AKTIVE: Advancing Knowledge of Telecare for Independence and Vitality in Later Life

A report of the AKTIVE Conference, University of Leeds, 8 – 9 April 2014
Introduction

The AKTIVE (Advancing Knowledge of Telecare for Independence and Vitality in Later Life) project was set up under the Technology Strategy Board’s Assisted Living Innovation Platform (ALIP) to put the spotlight on one of the central issues in the creation of an assisted living sector – that of understanding users’ needs and developing telecare products and services that meet these requirements.

The research consortium brought together by AKTIVE not only considered how telecare could help frail older people who are prone to falls, or suffering memory loss or dementia, to live independently. It also studied the impact on carers, considering, for example, issues around selection and installation of equipment, and how carers receive/respond to alerts.

AKTIVE has done this in an exhaustive way, with researchers carrying out everyday life analysis of 60 older people using telecare in Leeds and Oxfordshire over 6 – 9 months. This investigation was complemented by interviews with relatives, care workers and neighbours.

The project also included workshops that aimed to deepen understanding of the influence and roles of everyone involved in the provision of telecare, including staff in response centres and telecare equipment manufacturers.

With the three-year programme drawing to a close in May 2014, AKTIVE organised a conference at the University of Leeds on 8 – 9 April 2014 “Technology, care and ageing: Enhancing independence” to bring together researchers, industry, the voluntary sector and local authorities, to discuss the findings in depth and in the context of other research and developments in assisted living.

The 150 delegates from the UK and overseas heard from speakers at four plenary sessions and discussed and debated the latest research at 22 workshops and panel debates. This was accompanied by an exhibition and poster presentations.

The detailed findings from AKTIVE are presented in a series of working papers, available on the project website, www.aktive.org.uk.

Videos of the plenary sessions, highlights of the workshops, and presentations by a number of speakers are also available on the website at http://aktive.org.uk/2014_presentations
At heart, the AKTIVE project has been about understanding individual needs and how telecare products and services can meet these requirements. Now it is time for the industry to use this understanding to deliver one-to-one, personal care, that is tailored to an individual and flexes in response to changing circumstances.

The prerequisite is for "self-directed care" and not, “a shop front that says, ‘That’s all there is’”, said Alyson Bell, Managing Director of the Telecare Services Association (TSA). “We’ve got to focus care on the individual, on what they want and how they aspire to grow old,” she told delegates.

Rather than being devices that signify old age and dependency, the vision is to inspire: people are now performing all their day-to-day business and many social interactions through devices such as smartphones and tablet pcs that are seen as covetable consumer items. “Why need it be any different for the elderly at home?” Bell asked in her discussion, ‘Technology, Care and the Individual’.

As an industry body representing over 370 member organisations, including all the key players across research, industry, and infrastructure providers, the TSA is responding to the research outputs of AKTIVE and other ALIP projects, to put greater focus on service provision and service redesign.

The Health and Social Care Act 2012 created a mandate for integrating health and social care. Subsequently, the £3.8 billion Better Care Fund was announced in June 2013, establishing a single, pooled budget to enable health and social care services to work closely together in local areas.

Combining National Health Service (NHS) and local government resources will underpin a shift from hospital- to community-based care, improving services and value for money. From 2014 – 2017 there will be a rollout of a national delivery plan for integrated care, based on the commitment that care will be person-centred, coordinated and tailored to the needs and preferences of the individual, their carers and family. A similar plan is being rolled out in Scotland from 2012 – 2015.
“What does this mean to the marketplace? It means individuals are commissioners of their own care.” Bell said. One-size-fits-all services will no longer be acceptable. It is critical that commissioners understand the potential of telecare and telehealth to underpin the redesign and personalisation of service, Bell said. At a basic level, technology will enable the sharing of information. “You can’t say any more, I work in housing, I can’t share with social services. We need to share for the individual,” said Bell.

While technology provides the means, interoperability and integration is about people. “If we get the processes people and streamlining right, the reduction in budgets will follow; that’s the main driver,” Bell told delegates. The aim is to get to the point where services are bespoke and people can self-manage their care in the community, she concluded.

