The Long-term Care Revolution: Revolution Evolution

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The Long-term Care Revolution was launched by the Technology Strategy Board in 2013, with the ambition of transforming the conventions, perceptions and structures on which institutional care is based currently, leading to a radical re-thinking of how care is provided, and opening the way for the innovation needed to deliver on this vision.

The ambition is that rather than being seen as an economic liability, long term care becomes an engine of economic growth.

A meeting in London on 1st May brought together delegates from around the country and from different sectors and disciplines, to review progress, discuss projects and set out objectives for a National Challenge to take the programme forward.

The work will build on the experience and expertise developed since the Technology Strategy Board’s Assisted Living Innovation Platform (ALIP) set out in 2007 to meet the demand for independent living and improve the quality of life of the UK’s ageing population.

With the number of people living in care homes forecast to rise from 450,000 in 2013 to 1.13 million in 2050, the current model is unsustainable and not fit for the future. “We need to rethink institutional long term care, stimulating innovation and creating new and desirable alternatives, such as we have in the rest of our lives,” Marshall-Balloch told delegates.

The aim is to provide people with options if and when they need care. “This will develop a dynamic market for affordable lifestyles and care options that will drive economic growth,” Marshall-Balloch believes.

### The Long and Winding Road

At its heart, this drive to promote innovation and the application of technology to the issues of ageing is about preserving individual autonomy, said Jackie Marshall-Balloch, Lead ALIP specialist and the source of the vision behind the Long Term Care Revolution.

“This is about taking the first steps in addressing an intractable challenge in the UK – and one that is not seen as an area for innovation,” Marshall-Balloch said. Whereas ALIP has worked within the existing framework to develop products and grow markets that support older people to live safely and independently for longer, the Long Term Care Revolution aims to completely reform institutional care.
The Long Term Care Revolution is not about restructuring or reforming the current system. Rather, the intention is to build something entirely new. There is a “huge role for innovation” in addressing the demographic shift and creating national and global market opportunities. “The time is right and the Technology Strategy Board can add value to this agenda,” said Marshall-Balloch.

More than 300 people participated at workshops held around the country to begin to scope alternatives. Following this, a Sandpit meeting was held in which 25 people from academia, charities and SMEs representing businesses ranging from architecture practices to nanotechnology specialists were supported by four mentors to shape their thoughts, in an intensive, week-long event.

This planted the seeds for the first Long Term Care Revolution projects, Sandstorm, RITA, One Precious Life, CASA, SALTC, Poppins and Flourish, which got off the ground in January 2014.

“The Sandpit took people out of their comfort zone,” said Marshall-Balloch. “They came out with passion and commitment to disrupt the current model.” Now, it is necessary to bring that sentiment to the public, to communicate the need for a social revolution. Between May and July the Technology Strategy Board will sponsor three workshops to pull in partners, leading to another Sandpit exercise in September, to shape the National Challenge, which will be launched in November 2014.

At present the prevalent sentiment about long term care is denial. “It’s someone else’s issue: we think we won’t be in an institutional setting,” said Marshall-Balloch. Sadly, the main sentiment people in care express is ‘How did my life come to this?’ she said.

Following on from the initial launch of the Long Term Care Revolution, the Technology Strategy Board has scoped the issues in a programme of economic, social, ethnographic and branding and identity research.

This laid the ground for the first tranche of funding in which GBP2.4 million is being invested in attracting and bringing together individuals with the skills, insights and enthusiasm to articulate how long term care could be reformed, and thus remove obstacles and inertia standing in way of change.
Long Term Care Revolution – Mentors’ Views

Sylvia Wyatt, one of the mentors at the Sandpit, who is monitoring progress of three of the projects, said the key to the Long Term Care Revolution is earlier intervention. Healthcare professionals are only likely to interact with people who have a chronic disease for a few hours a day. The rest of the time patients take care of themselves. “They do it quite well most of the time, so why hand over so much responsibility to professionals?” Wyatt said.

The current system is geared to respond to incidents and crises – as a result people get late interventions with the result that whatever is wrong ends up being worse than it should be. For Wyatt, this is the root of the problem. “Currently, the system responds, it doesn’t anticipate,” she said.

The aim of the Sandpit was to come up with novel ways to reduce and eliminate the need for institutional care. The result was a patchwork of ideas that now needs to be worked on to form a complete picture of possible solutions, said Wyatt.

