ENGAGING COMMUNITIES IN HEALTH INNOVATION:

Learning from the Leeds URBACT Project

Contents

About this report

Scope

This report is a summary of some of the learning that has been gained from the Leeds-based projects affiliated with URBACT. Its main focus is around how community engagement can add value to all parties involved in health innovation work. There is scope to develop a better understanding of engagement in innovation from the perspective of the individual service users and communities involved. The report therefore summarises some lessons learned within the projects in Leeds and makes some suggestions for principles of community engagement and innovation in future practice. The report is primarily a piece of reflective learning and idea development rather than a formal evaluation or comprehensive case study. The interviewees have been limited to project leads and the report focuses on learning from their perspective.

Methodology

Semi-structured interviews were held with each of the project leads for the 5 Leeds-based projects affiliated with URBACT. Strategic leads for health and innovation were also interviewed. Desk-top research, consultation and attendance at Leeds URBACT meetings were also completed.

Report Authors

Rob Newton is a Health and Wellbeing Policy Officer in the Institute of Health and Wellbeing at Leeds Beckett University

Professor Jane South is a Professor of Healthy Communities in the Institute of Health and Wellbeing at Leeds Beckett University

Professor Alan White is a Professor of Men's Health in the Institute of Health and Wellbeing at Leeds Beckett University

Phil Swann is Managing Director of *Shared Intelligence*

About the Institute of Health and Wellbeing, Leeds Beckett University

The Institute for Health and Wellbeing exists to foster the generation of research and knowledge in specific areas relating to the health status of individuals, communities and nations. The Institute has a range of related disciplines within a single unit, including men's health, community engagement, pain and rehabilitation, children and young people and wellbeing and public health. The Institute was a partner in the steering group during the URBACT Project.

About Shared Intelligence

Shared Intelligence is a regeneration and public policy consultancy working with a wide range of clients in central, regional and local government, Non-Departmental Public Bodies and other voluntary and community sector agencies. They specialise in a number of areas including: regional and city-regional development; employment, skills and enterprise; community planning and partnership development; and health and wellbeing. Shared Intelligence provided facilitation, coordination and advice during the course of the URBACT project.

Introduction: The URBACT Project

URBACT: 4D CITIES

About

URBACT is a European knowledge exchange and learning programme. It aims to help enable cities to develop solutions which integrate economic, social and environmental factors for sustainable urban development.

4D Cities is a project within the URBACT programme. The objective of this project is to explore how local governments can promote innovation in health care whilst putting people at the centre of innovation and facilitating economic growth.

Aims

The stated aims of the 4D Project are to:

Develop integrated policies in Health Innovation

Create a new productive sector that contributed to diversification, competitiveness and improves economic activities

Increase the citizens' quality of life and the regions' social cohesion

Achieve a more prepared society to meet the constant challenges of the 21st century

Involve society in the design of these policies to become an active part of this growth

Establish closer links between European cities to learn and share experience for mutual benefit.

Participants

The cities participating in the URBACT 4D Cities Project were:

Lead Partner: Igualada (Spain)

Leeds (UK)

Novara (Italy)

Tartu (Estonia)

Plungė (Lithuania)

Jena (Germany)

Baia Sprie (Romania)

Eindhoven (Netherlands)

LEEDS PROJECT

At the outset of the programme in 2012, partners in Leeds had recognised the importance of the links between health and wealth and the role of innovation as a key tool to drive 'good growth' which benefits the community with better health and new jobs. The city recognised that it has unique assets across health and social care, and there was potential for a much greater impact in both health and economic outcomes by collaborating together.

The Leeds Innovation Health Hub was established as a virtual point of co-ordination for innovative new projects that would bring together all the healthcare system stakeholders in the city. Its aim is to provide the infrastructure required to create a world-leading hub for medical and healthcare innovation.[1]

With the establishment of the Leeds Health and Wellbeing Board, and other new structures of governance, commissioning and partnership, combined with a need for a more participatory approach with communities, it was envisaged that the process for new relationships and approaches could be initiated.

