Newsletter 4/2013

Dear reader,

The INDEPENDENT project consortium is pleased to announce its fourth newsletter!

The project newsletters aim to keep readers updated on the status and achievements of the project. The special focus of this fourth issue is on the evaluation results of our six pilots across Europe and what has been achieved in the last year of the project. More than 180,000 people have been able to access the services that we spent two years planning and designing, then twelve months piloting, honing and evaluating.

INDEPENDENT is a Europe-wide pilot project that brings together twenty partner organisations across six European Member States. Jointly, they have set up an ambitious work programme which aims at better capitalising on information and communications technology (ICT) when it comes to supporting older people in their communities. The ultimate goal is to empower older people to maintain their independence. A particular focus is on enabling, with help of technology, a better joining-up of social and health care services as they currently exist. There is also emphasis on strengthening the participation of the so called "third sector," family carers and voluntary community workers. The project started in January 2010 and ended in May 2013. It is part-funded by the European Union's Competitiveness and Innovation Framework Programme.

We hope you will enjoy this final newsletter! Please feel free to contact us for any further details, or with any comments, or just to share any experiences you may have in the area of ICT-supported integrated care.

The INDEPENDENT consortium, independent@empirica.com

We did it!

An overwhelming feeling of satisfaction, mixed with an undeniable twinge of relief, was the principle emotion as the INDEPENDENT project team prepared to meet for one final time for the Commissioners' review. Satisfaction that we had achieved our goals and relief that, despite all the difficulties along the way, we had managed our pilots within our resources and used precious funding effectively. And in the world in which we find ourselves, effective use of resources is every bit as important as eye-catching achievements.

But first, the achievements! More than 180,000 people in five countries across six pilot sites have been able to access the services that we spent two years planning and designing, then twelve months piloting, honing and evaluating. All of the sites discovered that at least 50% of the users they surveyed felt they had benefited from the service, with four of the sites seeing overwhelming user benefit rates of over 90%. Of the 'main users' we surveyed across the sites- the elderly people we first set out to support- an impressive number, more than 84%, wanted the service to continue. And these pilots at the heart of the INDEPENDENT project can become services that are not a drain on precious health and social care resources; in the five sites where this was measured and analysed, all showed that the services could be providing a socio-economic return on investment between one year and four years. In this newsletter you'll find details of the work completed and the knowledge gained across our pilot sites.

The relief is due to the fact that the economic landscape of Europe at the end of the INDEPENDENT project is almost unrecognisable from 2009 when we first got together to see whether we could work together to better integrate health, social and third sector/informal care. In that time governments have fallen and risen, economies have slumped in the worst recession across Europe in living memory and the very fabric of the social structures in some of the countries contributing to the INDEPENDENT project has been stretched to the verge of tearing completely. This has inevitably affected partner sites that have had to deal with delays beyond their control and manage their pilots over a longer period but with no more money.

So yes, satisfaction at our achievements and relief that we were able to complete our pilots without spending extra precious public money despite the difficulties we faced. So, come to think of it, perhaps that should be a source of satisfaction too!

Exciting: The evaluation results

Ireland

The focus of the Irish pilot implementation of the INDEPENDENT service model is on improving the situation of people with dementia and their family carers. Dementia in all its forms is one of the major health and social care challenges facing Europe, and in Ireland people living with dementia rely on a number of so far separate services. These include the Alzheimer Society of Ireland (ASI), a non-for profit home care provider organisation, Emergency Response Limited – (ERL), a commercial telecare provider organisation and family carers. Prior to INDEPENDENT, cooperation among these parties was restricted to an occasional exchange of paper reports. INDEPENDENT has enabled real-time exchange of client-related information which can be added to an individual's care plan and inform their home equipment management.

The Emergency Response call centre

This has been achieved by giving service users receive regular on-site support by a care assistant employed by ASI on the basis of personalised care plan overseen by an ASI care coordinator. Service users also receive a personalised telecare package so that the monitoring and management of responses to alerts triggered by the telecare system is provided by ERL. The package can include diverse home sensors and a push button alarm. Based on incoming data, the telecare operator at ERL executes a pre-defined protocol (e.g. in case of the assisted person walking outside the home) and alerts the informal carers.