The service is delivered under a contract with Tunstall, which Tomlinson said it the first of its kind. “It’s not just about getting kit into people’s homes.” Rather it involves assessment, installation and response.

Getting the telecare service up and running has involved training 2,000 people. The stand-out statistic is that 12,000 people have been enabled to stay in their own homes as a result. “It is getting help to people and lives are transformed,” Tomlinson said. For example, the parents of a child with severe epilepsy no longer have to keep watch at night because an automatic bed sensor sets off an alarm if the child has a fit.

The service has freed up resources, resulting in reduced waiting times for

---

Birmingham City Council is a trail blazer in integrating health and social care, first setting up a pooled budget four years ago. “This is working well and we have made progress,” said Jon Tomlinson, the city’s Director of Joint Commissioning, in his talk, ‘Implementing telecare and telehealth in Birmingham; the story so far’.

Over the past three years the city-wide telecare service has been used by 27,000 people. Initially, it focussed on falls prevention, but has since been expanded to meet the complex care needs of people with dementia and severe disabilities. There have been cost savings and users have been given peace of mind.
social care and savings of £12,000 per user per annum. A massive 99 per cent of users rate the service as excellent or good. “So it’s what people want, and we are making savings,” Tomlinson said.

AKTIVE is very different in kind from the Whole System Demonstrator, which set out to illustrate the benefits of telehealth through the hard end points, of lower mortality, fewer emergency admissions and a reduction in hospital bed days. Rather the aim of AKTIVE was, “to understand what happens when people become frail,” Yeandle said.

Market intelligence indicated telecare was not being taken up, or sometimes not being used once it was installed. Local authorities were currently in the lead, taking different approaches to service provision. Meanwhile healthcare professionals were often sceptical about the value of telecare, and users had limited knowledge about the equipment and services available.

AKTIVE put the focus on everyday life to understand how telecare fits in, and to explore options and barriers. The project drew together experts including designers, clinicians, health and safety specialists, and was developed with two industry partners, Tunstall Healthcare Ltd and Inventya Ltd.

While much detail remains to be distilled, Yeandle highlighted four key conclusions:

- Telecare products and services are not interventions, but tools for living;
- Products and services should provide support and give timely assistance;
- The aim should be to help people with frailties to live independently;
- Older people will reject telecare if the equipment and service offered is not appropriate to their needs.

Building on this, Birmingham City Council has just started a £1 million telehealth pilot in which it is working with commissioning groups to look at provision for people with dementia and long-term conditions.

It’s also necessary to raise more awareness of telecare and telehealth, to build understanding of its potential and of the services that are available at a community level, Tomlinson said. The council intends to work with third sector organisations to achieve this.

The Everyday Life Analysis of 60 older people, which was the centrepiece of the AKTIVE project has given important insights that can inform moves to turn policy ambitions such as enabling people to remain independent at home and integrating healthcare with social care into “lived reality”, said Professor Sue Yeandle, AKTIVE Project Director, opening her presentation, “Telecare, independence and Vitality in Later life: the policy relevance of the AKTIVE project.

In general, family and friends valued telecare but felt they did not know enough about it. When the right equipment was available, telecare was successful, not only in keeping people safe at home, but also in helping them to get out, increasing their vitality and reducing family and personal tensions about care.

As the AKTIVE research underlined, there are roles for everyone in ensuring successful adoption, from developers and the industry, to health and social care staff, and Health and Wellbeing Boards.

As the market begins to move on from a sole focus on provision by the statutory sector, to the supply of consumer products and services, new retail channels are needed. Older people feel left behind by technology. “Make them early adopters instead,” Yeandle told delegates.
One of the stark findings from the AKTIVE Everyday Living Analysis was the extent to which the constraints of frailty impoverished the daily lives of the 60 people in the study. Many of them felt lonely. While telecare is not necessarily claiming to end loneliness, technology can dull its edges, as Esther Rantzen told the conference, describing in her talk, ‘Old age is not for Cissies’, how her experience of living alone led her to set up The Silver Line, a telephone helpline for older people, in November 2013.