From the outset there was an issue as to whether partnerships would be sufficient to really unlock the barriers that prevented participation by citizens and patients at a scale and intensity needed to accelerate innovation in health, and thus fully realize the full potential of the city's assets in health. A key task of the 4D project was therefore to assess what more might be required.

Aims

The URBACT 4D Cities project for Leeds had a focus on establishing forums which enable learning between different people involved in health and innovation. This meant bringing in perspectives and contributions from private enterprise, social enterprise, patient user groups and citizens in the process of innovation in order to benefit the health of individuals and the growth of the local economy.

The work in Leeds included objectives to:

Ensure that Leeds has effective models and processes for engaging its citizens in health innovation;

Establish Leeds as the place to go for engaging communities in health innovation;

Ensure effective democratic engagement in the process;

Ensure that Leeds has access to sustainable sources of investment in health innovation;

Be an active member of the 4D Cities Network.

Projects

Five pilot projects were selected for their respective strategic importance in health and innovation. They all have potential contribution to 'good growth' of the Leeds Economy, with health and wellbeing outcomes for local populations and the creation of new jobs.

mHealth Habitat - the creation in Leeds of an environment for new mobile and digital health projects

The Innovation Exchange: a real and virtual space in which experts, innovators and financiers can interact;

Assisted Living Leeds – a new building for assistive technologies, community equipment and telecare.

The Leeds Care Record – a digital care record to include a range of health and social care information for care professionals directly involved in a person's care.

Medtech - sustaining a cluster of companies developing and manufacturing health and care products around 'learning' from public and patient involvement.

Background

LEEDS

Leeds is a large city in West Yorkshire with a population of over 750,000. Partners have a collective vision to be the 'Best City in the UK' by 2030.[2] In terms of health, outcomes in Leeds are generally lower than the England average with challenges associated with an ageing population and economic disadvantage. Health inequalities are stark in the city: the life expectancy of a man in a deprived neighbourhood is 12 years lower than someone living in a more affluent area. The Leeds economy has an estimated worth of £18bn. It is the second largest city in terms of employment in the UK and is home to over 25,000 businesses. Healthcare has the largest amount of employment, with over 170,000 people working in the Leeds City Region. Of these, over 11,300 people are employed in 'high technology employment'.

Joint Health and Wellbeing Strategy

The Joint Health and Wellbeing Strategy sets a vision that 'Leeds will be a healthy and caring city for all ages, where people who are the poorest, improve their health the fastest'.[3] One of the five outcomes in the strategy is that 'People will be involved in decisions made about them'. Within this there are priorities to 'Ensure that people have a voice and influence in decision making' and to 'Increase the number of people that have more choice and control over their health and social care services'.

The Joint Health and Wellbeing Strategy is produced by the Health and Wellbeing Board, which is a strategic partnership board across the city's commissioners, providers and third sector groups. It is the first time that partners have come together in such a format and represents an opportunity for a fresh approach to partnership working and integrated decision making across health and social care.

Health and Wellbeing Boards

Health and Wellbeing Boards are a statutory partnership body of each upper tier authority in England. They bring together decision makers from the NHS, public health, local government and the third sector to jointly plan provision and commissioning for local health and care needs.

Best City for Health and Wellbeing

Leeds has a stated ambition to be recognised as the best city in the UK by 2030. For Leeds to be the best city for health and wellbeing it must provide high quality health and social care services. But the city must also create opportunities for business, jobs and training, be a city made up of sustainable communities and be a great place to live. These factors are vital determinants of population health and combine to help with the city's ambition to create a high quality, sustainable health and social care system.

Civic Enterprise

In 2012 Leeds City Council hosted the Commission on the Future of Local Government, which produced a report and considered the concept of 'Civic Enterprise'. This is defined as "a new leadership style for local government where councils become more enterprising, businesses and other partners become more civic and citizens become more engaged."[4] At the core of the

commission's propositions is the notion of councils becoming more entrepreneurial and businesses becoming more civic. As part of this way of thinking, the aim is to undertake collaborative projects in a way which contributes to the health and wellbeing of the people of Leeds, helps service providers cope with demographic and financial pressures and enables Leeds-based companies to grow their market share and act as a catalyst for new businesses to move to or grow in the city. Alongside this is a recognition that the Local Authority will shrink in size, but needs to 'grow in influence'. This approach is in keeping with the aims of the URBACT project.