“We are trying to get to the end of the rainbow. This will always be just out of reach but we can see clearly some of the elements. We will find how to get most of the way, and help people live at home, or wherever they want to live, for longer,” Wyatt concluded.

Another mentor at the Sandpit and supporter of two of the Long Term Care Revolution projects, Ian Spero of Creative Skills for Life said he was inspired by the prospects opened up by the Sandpit to develop products and services that will enable people of any age to have a better quality of life. “Creativity aligned with technology can be used as a catalyst for personal development and coping with long term conditions,” he said.

Older people are becoming more technology literate and as a result, “we are just scratching the surface of the potential of innovation to empower people to become and maintain their independence for longer,” said Spero.

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Although not providing a complete answer, the Sandpit did articulate the values and principles which should guide future work:
- Mutuality – support of each other; helping neighbours
- Empowerment – using technology
- Alternatives – finding new ways of doing things so that people can stay at home
- Resilience – find ways to help people carry on doing what they like, whatever their
- Nurture – take the small ideas, foster them and help them grow
The need for early standards setting

One of the key findings of ALIP – and a barrier that remains to the successful implementation of assisted living on a large scale – is that standards are needed to ensure systems and organisations can interoperate.

In the Long term Care Revolution standards have been given priority at the start of the process, to ensure the experience of ALIP (and many other technical projects), is not repeated, Rob Turpin of the British Standards Institution told delegates.

The Technology Strategy Board and the British Standards Institution agreed in September 2013 to look at early standards setting in four emerging areas of technology, including assisted living. The focus is on removing silos and creating a single movement in which participants can drive standards forward.

Appropriate standards will be ones that empower consumers, not those that suit companies and professional bodies, Turpin said.

The British Standards Institution has carried out research with paid and informal carers, nurses and the general public as the basis for the assisted living standards strategy. As a result of this exercise different components of long term care were identified:

- Medical and health needs and how these services are run
- Well-being
- Combatting isolation
- Delivering personal care
- Daily living
- Financial aspects and concerns
- Physical security

The challenges and barriers to the Long term Care Revolution were also flagged up by the research:

- The need to provide person-centric care
- The need to ensure quality of care
- The lack of access to activities for older people
- Developing the home as an independent living space, with IT, wet rooms, etc
- Overcoming resistance to digital healthcare; reassuring people they are not being offered digital products and services in place of face-to-face professional care
- Societal attitudes to ageing and the aged
“The key finding is that people want tailored care coordinated via one key contact,” Turpin said.

Following on from this scoping research, the British Standards Institution has picked two aspects of the Long Term Care Revolution – digital health apps, where it will set out principles for good apps; and managing money, where it will look at standards for paying for goods and services, planning financial futures, involving others in planning, making sure people get all the benefits to which they are entitled and avoiding financial scams.

Guest Speakers describe experiences of institutional care

Jade Marshall-Kuca, a participant in the Sandpit and a speaker at the meeting, is in no doubt of the need for reform. Based on her experience as a professional carer, she told delegates, “The system is extremely flawed, it’s unfixable, it needs to be scrapped.

In particular she pointed to:

- Examples of abuse
- Persecution of whistle blowers
- Institutional secrecy
- A lack of funding which means there are not enough staff to provide proper care

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The intention is to deliver a standards strategy document with roadmaps of these two areas, which the British Standards Institution will start to shape and deliver in 2015.
Older adults in the care system “are living a daily nightmare, and nobody speaks for them,” Marshall said. “It’s the responsibility of all of us to do something. Even one small step forward can make a difference.” Similarly, Ashley Rhodes, a participant at the Sandpit and guest speaker, who was in institutional care whilst growing up, told delegates how his autonomy was limited. “I needed freedom and choice and I didn’t get it; people in care can’t get access to technology.”

However, he cautioned that machinery can mask problems; what people crave is communication with humans. “The internet can’t do what humans can; computers and machinery may exacerbate the problem,” Rhodes said.

Sandstorm: Witness View and the Sandpit Vision Re-visited

The testimony of Marshall and Rhodes joins that of many others in highlighting the need to change the system. To make a successful revolution people need to share a common cause. In an unprecedented move for the Technology Strategy Board one of the projects – Sandstorm – will aim to build the public sentiment needed to deliver the Long Term Care Revolution.