Three years ago, Rantzen moved from the family house to a two bedroom flat. “I was alone for the first time, aged 71 and didn’t enjoy it,” she said. “I had plenty of people to do something with, but no one to do nothing with.”

It is becoming clear from calls to Silverline that loneliness is about loss, Rantzen said. This can be loss of a partner, family growing up and leaving home, loss of sight or hearing, or having to give up a driving licence. There is a huge and damaging physical impact. People don’t cook for one, or go out for walks alone. “The front door becomes an insuperable barrier,” Rantzen said. Compounding this, there is a stigma about loneliness. “You are the empty restaurant no one wants to dine in,” said Rantzen.

In a survey carried out for Silverline, 15 per cent of respondents over 55 said they are often lonely equating to 2.5 million people. They don’t tell anyone for fear of being a burden, but find it helps to chat on the phone, said Rantzen. As one caller in the pilot phase of Silverline put it, “When I get off the phone, I feel like I belong to the human race.”

One important point is that older people who are lonely are not necessarily within the health and social care system and would not like to access support services like Silverline through that route.

The Silver Line is currently training 1,000 volunteers who will make regular, booked calls to people they befriend. In addition the Helpline, open 24/7, is free, confidential and is taking 1,000 calls a day, on 0800 470 8090.
As a technology buff and bioengineer, who still leads a research team at the age of 86, Heinz Wolff, Professor of Engineering and Doctor of Science at Brunel University, has a unique perspective on the role technology can play in maintaining independence in old age. He spoke movingly of personal experiences in his discussion, ‘The place of technology within an assisted lifestyle: when, what and the need for carers’.

Technology provides, “tools for living” but it cannot be used to mechanise care in the same way that technology has mechanised other sectors and aspects of life. The combine harvester replaced much agricultural labour, but the modern-day hospital still needs as many people to function as its Victorian counterpart. “You can’t get machines to care,” Wolff said.

Speaking from experience, Wolff suggested people should be encouraged to downsize and shape their domestic environment for old age in their seventies, when they are still adaptable. He and his wife waited until in their 80s, when his wife hated being uprooted and they found it difficult to adapt. If people were offered assisted living technology before they need it, they would be able to make their own purchasing decisions and learn how to use it with confidence, Wolff said.

Wolff suggested this could include installing stair lifts, switching from gas to electric cooking, testing out ready meals for when it is no longer possible to cook. “These are not new inventions, they all exist. People have to be encouraged to plan so they don’t end up being incapable,” he said.

Innovation is needed in finance to enable people to pay for such preparations, for example, equity releases on property and advances on pensions, Wolff told delegates. “If the makers of cars and sofas can do it, we should develop a system where people can pre-equip themselves.”

Wolff said innovation is also required to find ways of doing unpleasant jobs. His research team is working on sanitary arrangements. The aim, “is to see if we could get over the bottom-wiping problem, which is such a big put-off in terms of recruiting carers,” he said.

Another project aims to make “anti-geriatric” small white pills easier to handle and to swallow, by printing drug molecules onto coloured rice paper.

Wolff has also suggested increasing the supply of care without increasing the cost, through Care4Care, in which people who are capable provide care now, building up credits which they can cash in when they need care themselves. This would, “remove care from the monetary system” and create a new type of volunteer, “who isn’t quite a volunteer,” Wolff said.
Building on this, the Department of Health announced 3millionlives, to scale up the benefits. This was originally conceived as a healthcare-driven project, but with the NHS reforms of 2012, will now put greater focus on redesigning processes and on the integration of health and social care (more detail on the status of the project appears later in this report).

Meanwhile, the £37 million Dallas (Delivering Assisted Living Life Styles at Scale) programme is being rolled out to thousands of people, in four community projects.

Worsley himself has spent much time on the Economic and Business modelling research funded by ALIP. He noted there is a significant overlap between this and the Social and Behavioural projects, of which AKTIVE is one.

For Worsley, ensuring data can flow around silos is essential. “It is key to keep information moving between statutory and private, and between all the different actors,” he told delegates.

Findings from three other ALIP Social and Behavioural Studies were summarised by researchers on the project.