Health and Innovation

The city of Leeds has a unique health and social care ecosystem with collaboration across private, public and voluntary sectors. It is has three universities with specialisms in health, hosts the headquarters of four National Health Services bodies, has a thriving third sector, and is in a City Region which employs 193,000 people in health and life science jobs.

By combining these assets with the strengths of its communities, Leeds aims to be a global city for health and innovation.

This approach was behind the conception of the Leeds Innovation Health Hub in 2013. It is based on the premise that promoting the existing asset base of Leeds will attract new health-related businesses to city, leading to jobs and economic growth. This will in turn lead to local health and care providers benefiting from stronger links to businesses. Health and care staff will benefit from participating in the development of innovative

products and services as will the national bodies in the city. And local communities and people will have the advantage of co-designing new approaches to health and social care.[5] This has been based on a partnership model between organisations in the city with the aim to:

- Build a strong international reputation for Leeds as a centre of excellence for innovation in health and medical technology;
- Attract inward investment to drive innovation in health and medical technology in the city;
- Foster enterprise and new business opportunities through health and medical technology;
- Create jobs and training opportunities through innovation in health and medical technology.

Work has encompassed the following three themes:

Medical technology - using technology to ensure that when medical intervention is necessary it is carried out in the most effective way possible;

Health and social care informatics - in particular the transformation of data into value-added knowledge for patients, the public, providers, clinicians and care staff;

Engaging communities - most notably, working with communities to co-produce, co-design, test and implement new innovative products, services and transformational plans.

NATIONAL

Five Year Forward View

The NHS England Five Year Forward View, published in November 2014,[6] sets out the direction of health services in England. It calls patients and communities the 'renewable energy of the NHS'. It states that the NHS "will raise our game on health technology – radically improving patients' experience of interacting with the NHS. We will improve the NHS' ability to undertake research and apply innovation." The Forward View refers specifically to improving the information people have access to. On engagement it states: "We need to engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services." It also emphasizes the importance of co-designing the proposed new care models.

Health and Social Care Act 2012, The Care Act 2014 and Integrated Care

The Health and Social Care Act 2012 states that: "There is a consensus that patients should be at the heart of decision making and that we need strengthened local accountability and shared responsibility to develop and deliver improved services through health and wellbeing boards". There has been a significant focus on integrated care, for which National Voices were commissioned by NHS England to create a Narrative for Person Centred Coordinated Care.[7] The narrative provides a vision for care which is integrated around the needs of the individual and in which they have choice and control. The Care Act 2014, as the most significant reform of social care legislation for

60 years, puts new focus on user involvement and the control that individuals and their families have over the care they receive.

The NHS Constitution

The NHS Constitution for England brought together the principles, values, rights and responsibilities that underpin the NHS. Its objective is to empower patients, the public and staff within the NHS. It states that people "have the right to be involved… in the planning of healthcare services commissioned by NHS bodies, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services".[8]

Innovation, health and wealth

The NHS 'Innovation, Health and Wealth' report makes a strong connection between health outcomes and economic growth.[9] The National Strategy for UK Life Sciences states the ambition that the UK will be "the global hub for life sciences in the future, providing an unrivalled ecosystem that brings together researchers, clinicians and patients to translate discovery into clinical use for medical innovation within the NHS."[10]

INTERNATIONAL

Health 2020, the World Health Organization Europe's policy framework and strategy, calls for civil society to have a greater role in health and also commits to building people-centred health systems and more resilient communities.[11]

In 2013 the World Economic Forum (WEF) commissioned a series of discussions on

sustainable health systems.[12] This work highlighted the importance of data and information which, it concluded, had the potential to "change the way that health systems operate and make decisions". It also argued that the health care delivery model is "firmly stuck in the past" and that it was important to "break[ing] the traditional delivery mold and create space and opportunity for innovation."

