context of the client’s life is needed to understand how the service could fit into daily practice and provide real support.
- Provide version of for example the interface for clients who have no computer experience but also more advanced versions for clients who do have computer experience.
- Disability awareness
- Facilitate diversity in the use of a specific service
- Also take the environment where the service will be used into account
- Take into account the level of personalisation that is of added value. Sometimes consistency is key to a good service, like for example the way an integrated care or Health Record is set-up.
- Use the creativity of care professionals to optimize services and develop new services.

The beneficial effects of group factors were highlighted during the INDEPENDENT pilots. This is an area that requires more research in order to fully benefit from its effects.

Within the INDEPENDENT pilots the participants took an active role in being involved in the pilot and by expressing their experiences. This is however one step before people taking an active part in their care process. In order to explore this aspect the service should function without flaws and can incorporate aspects that would make the client interested in data generated. When informing the client about the collected data it means the client is aware of an issue first and can give their view. This sharing of information and providing people insight into their health condition is an important aspect to allow clients to take on an active role in their own care process.

Support of informal carers is an increasingly important aspect of offering services. Within INDEPENDENT positive experiences have been gained with giving informal carers access to data about the client. This can lead to a sense of reassurance. When clients make use of services that enhance their well-being they have more possibilities to be independent without the assistance of an informal carer. The informal carer can also be supported in dealing with the disease of a client; by learning about a disease but also by sharing frustration and feelings through psychological support remotely.

The attitude of care professionals that participated in the INDEPENDENT pilots was already rather positive due to previous experiences or willingness to participate. During the pilot reduction of workload appeared and a positive effect for the clients are important motivational factors. This willingness to participate is a vital aspect to be able to carry out the pilot. Care professionals who already have gained experiences with the use of ICT can act as ambassadors for other care professionals. They can educate less experienced care professionals.

Cooperation between disciplines increased during the INDEPENDENT pilots. It however sometimes got to the point where regulations, financing models and technology prevented further and even more intense cooperation. Therefore more emphasis should be placed on aligning organizational, technical and regulatory aspects needed for optimal cooperation between disciplines. However, as previous projects in this are INDEPENDENT has shown that making integrated eCare a reality is possible even though political preconditions could be improved.

Depending on your own organization a procedure on how to share and interpret data needs to be in place. This procedure should be in line with current practice and level of cooperation required. Don't overdo because of technical possibilities. It must have added value. When setting recruitment criteria make sure that the criteria are in line with the goal of the pilot and your overall organisation. Be aware that setting a lot of criteria might make the group of potential candidates very small whereas setting very broad criteria might lead to on large group of potential candidates that needs to be filtered.

Within integrated eCare projects that include fragile target groups there is a trade-off between testing a service in practice and learning from it and sound scientific research. A balance must be found between being able to offer real support to participants and being able to deliver scientific data on the effect of using the services. There are some known risks when testing with fragile user but that shouldn't prevent somebody to try out services with this target group. Before the start of the pilot tests in real life should have proven that the system is ready for the pilot through e.g. onsite tests as carried out in INDEPENDENT.

In terms of installation and maintenance of the technical equipment roughly there is a distinction between outsourcing to a third party and having a technical team within the own organization. When outsourcing it is important to have a good communication channel and agreement on used terminology to describe possible problems. When providing maintenance within the own organization this needs to be incorporated into the organizational structure of the entire organization and not as a separate activity.

When a pilot has started a clear strategy needs to be in place on what to do in case somebody requests a change or needs support. On the one hand it is important to guarantee the reliability of the system but on the other hand it is important to take into consideration feedback of users and act upon their suggestions to show that their input is valued.

Even when a pilot is concerned and not a market product reliability of the technical system remains one of the most important aspects to even be able to carry out the pilot. Involving a partner with previous experience on the integration of the components of the set-up is a huge advantage for the pilot.

In relation to technical issues the entire system including supporting architecture must be considered. The use of automatic detection within the system is recommended for early detection of problems so that they might even be solved before the user even notices the problem. Furthermore in case problems do occur a procedure must be in place that also includes reporting procedures and feedback to the party that reported the problem. When critical services are offered sometimes other rules can apply for example in relation to response time.

In terms of risk management first thing to take into account is a back-up facility to not lose any

information. Second step is to make it possible to still retain some of the functionality in case of system failure. Clear risk strategy plans are needed for a) the pilot duration and b) the mainstream service.

Reliability is a pre-condition for exploitation and scaling of the pilot. Furthermore when the service isn't running fluently people find it not easy to indicate how much they are willing to pay for the service. When talking about exploitation the organizations that take on the exploitation can be a different team than the team involved in the pilot. Clear agreements need to be made about the envisioned role of each of the pilot partners after the pilot has ended. Real integration into current care practice, and not as an experiment on the side, makes it easier to continue the services after the project has ended.

It is difficult to include other organisations to play a role in financing the services after the pilot has ended. When the involvement of such organizations is needed they should be involved when setting up the pilot so that they can also indicate what is important for them to test during the pilot and to have their initial commitment.

In terms of laws and regulations the aspects that influenced the pilots the most are related to data protection, lack of standardized Electronic Health Records, and the needed CE marking on health care devices.

The care continuum does not refer to social versus medical care, rather it looks at care as a journey. Depending on the type of pilot conducted the focus was more on medical care or more on social care.

In the following important "to do's" are presented that can be derived from the experiences made in setting up and running the INDEPENDENT services in different pilot site contexts.

In the following, some important lessons learned in relation to setting up and running integrated services across the INDEPENDENT pilot sites are presented.

