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## Dementia

# Working collaboratively to support people living with dementia

Lisa Woods and colleagues report on how a 'living lab' approach can help service users

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#### Abstract

This short paper introduces the 'living lab' concept in dementia care and outlines its value as an innovative and cost-effective strategy.

#### Key words

Dementia, services, living lab

#### Reference

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#### Introduction

Dementia is one of the greatest challenges facing our ageing society. Recent figures suggest that around 830,000 people in the UK currently have a dementia diagnosis (Alzheimer's Society, 2014), which equates to 1.3% of the entire UK population (Prince, et al, 2014) and cost the UK economy £23 billion a year (Alzheimer's Research UK, 2014).

However, these figures are only an estimatie, as only half of those living with dementia have a formal diagnosis and so the real figure is likely to be much higher (Department of Health, 2013).

Diagnosis rates for dementia are expected to rise significantly in the UK in the coming years, and as current methods of supporting people are economically unsustainable, innovative approaches to care delivery and health and social care planning are essential.

Since the National Dementia Strategy for England was released in 2009 (Department of Health, 2009), many policies have been published aimed at improving experiences, outcomes and quality of life for people with dementia and their carers.

The increasing numbers of people living with dementia and the recognition that current health and social care systems are struggling to care adequately for people with dementia has increased the drive towards developing innovative and cost-effective health and social care strategies.

A key principle underpinning improvement and innovation is the concept of personcentred care, as detailed by Kitwood (1997). This can only by genuinely achieved through authentic user engagement and dialogue.

Understanding the experience of dementia from the perspective of people living with the

condition is integral to the success of personcentred models of care, enabling services to be designed and delivered around the needs of those who use them.

Traditionally services have been designed and developed by professionals and policy makers, excluding people living with dementia and therefore creating services that do not match the expressed needs of people with dementia, their family members and carers.

#### The 'living lab' approach

A relatively new approach in health and social care that is gaining popularity and momentum is a 'living lab'.

This is an innovative method of engaging people using services in innovation through a process that brings users of services together with health and social care professionals, academia and businesses in a quadruple helix (see Figure 1).

The living lab approach facilitates true collaboration and the sharing of each partner's expertise, and places service users and carers at the centre of the research-to-innovation process.

Information communication technologies, urban planning and media living labs have been in use for over 25 years (Von Hippel, 2005), however the living lab methodology in health and social care is a new and transformational approach that values users in product, process and service innovation.

The living lab provides the framework to collaboratively explore everyday challenges that are experienced by partners within the quadruple helix.

The systematic exploration, co-creation, design, testing and evaluation process can

produce innovative solutions that address population needs, ultimately producing userfocused, cost-effective care strategies to 'fit' the real needs of the person (see Figure 2).

#### Innovate Dementia

Innovate Dementia, a three-year Interreg IVB European funded project led in the UK by Mersey Care NHS Trust and Liverpool John Moores University, is collaborating with European partners from The Netherlands, Belgium and Germany to develop, implement and integrate innovative, long-lasting solutions to the socioeconomic challenges associated with ageing and dementia.

Innovate Dementia aims to strengthen transnational co-operation across all partners to address the challenges that go beyond national borders and for which satisfactory solutions can be developed and shared nationally, regionally or locally.

The Innovate Dementia project uses a 'living lab' approach to explore innovative approaches and positions people living with dementia at the centre of the research-toinnovation process.

#### Innovate Dementia living lab

The Innovate Dementia living lab, managed by health clinicians and academics, provides the framework to facilitate the innovative co-creation process with people living with dementia.

It is the crucial link in the innovation chain that provides a safe space, where people living with dementia are central to the cocreation process, both in terms of driving and shaping priorities and in influencing the development of new or improved quality services, processes and products.

Innovate Dementia's definition of a living lab, based on a literature review and developed from evidence is: 'A pragmatic research environment which openly engages all relevant partners with an emphasis on improving the real-life care of people living with dementia through the use of economically viable and sustainable innovations' (Woods et al, 2013).

#### Principles

The underpinning principles that govern the living lab are:

• Continuity: providing a consistent open approach that ensures sharing of learning, knowledge, expertise and innovative practices. • Openness: facilitating an open, inclusive innovation platform.

Realism: prioritising the needs and real experiences of people living with dementia.
Empowerment: empowering people using services to shape the innovation process.
Spontaneity: encouraging and exploring spontaneous and novel ideas.