In the preface to the WEF report the forum's executive chairman, Klaus Schwab wrote: "Sustainability is unlikely to be achieved through incremental changes. Instead transformational solutions will be needed – solutions that require cooperation across industry sectors and governments, and thereby challenge the current boundaries of health care and the established norms of operation."

The WEF report argues that a lack of cross-stakeholder dialogue constrains our ability to find innovative solutions. It argues; "There is a need to bridge the gaps between supply and demand, population health and individual healthcare, and healthcare and other related industries. Achieving tangible widespread change requires a coordinated approach that encompasses a broader diversity of actors from across and beyond the health sector." Creating a space for this dialogue is precisely what health and innovation projects are designed to achieve in Leeds.

Community Involvement, Health and Innovation

What is community involvement and why do it?[1]

The core idea behind community involvement is people's active participation as opposed to being passive consumers of health care. Many terms are used to define who is involved –'health consumer', 'service user', 'community', 'citizen' and 'public'. Communities can be place-based or groups of people linked by a common interest, but in reality people have many different allegiances and identities. Some citizen involvement is about the individual dimension, for example shared decision-making between clinician and patient. The collective dimension working with communities is also important for health and wellbeing.

Citizen involvement should lead to a shift in the balance of power. Various ladders of participation show the continuum from tokenistic involvement through to consultation, collaboration and finally citizen control. This is an important but simplified way of viewing involvement; built on an assumption that empowerment is the only goal. Contemporary debates acknowledge that there are many dimensions to citizen involvement and different situations call for different approaches which should be fit for purpose.[13]

---

[1] This section is adapted from a thinkpiece produced by Professor Jane South for a URBACT 4-D Cities event held in Leeds in March 2015

The rationale for citizen involvement has been well advanced over the years. Justifications fall into three broad areas:

1. Involvement as a means to bring about better, more effective services or public health programmes better attuned to needs.

2. Empowerment as a health goal. Here, participation is valued as both a process and an outcome leading to greater individual or community empowerment, and increased citizen control.

3. Rights-based justifications that emphasise democratic values and citizenship. These encompass the right of citizens to participate in their health care and collectively to have some voice in health planning.

The role of and potential value of communities has not always recognised in professionally driven health systems.[14] But this has to change if sustainable health systems which work for everyone are to be developed. The added value of community based approaches includes:

1. Active participation in healthcare and community networks **enables increased local representation and local leadership**

2. Engaging with communities provides opportunity to **better understand local needs and aspirations**

3. With increased use of personalised technology within public service provision, **services need to be better designed around user needs**.

4. Engaging communities can **directly address** social exclusion and **health inequalities**.

5. Community engagement provides more opportunity and facilitation of **local accountability and community ownership**.

How does citizen involvement work?

Citizen involvement is a broad field where there is a huge range of methods, tools and frameworks for practice. This is not because of a lack of consensus on what to do, it is because different involvement methods need to be matched to the purpose of involvement, the social context and population. For example, the methods used to involve individuals with lived experience of diabetes in designing health education materials would be different from a community consultation around health impacts of a transport strategy. A recent project by Public Health England and NHS England has mapped the different approaches that can be used to actively involve communities in health. The 'family of community-centred approaches for health and wellbeing' includes community development, time banking, volunteer and peer models, community engagement in planning, research and regeneration and community hubs.[15]

Community-centred approaches are complemented by individual-level approaches. The concept of patient activation is about how individuals can gain the skills and confidence to engage in their own health and care.[16] There has been a growing interest in the UK in co-production approaches, where design and delivery of health and social care is achieved through genuine partnerships between professionals and service users.[17] Co-production encourages a more equal and reciprocal relationships between individuals and professionals and has an important role to play in designing public services which make best use of community assets.[18]

What emerges from the rich tradition of citizen involvement in the UK and internationally is the importance of the quality and depth of relationships between citizens and public services. The UK's National Institute of Health and Care Excellence identify five prerequisites for success when undertaking community engagement: [19]

• Taking account of lessons learned from existing community initiatives
• Investing in long-term initiatives
• Identifying the changes needed within the organisation to support community engagement
• Agreeing levels of engagement and power sharing between statutory and community organisations
• Building mutual trust and respect between statutory and community organisations.