In setting out to examine the reasons behind the slow uptake and adoption of many assistive living technologies, COBALT (Challenging Obstacles and Barriers to Assistive Living Technologies) took a different view from other projects, in that rather than studying specific technologies, it looked at what technologies people with dementia owned already and what decisions they made to purchase devices and equipment.

Astell let the testimony of Brian, one of the people COBALT has worked with, highlight the importance of appropriate technology and the need for extensive and continuous training and support from professionals and family members. Brian was diagnosed with dementia at the relatively early age of 60. As a former carer himself, he was well aware of the implications of the diagnosis. Brian lost the ability to use a computer and was having problems with his mobile phone and TV remote control.

“I want to make sure everyone understands the context of AKTIVE in a much larger body of research,” said Graham Worsley, Lead Technologist, Technology Strategy Board Assisted Living Innovation Platform, opening the morning plenary on day two of the conference.

Statutory provision can be a deterrent, if something is prescribed for a reason, “rather than someone making their own choice,” said Arlene Astell, Research Chair in Community Management of Dementia, Ontario Shores Centre for Mental Health Services, University of Toronto and Professor at CATCH (Centre for Assistive Technology and Connected Healthcare) at Sheffield University.
Through COBALT, Brian was helped to relearn these skills, gaining in self-confidence. He has kept a blog of his progress on the COBALT website, in which he says, “Before I was asked to take part in COBALT, I had very little interest in relearning, or in fact, learning something new”.

As one of its work streams, the Malt project (Mainstreaming Assistive Living Technologies) has explored the hurdles, and investigated how to facilitate the use of telehealth, for monitoring people with chronic obstructive pulmonary disorder and chronic heart failure in their own homes, through case studies in four sites and interviews with over 150 patients, carers, frontline staff and managers.

Despite continuing efforts (18 months into the project) there remain barriers. Some are related to the system itself and its cost, others are around the evidence base for telehealth. Securing long term investment is really difficult. A low level of awareness and engagement among both end users and healthcare professionals also presents problems with uptake, Nicholson concluded.

Jo Nicholson of the Rehabilitation and Assistive Technology Research Group at Sheffield University outlined the key messages from this research:

1. Healthcare providers and clinicians are users of telehealth – although they have different requirements from patients they are end users. Clinicians are also gatekeepers to patients, providing care, helping to reduce anxiety, educating about telehealth and improving self-management.

2. Staff and patient interviews identified a number of potential benefits of telehealth for patients. They also revealed that telehealth helps nurses and aids clinical practice. It provides a new opportunity to monitor people closely in their own homes and to gather information that was not previously available. This can inform clinical decisions such as when to visit and titrating drug doses.

3. Staff acceptance is dependent on realising the value, and can be a slow and fragile process. While some barriers have been overcome, others remain and require further work. “It’s an ongoing process of trial and error and re-configuring,” Nicholson said.

4. The way in which telehealth is deployed has to date, been shaped by existing care pathways. Monitoring and responding to alerts introduces new processes; this has cost implications and can shape how care is delivered.

5. People with long term conditions have ongoing needs that require a range of inputs from healthcare professionals. While telehealth can promote self-care, it can also encourage dependency, as people get comfortable with the idea of being watched over.

6. Telehealth is suitable for some patient groups but may not be cost-effective in all cases.

The overall message from the Athene project (Assistive Technologies for Healthy Living in Elders: Needs Assessment by Ethnography) is of the requirement “to pay more attention to the mundane realities of ageing”, said Rob Procter, Professor of Social Informatics at Warwick University. “There’s a need for a turn to the social in the way we look at assistive living day-to-day, he told delegates.

This conclusion is based on fieldwork involving ‘cultural probes’ to gain insights into how a technology fits – or not – into the particular home environment of 38 individuals aged 60 – 98.

Devices such as alarms and monitors require adaptation and personalisation to suit the needs of individuals, and often it is informal carers who do this. The modification
may be simple and crude, for example disabling buttons on a TV remote so the wrong buttons cannot be pressed, or using a jam jar to disable a door access system that opened at the wrong times.