An extremely important role of Innovate Dementia in the living lab process is the unique management and governance responsibility of bringing the quadruple helix together with a group of individuals who can be vulnerable.

A governance framework facilitated by healthcare professionals and health academics provides the supportive milieu for investigation and evaluation of new innovative concepts, while ensuring a person's autonomy, rights and risks are protected and the person's best interests are central. The Innovate Dementia living lab process has three crucial stages, reflecting similarities with other living lab business excellence models across Europe (Katzy, 2012):

 Open innovation community: a real-life innovation space, where a wide range of stakeholders; people living with dementia, health and social care professionals, academia and business come together to openly explore potential ideas, concepts, challenges and possible 'matchmaking' opportunities. A selected range of product, process and service innovations explored will mature in the living lab co-creation process.

• Co-creation process: a staged process for product, service or process innovation. The co-creation process brings the right people together to explore, design, test, evaluate and validate product, service or process innovation, considering market positioning to prepare adoption of the solution.

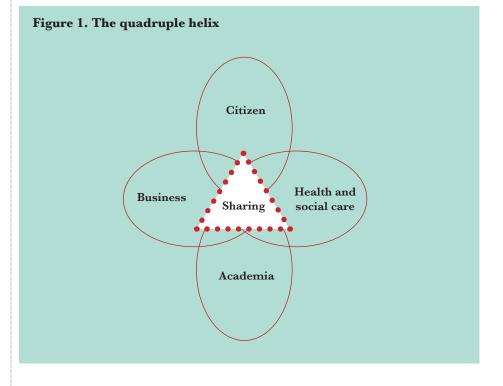
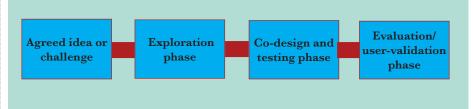


Figure 2. Designing a co-creation process



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• Knowledge business acceleration: an established framework for knowledge and business acceleration to share the value and impact of product, service or process innovation undertaken in the open innovation and co-creation processes. The approach generates intelligence that can to be used in the development of innovative services and technologies that ultimately improve the lives of people living with dementia.

#### Value of a living lab approach

Feedback from the Innovate Dementia living lab, supported by other living lab experiences (Katzy, 2012; European Network of Living Labs, 2014), demonstrates a number of benefits for all partners.

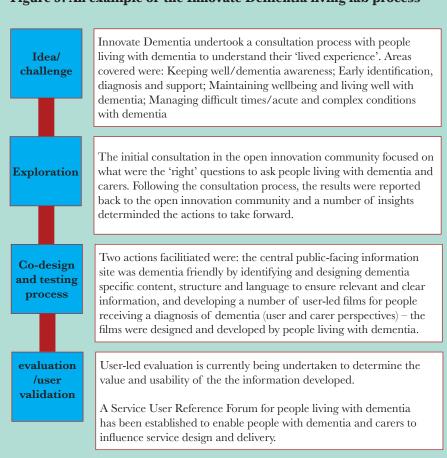
The collaborative user-centred design approach ensures innovation is likely to make significant impact on a person's health and wellbeing, creating a sense of role, value and ownership.

The generation of both internal and external sources of ideas can co-create original, creative, cost-effective and sustainable solutions to a number of health and social care challenges that may not have been considered through traditional methods of design or improvement.

The living lab framework facilitates the early stage of innovation, avoiding wasting time and resources on concepts that are not right and products that will not meet expressed need of the end user.

It is difficult for businesses to gain first person knowledge and 'access and work with' end users. However, the living lab approach provides opportunities for businesses to listen to and engage with people using services and products.

The development and testing of innovations in real life environments with end users ensures the evaluation is realistic and more accurate resulting in processes which



address user needs, creating a better 'fit' and adoption of products or services by users as they have invested in their production.

The open innovation process accelerates innovation. Innovating in partnership with experts from all groups of the quadruple helix and sharing risks and rewards means that learning is harnessed and built upon.

The approach transforms service, product and process innovation at a quicker and more dynamic pace rather than improvements being designed in isolation, or people 'reinventing the wheel' when innovation may have already previously been created, optimised and tested by others but not shared at scale. This ultimately improves the quality of life and well-being of individuals, families and communities.

The model and experience of using this methodology to engage stakeholders in the Innovate Dementia project should be highly transferrable to wide range of conditions across the health sector to improve quality and effectiveness, and ultimately ensure that innovations 'fit' the needs of the end user. MHN

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#### Figure 3. An example of the Innovate Dementia living lab process