- ***Take your time to obtain a detailed understanding of the current business/service processes, priorities and future direction of all stake holders to be involved in joined-up care delivery***

Depending on the given local context, there may be different motivations for achieving integrated service delivery around older people with help of ICT. In some cases the need for ICT-based service integration may be due to the over-burdening of financial or other resources. Or it may stem from a high-level strategic review of organisational priorities. For ICT-based service integration to meet expectations a process is required which gathers together the required knowledge and information across all organisations and stake holders to be involved in joined-up service delivery so that an informed decision can be made as to how to proceed and what expectations are to be ultimately met. The effort and time required for acquiring knowledge concerning the joined-up care interventions envisaged, how to deliver it, and its impact on current service delivery can easily be underestimated.

- ***Carefully plan and implement process change in a multi-stakeholder service environment***

Simply adding ICT to existing services does not work. Horizontal integration of care delivery is much more than simply establishing or improving links between different entities with help of ICT. In fact, implementing joined-up care delivery with help of ICT may change the cooperating organisations themselves at the interface to their environment, giving them a new profile and new content. Existing services need to be re-

engineered to embrace the new ICT-based service under an appropriate migration control. Practical strategies to support change and promote engagement across the various organisations involved are necessary. A dedicated effort needs to be made to convince staff at each organisation involved in joined-up service delivery to ‘champion’ the ICT-based services that are to be newly established, in particular where large-scale service schemes are concerned.

- ***Do not underestimate the effort required for ensuring that all staff involved in the delivery of the newly integrated service has the necessary skills, and feels comfortable using the ICT infrastructure put in place***

This aspect needs to be dealt with sensitively. There is likely to be some concern over the use of the newly established ICT systems or components of the system. It should by no means be assumed that all staff will welcome the envisaged change. Carefully planned and conducted training measures are required to make all staff involved confident that they indeed do have sufficient technical skills and be able to operate required devices and system interfaces. A wide variety of competencies and views that may be present among staff need to be appropriately acknowledged. It needs to be ensured that all relevant stakeholders receive appropriate training. In fact, the training should not be restricted to just understanding any particular technical aspects, but how the entire system works so that the desired service is delivered.

- ***Make sure that you achieve a high level of ICT system and device usability, particularly where users are required to interact with the pilot system / devices in a more complex manner or under external constraints***

Despite the fact that considerable effort was spent for the purposes of user-driven requirements analysis and prototype testing within INDEPENDENT, evaluation outcomes suggest that there is still room for improvement when it comes to particular usability aspects. In relation to older end users, the loss of functional and/or sensory abilities sometimes puts very high demands on the usability of service interfaces. When it comes to professional users, e.g. care staff, environmental constraints may need to be considered as well. For instance, frequently changing usage sites or time constraints experienced at least by some staff may require accessibility of relevant data/information through mobile devices/interfaces rather than desk-top solutions.

- ***Do not underestimate the efforts required for technically integrating any legacy systems and devices***

The goal of INDEPENDENT architecture has always been the effective integration of heterogeneous systems in such a way that they cooperate together and provide the final users with more than the sum of its parts isolated. Health Care and Social Care information systems and technologies already exist and are currently deployed throughout all the regions in Europe. However, when thinking in connecting them together in order to follow the Integrated Care paradigm, there are a number of technical challenges to face:

- Combinations of client/server applications
- Mix of programming languages
- Different types of database management and products
- Different middleware solutions for communication
- Multiple information transmission models, including publish/subscribe, request/reply, and conversational

- Different transaction and security management middleware
- Different ways of sharing data
- Legacy hardware and software

For this reason, INDEPENDENT focused the attention on Service Oriented Architecture (SOA) techniques, which are based on providing each platform, application or components as a service. INDEPENDENT reinforced the philosophy behind a predecessor initiative (CommonWell), and identified a number of connectors that the different existing system needs to implement in order to make possible that systems collaborate in sharing information independently from the technology chosen for its implementation. The benefits of using the approach implemented in INDEPENDENT are listed hereby:

- Adoption of this architecture approach allows that the changes to be done at the already deployed system are minimized to the development of components that connect the existing system to the general common communication bus at each site. This is beneficial since it allows the integration of existing products saving not only effort but also money.
- Adoption of this architecture allows the use of different technologies, in a way that connectors can be implemented in any of them. This is beneficial for the IT system at health care and social care information systems since they do not have to learn about new technologies to communicate one to each other.
- This Architecture implementation and methodology have been validated and tested in several contexts, showing that the main problem to connect health care and social care system is organizational and not technical anymore.

However, there are also constraints in using this approach:

- In simple cases where only two subsystems are connected maybe it makes more sense to make a direct integration of products instead of developing two connectors.
- Current implementations of some connectors are proprietary. However, some examples of connectors, those more relevant to INDEPENDENT context, are provided elsewhere (D3.2).

The methodology that should be followed by new adopters is:

- Initial readings of public deliverables that could give an idea of the overall service definition and INDEPENDENT architectural approach, in particular D3.2.
- Identify the use cases that define your integration.
- Identify the clients and services, and the corresponding connectors at INDEPENDENT architecture.
- Evaluate how many of them already exist from INDEPENDENT project and how many are not discovered yet.
- Make a decision of which technologies will you use for the implementation of your connectors. In case you're chosen technologies are in common with those already developed in INDEPENDENT try to access to the implementation as an example to follow, and consider any potential IPR constraints (for details see D3.2).
- Implement the connectors as your use cases establish, and considering the reusable components from INDEPENDENT.
- Integrate, test and deploy to production, according to your internal quality assurance processes for software production.