Work at the Alzheimer Society

This has proved positive with users and their carers, with 91% of carers reporting benefits, with an impressive 73% showing major benefits! Not surprisingly, these people are very keen for the service to continue. In the words of one carer the best thing about the INDEPENDENT service is "Security and knowing that help is available at the touch of a button should the need ever arise." More simply, but equally powerfully, one carer told us, "She [the person with dementia] can stay in her own home." If anything sums up the mission statement of the INDEPENDENT project it is that.

Geldrop, the Netherlands

In the Netherlands the focus of INDEPENDENT has been on supporting people who suffer from chronic obstructive pulmonary disease (COPD) and the pilot service has been implemented within an insurance based care system. The service for people prior to INDEPENDENT involved a for-profit provider of physiotherapy services (TopSupport), a hospital (St.-Anna Hospital) and family carers,

but was hampered by a lack of communication and cooperation within these organisations.

INDEPENDENT set out to change this.

People suffering from COPD who have been positively assessed by a physiotherapist are now offered remote therapy sessions through the INDEPENDENT ICT infrastructure, in addition to unsupervised home exercises recommended by the physiotherapist.

Service providers in Geldrop

At first, all patients start an exercise program at the premises of TopSupport or in the hospital until the patient and the physiotherapist are confident in the patients' ability to do these at home. During the remote sessions, a physiotherapist coaches the TopSupport clients through a live video/audio connection while they are doing their physical exercises at home. After each session, the physiotherapist documents the remote exercise session into a joint client data base accessible by all stakeholders involved in the care delivery process.

Physiotherapist accessing the joint client data base

Has it worked? We asked the users and they told us, Yes it has! 96% of users reported positive benefits, with just 4% reporting no positive benefits at all. Despite issues of ICT reliability that had to be managed at the beginning and the need to get used to less face-to-face contact with a physiotherapist, the reaction of the overwhelming majority can be summed up in one response; "I feel fitter which motivates me to be active." And that is what INDEPENDENT was always about.

Hull, United Kingdom

In Hull, driven by work done with local service users and their carers we pursued an ambitious dual strategy to meet the needs of users living in their own home, and people living independently but in sheltered housing. For people in their own home living with heart failure and supported by a mature telemonitoring system, we enhanced this by adding a portal system that allowed messages to go to relatives or a voluntary worker for additional social care support.

High-intensity monitoring system at home

For those in sheltered accommodation, living with long term conditions that required them to access support by visiting their GPs, or by ignoring problems until they became really problematic, we provided Multi-user Telehealth systems that allowed blood pressure, weight and pulse oximetry to be recorded and monitored by the same

monitoring team looking after the heart failure patients at home. In addition, people had the opportunity to use the systems to send message to the monitoring nurses or to access a directory of services for social care services.

Low intensity monitoring in sheltered housing facility

Excitingly, 90% of users in the shared care system found that they were better able to manage their condition than previously, with 20% saying they could manage it a lot better than before. Whilst the results were less dramatic in the home monitoring group, no-one felt there had been any downsides on their health and some had seen a benefit to a service that we already knew worked well. On both sides of the service, the desire to continue beyond the pilot was overwhelming, at an impressive 80% and 90% respectively.

Monitoring nurse in Hull

Importantly for principles of integration, we demonstrated that two different monitoring systems (Philips Motiva and Tunstall ICPTM) can be used together by the same monitoring staff at the same point of access to successfully support patients with different needs. We think this is the first time this has been demonstrated. And our users felt less isolated, using the monitoring of their health as a way to interact with friends and neighbours. And the importance of this sort of support can be heard in the words of one of our users; "It's been great. It's made me look after myself more and we've met up and had a laugh too. What more can you ask for?" What more indeed!

Milton Keynes, United Kingdom

The focus of the pilot service implementation in Milton Keynes is on helping family carers and their loved ones who are currently not well supported by any of the formal community care schemes available in Milton Keynes.

Carer at CarersMK

Prior to INDEPENDENT, service delivery involved an existing support network maintained by a third sector organisation, Carers MK, and Milton Keynes Council which runs a dedicated PC lending scheme to people in need of support. The aim of the INDEPENDENT service is to provide a 'front end' service development where the local authority reaches forward to engage with Carers MK in order to address the needs and wishes of family carers and their loved ones.

How did we do it? We arranged for case managers at Carers MK to provide personalised advice to the family carer of the assisted person and the assisted person himself. At each session the case manager accesses a personal electronic client record containing information on the assisted person condition. And the carers have seen a real difference in the service, with 73% of them seeing some or even major benefit. As always, it's better to take the word of our clients, rather than ourselves. Interestingly, pointing up the desire throughout INDEPENDENT to help people to support each other, one carer said, "I feel like we are working together rather than me working for my sister." Whilst one, talking about her difficulties and how these have been helped by the sharing of information and resources, simply said, "It made me realise I'm not alone."