Procter describes this amateur adaptation of technology to individual needs as bricolage – or pragmatic customisation, by someone who knows the user well. "We all do this with technology, because it is all designed with a generalised view of user needs. Some designers do design in adaptability, but that is not a feature of telecare and telehealth currently," Procter said.

Athene has also highlighted the need for standards to allow devices to interoperate, allowing them to be configured into a more supportive infrastructure in the home.

In addition, there should be less focus on the technology in smart homes and more reliance on networks to support ageing in place, said Procter. ‘Ageing in place is complex, with lots of actors; we need to recognise this in the way we deploy technologies. Everyone in the network, from people in call centres, to friends and family, all know something useful that’s important in supporting a person. We need to tie this together more efficiently,” Procter told delegates.

In common with Athene, the AKTIVE project has involved extensive field work. Everyday Life analysis was completed with 60 older people and their carers, with the aim of increasing understanding of what telecare can offer, not just in terms of supporting independence, but also in promoting vitality.

The evidence is that telecare can improve relationships and strengthen ties, but it is important to avoid intrusive support and ensure the right configuration of devices. The research also revealed, “frustrations and fixable problems,” said Sue Yeandle, Professor of Sociology and AKTIVE Project Director, CIRCLE, at the University of Leeds.

One example is the need for better installation and training in order to avoid false alarms that can put people off using equipment. “There needs to be more information in a format users can understand and come back to. Often they get information at installation but can’t refer back to and use it later,” Yeandle said.

While telecare connects people to monitoring centres, this facility is only used in the event of an alarm. This raises the question of whether these connections could be used to supply more continuous support.

In terms of how the findings of AKTIVE can help telecare assessors and commissioners, Yeandle said the research highlights that getting in early, and recognising things change at unpredictable timescales, is crucial. “You can’t upgrade every six months; sometimes things change in six weeks; sometimes they are stable for two years,” she noted.

Support must be timely, users must be consulted, and it must be understood that caring networks differ from one individual to another. “From installation onwards, everyone must be able to get the best out of the technology,” Yeandle concluded.
The pressures the UK’s health and care systems face as a result of the ageing population are replicated elsewhere in Europe and around the world. In relative terms, the demographic profile here is even more challenging as in some other European societies including Germany, with the currently oldest population in Europe, as Andreas Hoff, Professor of Social Gerontology, University of Applied Sciences Zittau/ Görlitz, Germany, highlighted in his presentation on ‘Strategic Development of AAL Technologies in Germany and the EU’.

At present, 20 per cent of the population of Germany is aged 65 and over; in ten years’ time 25 per cent of the population will be 65-plus. The UK in contrast will not reach 25 per cent of 65 and over until 2060, Hoff noted.

In both countries there will be a marked increase in the number of people aged 80-plus who are likely to need care. In Germany, 4 per cent of the population was in this age bracket in 2000; by 2025 it will be eight per cent, by 2050 14 per cent of the population will be over 80. Five per cent of the UK population will be aged 80 and over by 2025, rising to nine per cent in 2050.

The averages mask the fact that the age profile will be even less favourable in some regions, and in rural areas versus cities. In the state of Saxony for example, 25 per cent of the population is over 65 already. The vast majority of 93 per cent of people aged 65 and above live in their own homes and children are obliged by law to look after them. Pensioners are still reasonably well-off although this is projected to change in coming decades. “Why do I tell you this? Hoff said. “Because ambient assisted living can contribute to solving this challenge. It won’t be a perfect solution, but it will help.”

Hoff pointed to Living Age, Living Home, a programme funded by the German government and run by the Saxon Federation of Housing Associations, which is building a large number of fully-equipped smart homes, with the aim of generating economies of scale and factoring in technological progress. The investment per room has fallen from €30,000 in 2010 to €10,000 in 2012 and is projected to further decline to less than €5,000 in 2014. This equates to an additional €3 per square metre and would cost an elderly couple downsizing €150 per month for a 50 square metre flat, which Hoff said, “is affordable for most.”

The demographic challenge has led the German government to make a number of investments in assistive living across a number of different ministries. Most recently, a new national research agenda – The New Future of Old Age – was launched with a €400 million budget to develop new products and services.