Tracey Parsons, a member of the Sandstorm project, said, “The system’s not good enough, it has to change, which means we all have to change.” Such change usually comes after a wake-up call, for example, when a heart attack prompts a shift to a healthier lifestyle, or when a fall persuades someone to start wearing a pendant alarm.

Sandstorm intends to get people out of their denial in advance of the wake-up call, by making them project forward and think about what they want their 100th birthday to be like. “Today is the first step in widening out the conversation” Parsons said.

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The Six Innovation Projects

RITA – Responsive Interactive Advocate

RITA aims to harness technology from the entertainment industry to underpin new models of personal care that restore autonomy. “The project came together around the need to give back choice and control,” Valerie Carr of We are Snook told delegates. The ambition is that RITA as a service and brand becomes as important and significant as the Apple iPhone.

Using avatars - artificially intelligent virtual companions, RITA will help older people stay living comfortably and safely in their own homes for longer. Each person will have a tailored avatar capable of intelligent communication, which will monitor their health and well-being and provide a single link between the individual and family, friends, professions and services.

The avatar will have access to a comprehensive database of personal information, ranging from health records to personal preferences and even character traits, to inform its communication and decision-making.

The avatar might appear as a figure on a television screen or a tablet computer, and will link with other services and devices for monitoring heart rate and blood pressure, reminding people to take medication. It would sense if they have a fall, or are in pain, and send an alert.

RITA will be a constant, empathetic presence, analysing speech, movement and facial expressions to detect mood and respond accordingly. The intention is that the system is as easy to use as a television. “This will empower older people with complex needs to stay at home. It is a viable and significant answer to many issues in care at present,” Carr said. “We are developing RITA for ourselves – to fit our vision of how we would like to be supported as we age.”

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Poppins

The Poppins project is exploring the use of a parallel virtual currency as an enabler of initiatives that promote independent living. It will use the currency to change attitudes to the elderly, helping shopkeepers to establish a relationship with a key – and growing – sector of their customer base.

At the same time, the currency will provide users with access to community resources that will be a focus for meeting people, reducing isolation. “Poppins is fundamentally about making connections that can help people move forward,” said Kay Hutchinson of Belle Media, the company leading the project.

The Poppins project is based in Greenock, Scotland, where, as Hutchinson described, there is “a fantastic heritage” but a challenged community, with more single person households, more deprivation and more old people, than the average for Scotland.

In the Poppins project the virtual currency will be given out by shopkeepers as part of a rewards scheme to drive trade in the Oak Mall Shopping centre in Greenock. The currency can be spent in a community centre that is being set up in an empty shop.

The community centre will be a place to access huge archives of photographs, videos and interviews relating to Greenock, reconnecting people to the past and using ‘image therapy’ to spark the sharing of memories and stimulating conversations.

“There are lots of different things going on in Greenock, but people are stuck at home. We want to get them out and get them talking so they are more connected to the community,” Hutchinson concluded.
Flourish: Aspirational Ageing

The Flourish project aims to reframe the concept of need, moving away from a care system that provides physical support alone, to one that focusses on well-being. “It will identify aspirations that make life worth living and then deliver this in personalised plans, to help people realise them,” Suzi Bentley Tanner of Digital Laundry, the project leader, told delegates.

Flourish will work with older adults to develop tools that help them get over the barriers to doing those activities that give meaning to their life – helping someone with arthritis to keep baking, or a gardener to keep digging, for example. “This will be a self-service tool that has a disruptive effect on the care system,” Bentley Tanner said.

Researchers in Flourish are now talking to people in their 80s and 90s, doing interviews in care homes to understand what constitutes meaning, has commissioned a poll of 2,000 over 65s and is doing additional research on a ‘strivings bank’ to provide further insights.

One Precious Life

This project is applying the principles of high performance athletics training, service and support, to people with long term conditions including diabetes, heart disease, dementia, the after-effects of stroke, asthma and arthritis.

“We will treat everyone as an elite athlete,” said Ryan Ward of Rescon, who is leading the project. Experts with a background in high performance training have worked with people from health and social care to develop 26 modules to train coaches, who will then support people with specific long term conditions.