Andalucia, Spain

The focus of the INDEPENDENT pilot service implementation in Andalucia is on improving the situation of older people suffering from general age-related decline who are in need of social and healthcare services. Traditionally, these have been addressed by two different ICT-based services available throughout the region of Andalucia; a telecare service operated by ASSDA on behalf the regional social care authority and a medical call centre services operated by SALUD on behalf by the health care authority. In accordance with regional legislation, both services have been operated under different governance schemes without any linkage. In INDEPENDENT, we've joined-up the service delivery and have

encouraged the family carers to become involved.

A personalised telecare package is installed in the assisted person's home. The monitoring and management of responses to alerts triggered by the system is provided by ASSDA, who's telecare operator also provides on-demand advice in relation to social care issues.

The ASSDA call centre

Service users often contact ASSDA in order to request an appointment with a doctor. If the call is not an emergency, the operator transfers the call together with the client data directly to Salud Responde, who's operator can check availability of dates for a doctor's appointment and schedule an appointment, or, in the case of health advice, the nurse can provide the required assistance.

Service quality manager at ASSDA

Once the call with Salud Responde is concluded, the user is transferred back to ASSDA, to check that the user is satisfied and deal with any other queries the user may

have. And the medical call centre operator initiates the same process in cases where he receives a request that concerns social care issues. Thus, both operators are able to provide a more agile and bespoke response to incoming client requests, providing expertise in 'real time' linked to a joint client database; none of this was possible prior to INDEPENDENT.

This INDEPENDENT service has been used by an astonishing 180,000 people so far! And they have liked what they've seen, with 90% of those accessing medical services feeling that the communication systems were good and around 60% feeling that they were 'calmed down' by the way their call was handled. So an ambitious project, based on almost four years worth of detailed planning and preparation, has been brought to fruition, and INDEPENDENT has enabled an important region of Spain to take a real step in integrating health and social care, supported by ICT.

Trikala, Greece

The INDEPENDENT service implementation in Greece builds upon existing services that are directed towards supporting people with mild cognitive problems and mild depression and their carers in the region of Trikala, a mountainous and remote area in the countries northern region.

The eTrikala call centre

Here, the majority of older citizens suffering from these problems live in their own home with a member of the family - in most cases a spouse - acting as their informal carer. In many cases the carers face health problems themselves, typically psychological problems combined with the common pathologies of old age.

DEKA psychologist undertaking a remote counselling session

In INDEPENDENT we have supported these people by means of remote counselling sessions offered by a psychologist. The psychologist shares access to a joint client data base with a general practitioner who provides medical support. Clients access the services through two main electronic channels. Access from home, particularly important for this region, is enabled by means of personal video telephony equipment installed at the client's home. Home access is of particular relevance for people living in this region. For those living within the reach of a KAPI open care community support centre, access is provided through multi-user

equipment installed at three such centres in the region of Trikala. KAPIs have been set up by many municipalities across the country over the last decade. In INDEPENDENT, incorporating psychological support provided by another municipal service organisation, DEKA, and onsite medical consultations, KAPI centres have become focal points for social and medical service provision to older people in the non-rural parts of the pilot area.

One of the KAPI centres in Trikala

And then results have been impressive. 57% of carers told us that they had seen major benefits in reducing the strains on them of caring for their loved ones. They now feel they have effective help. Carers told us, 'I don't feel alone coping with my problems' and 'I am more calm and confident with my situation and more optimistic overall.' Importantly, the benefit hasn't just been to the carer. Many people told us how it had improved their relationship with the person they care for. One simply said, movingly 'I have a better relationship with my wife.' What a privilege to have been a part of a programme that can help someone to this!

NEWS & VIEWS

Pilot site videos now online!

As part of the dissemination strategy of the INDEPENDENT project we've made videos at all of the pilot sites to give a fuller, richer picture of the work we have done and the people we've involved. We interviewed health care professionals, telecare operators and case managers and got them to explain what they had done with INDEPENDENT, how it has changed their working practices and how they hope it will benefit the people they serve.

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And of course we asked the most important people of all; the service users gave us their unique and direct view of the work that we were doing why they thought it was helping, and they were not shy of telling us when they thought we needed to do more and why. This helps to give anybody watching a full and lively picture of the work of INDEPENDENT done in the different ways across six sites in five different countries.