Hoff also pointed to the EU’s Ambient Assisted Living Programme, which invested €700 million from 2008 – 2013, with the next programme from 2014 – 2020 under discussion.

In terms of challenges ahead, the most obvious requirement in Germany and the UK is to transition from projects and pilots into full-scale implementation. “What’s also missing is integrated systems,” Hoff concluded.

Achieving scale-up was one of the central objectives of the Department of Health’s 3millionlives programme, set up in December 2012 to build on the evidence from the Whole Systems Demonstrator that telehealth and telecare can reduce mortality, hospital admissions and hospital bed days for people with long term conditions.
Following on from the Health and Social Care Act 2012, the programme has been recast to better reflect the aim of seamlessly integrating care, and renamed Technology Enabled Care Services, as Annie Thompson, Collaboration for Excellence Lead, NHS England, described in her presentation, ‘Delivering technology enabled care services: an update on the evolving national picture’.

However, technology alone is not the whole answer; it is an enabler. Also required are partnerships, reform of service delivery and transformation of care pathways. “That’s what we learned from the early stages of 3millionlives,” Thompson told delegates.

To reflect this, the project will now be broader. Rather than engaging only with people who have complex co-morbidities, the project aims to encourage the use of technology for a wider set of patients, and for prevention as well as management of conditions. It will encompass a wider range of assistive technologies, taking in telemedicine and telecoaching, in addition to telecare and telehealth, under the umbrella of Technology Enabled Care Services.

NHS England has worked with industry, commissioners and providers to identify barriers to achieving this vision, singling out the following requirements:

- Improving procurement, increasing flexibility and working with industry in a strategic, rather than a transactional fashion;
- Development of commissioning skills to underpin the move to outcomes-based commissioning;
- Reforming information governance to allow data sharing and educate people about the importance of doing so;
- Developing metrics against which to evaluate progress and build the evidence base of the benefit of these technologies.

Patients will be empowered to manage their own conditions and given help to keep healthy at home. “It’s time for patients and clinicians to let go of the idea that you need to go to hospital to get care,” Thompson said.

Technology can play a role, enabling parameters such as blood glucose, temperature, heart rate, blood pressure, to be measured at home or on the move, and allowing patients to access healthcare when they need it, rather than as dictated by appointment schedules or outpatient clinics. “Patients are the experts in their conditions, the healthcare professional is a partner,” Thompson said.
Four groups set up to work on each priority have reported back and the Technology Enabled Care Services Improvement Plan 2014-17 is due to be published in April.

The changes in the objectives and scope of the programme underline the change that is coming in the way health and social care is delivered. It will be done at scale and yet be person-centred. As a result, assistive living will be moving into a more mixed economy, rather than being delivered solely through statutory provision, said Graham Worsley, Lead Technologist, Technology Strategy Board Assisted Living Innovation Platform, summarising ‘Future Directions of the ALIP programme’.

The funding provided by ALIP has fostered the development and maturing of a number of assistive living technologies, and Worsley suggested it is important to keep funding the translation of university research. He cited research into body sensor technologies being carried out in a research council funded programme led by Bristol University, which is looking at sensors to predict falls, detect strokes, ensure people are eating healthily and taking medication, and to detect depression, as an example of future enhancements of assistive technology.

As a result of being limited to statutory provision, the market for assistive technologies has not grown to any extent since ALIP got underway, and given budget cuts, there is little scope to build the market for existing products and services. However, change is on the way, with assistive living expanding to take in more products, such as fitness and games apps. As a result the ecosystem is growing and there is potential to grow the market from around £100 million now, to £450 million, Worsley believes.

The changes in the objectives and scope of the programme underline the change that is coming in the way health and social care is delivered. It will be done at scale and yet be person-centred. As a result, assistive living will be moving into a more mixed economy, rather than being delivered solely through statutory provision, said Graham Worsley, Lead Technologist, Technology Strategy Board Assisted Living Innovation Platform, summarising ‘Future Directions of the ALIP programme’.

In conclusion Yeandle said her key message to delegates is to use the AKTIVE research “to get where you are going faster” and to “challenge us to share it in ways that suit you.”