“It’s not about cure or prevention, but about performance enhancement,” Ward said. Dealing with the difficulties – including emotional, physical, mental and social frailties – that come with long term conditions can be tough, but a change in attitude and having the support and tools for coping can make a difference.
SALTC – Simulating Ageing and Long Term Conditions

The aim of SALTC is to develop a simulation of what it is like to live with a long term condition across the likely course of the disease, and use this to explore acceptance thresholds. "It will simulate ageing and what it’s like if you have a long term condition, and help optimise the end of life," said Chris Crockford of project leader Cardiocity Ltd

Rather than starting from the initial diagnosis, SALTC will start from the end of life and project backwards. This will make it possible to identify trigger points where more help is needed and give a greater understanding of their disease and the costs associated with each stage.

"SALTC will provide a tool to enable everything to be planned for in advance, both legally and financially, to ensure individuals maintain autonomy," Crockford concluded.
CASA – Connecting Assistive Solutions to Aspirations

CASA, led by Leone Services, intends to transform the assistive technology market as it stands at present, by integrating new and existing technologies in ways that create a better fit with an individual’s environment, social networks and lifestyle aspirations.

The result will be consumer products and services that help people maintain enjoyable, independent lives. Currently, telecare services are focussed on age-related decline, which means they are far from being what consumers would choose to buy, or what they want in their home. CASA aims to transform this out of date approach, giving older people and young adults with learning difficulties the opportunity to work with dementia and care experts to co-design products and services.

In parallel with creating and testing models of technology-enabled independent living, to ensure they are commercially viable, CASA will create new models for financing assistive care and plot better routes to market than those open to existing products, which in the main are only available from statutory agencies.

The customer-led design approach will ensure services are not second rate – they will not be based on needs assessment, but on what users want.

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While the need for the Long Term Care Revolution is self-evident, this momentum needs to be translated into a programme of research that is business, technology and innovation focussed.

The delegates broke into four workshop groups to consider the key issues that should be tackled in the next phase – a National Challenge to take things forward.

National Challenge: What we Know and More Importantly what we don’t know yet

Jackie Marshall-Balloch set the scene, asking delegates to consider the following questions:

- What should the next focus be?
- How can the Technology Strategy Board ensure the overall programme stays on the right track?
- How can the Long Term Care Revolution build the collaborations that will be needed to deliver the vision?
- Where are the gaps in current thinking?
- What evidence will be required to demonstrate progress in what will necessarily be a long process of reform?
- How can businesses be involved?
- How are products and services to be scaled up?

Recommendations and feedback from the workshop to inform the National Challenge

1. Undertake work to promote the commercial viability, in particular considering how products and services can be scaled-up
2. Connect up the system – there are many relevant initiatives spread across the landscape, but there is no single overview
3. There should be a role established for ‘key connectors’ to help communicate progress and requirements to policy makers, and to help SMEs to connect to big companies that win contracts
4. In general, better intelligence is needed to help SMEs get business, one example would be to provide help in accessing the funding available under the £3.8 billion Better Care Fund, announced in June 2013, which is establishing a single, pooled budget to enable health and social care services to work together to support the move from providing care in hospitals, to delivering it in the community
5. Work is needed to build supportive communities that can underpin the delivery of the products and services developed as part of the Long Term Care Revolution

6. A single public access point to services is needed so that people know what is available and how to get it. This should include an intelligent search function, enabling people to key in queries such as, ‘I need help to pull up my socks’

7. Despite work carried out under ALIP there are still no reliable business models or efficient routes to market, this gap needs to be filled

8. Technology must be suitable for users from one end of the system to the other, including for informal carers, and to enable caring at a distance. Carers should be included in the next Long Term Care Revolution event to capture their needs and insights

9. It is important to learn from the past and from what exists in the assistive living landscape at present, to avoid reinventing the wheel and help people identify and build on what exists currently

10. The National Challenge must embrace the themes of mutuality and empowerment and ensure the focus is on humans plus technology, not technology for technology’s sake

11. Many older people face economic hardship and it is necessary to consider how to overcome this in using technology to provide autonomy and independence

12. There should be work to get more big companies that have existing products, services and customer channels that are relevant to the Long Term Care Revolution involved and to create more noise about the National Challenge

13. Between independence and dependence lies a grey area of “interdependence” and the Long Term Care Revolution needs to consider specific types of needs that arise in this middle ground

14. Create a business to monitor well-being

Marshall-Balloch concluded the meeting, thanking delegates for their contributions and undertaking to factor their recommendations into the work of taking the Long Term Care Revolution forward under the National Challenge.