The videos are uploaded on YouTube and on the INDEPENDENT project website and have proved to be popular watching so far. But there's no need to take our word for it; go to www.independent-project.eu and have a look at them yourself. Happy viewing!

Future care in the Netherlands

Smart Homes organised 3 workshops on "Future Care" in its so-called Smartest House of the Netherlands. Small groups were invited to discuss about current care trends to investigate whether the market is ready for innovation in care delivery. Participants also had the opportunity to experience the INDEPENDENT service in Geldrop. Together with the participants the services were evaluated with respect to promising features, possible improvements and future exploitation planning.

Future care workshop in Eindhoven

The groups consisted out of health care insurers, social and healthcare professionals, technology providers, system integrators, researchers, service providers and policy makers. The diverse background of workshop participants, their field experience and their view on care and technology resulted in lively and interesting discussions. Outcomes from these workshops were used to frame the guidelines for integrated eCare, and to set up the exploitation workshops in the pilot countries.

Visit us at the World Congress on integrated care 2013 in Singapore

Along with a major contribution of the Pilot A SmartCare, results from INDEPENDENT will be presented at the world congress on integrated care in Singapore with a focus on cost-benefit and evaluation results. This year, the conference committee collaborates with the International Foundation for Integrated Care (IFIC) and McKinsey & Company, to create a rich and comprehensive programme. The theme is "Act, Collaborate, Translate: The Global Response to Care Integration". The World Congress on integrated care 2013 will take place in Singapore this year from 7-9 November. Find our more at: http://www.integratedcareconference.sg/

A legacy of the INDEPENDENT project - experiences converted into guidelines

The INDEPENDENT project has helped join up services in a cost effective way for hundreds of people, and provided plenty of evidence that these people want the services to continue. But that's not the end of the work. In the course of developing, testing, implementing and evaluating these integrated services, valuable knowledge has been created across the pilot sites.

One of the ways that this knowledge can be used is in the development of guidelines that can guide future work done in this area. One of the strengths of the INDEPENDENT project is in the differences in the work done at the various pilot sites, as pilot sites have met local needs within their particular national systems and laws. To reflect this, each site has provided its particular local input to the project as a whole. This information has then

been constructed into a set of guidelines, looking at areas such as implementation, the use of technology, efficiency, laws and regulations and the ability to integrate care in the most effective way. This, combined with work done on other projects in a similar area, such as the CommonWell project, can help to strengthen the body of evidence around the emerging area of integrated care, and will soon be available to everyone via the BeyondSilos and INDEPENDENT websites at [www.independent-project.eu and www.beyond-silos.eu].

An advantage of this approach is that these guidelines will help future research into this area by allowing the researchers of the future to both build on our successes and avoid our failures- we had to learn many lessons as we completed our work. In this way the legacy of the INDEPENDENT project will not just be in services, but in increasing what we know about this crucial area and making it known to others.

Major Pilot A launched on ICT-supported integrated care

In March 2013 a CIP pilot A called SmartCare has started aiming to define a common set of standard functional specifications for an open ICT platform enabling the delivery of integrated care to older European citizens. A total of 24 regions and their key stakeholders will define a comprehensive set of integration building blocks around the challenges of data-sharing, coordination and communication.

Ten regions will then pilot integrated health & social services to combat a range of threats to independent living commonly faced by older people while the other will prepare for early

adoption. In a rigorous evaluation approach, the pilot will produce and document much needed evidence on the impact of integrated care, developing a common framework suitable for other regions in Europe. Guidelines and specifications for procuring, organising and implementing the service building blocks will be produced. The organisational and legal ramifications of integrated care will be analysed to support long term sustainability and upscaling of the services.

SmartCare regions

SmartCare services will provide full support to cooperative delivery of care, integrated with self-care and across organisational silos, including essential coordination tools such as shared data access, care pathway design and execution as well as real time communication support to care teams and multi-organisation access to home platforms. The services build on advanced ICT already deployed in the pilot regions including high penetrations of telecare and telemonitoring home platforms. System integration will be based, whenever possible, on open standards and multivendor interoperability will be strongly encouraged. The common services will allow efficient cooperative care delivery and empower all older people according to their mental faculties to take part in effective management of their health, wellness, and chronic

conditions and maintain their independence despite increasing frailty. http://pilotsmartcare.eu/project/project-overview/

<u>Note</u>

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