Why does community involvement matter for health and innovation now?

The Leeds URBACT project has aimed to explore the benefits from combining community engagement in health and innovation. There are a number of themes and strategic drivers which make this an important area of focus for the health and social care system.

Firstly, there are increasing numbers of people who have **more than one long term**

health conditions to manage. The number of people across the UK with three or more long-term conditions is predicted to rise from 1.9 million in 2008 to 2.9 million in 2018. The prevalence of multi-morbidity is much higher in areas of deprivation. As a result there is a strong link to health inequalities, and a significant burden on health and social care expenditure, with around £7 in every £10 of total spend estimated to be spent on treatment and care for people with long term conditions. Managing long term conditions requires more self-management and a shift to more community-based care.

There is evermore focus and need for more **joined-up integrated care**. This means more integration between physical and mental health, primary and specialist care and health and social care. For this to happen there could be significant organisational and culture change, underpinned by new types of partnership.

A sustainable health and social care system requires a **shift to asset based models of care**. The assets within communities, such as the skills and knowledge, social networks and community organisations, are building blocks for good health.[20] Over a decade ago a review by Derek Wanless on the long term requirements for the NHS concluded that high levels of public engagement are needed in order to keep people well and manage rising demand.[21] As the NHS Five Year Forward View makes clear, harnessing the 'renewable energy' of patients and communities is crucial for future sustainability of health and care services.[6]

Technology continues to advance and has the potential to bring significant benefit to the provision of health care. Technology solutions will inevitably transform the operations of the whole system and how people receive healthcare and manage their health. As new technologies are developed, it is crucial that products are designed around the needs of patients and help to reduce rather than widen inequalities.[9]

There is an increased focused on providing **personalised care** where people are more in control of what care they receive and how they manage their health. This is the case for people with long term health conditions, who can often have a similar level of expertise to the medical professionals who they see. The increased use of personal budgets, individuals accessing their care records and personalised medicine mean that in the years ahead we can expect a significant shift in how people are involved in their health and health care.

Projects Overview

The five projects chosen in Leeds cover different forms of innovation and different domains of health and wellbeing. Forms of engagement across the spectrum are currently being deployed, from conventional user groups to technology hack days. Each project is at a different stage, from initial conception of an idea to full implementation of operating models.

The types of innovation include:

- The development of new products and services, including surgical devices, apps and web-based platforms and new forms of assistive technology;
- Data sharing and other data-related developments;
- The creation of new physical and virtual spaces to support and enable the innovation process.

The projects are also employing a range of different approaches to engagement including:

- Surveys of and focus groups with users, patients and citizens;
- User representation on project boards and teams;
- Developing the role of user groups to encompass product design and development and engagement with businesses;
- The development of new spaces (real and virtual) to create the conditions for engagement and collaboration;
- The use of personas and simulations to inform service and product design and development;
- Collaborative design and product development.

MHEALTH HABITAT

What is it?

The 'mHealth Habitat' is a programme of work with the aim to create in Leeds an environment in which digital tools can be developed to improve experiences and outcomes for people accessing health and care services.[22]

Who is involved?

The mHealth Habitat is funded by Leeds and York Partnership NHS Foundation Trust and Leeds Community Healthcare NHS Trust with support from North Leeds Clinical Commissioning Group and other income streams

There is user representation in the project team and project board and the scope of user engagement has been extended from individual projects to shaping the programme as a whole through the "Heart of the habitat" initiative.

What has happened?

A digital innovation pathway has been developed which includes the role of citizens and users at key stages. A website and blog has been established and a number of co-design workshops have taken place and are planned. Extensive use is being made of hack days, discovery days and show and tell sessions, and the project has become increasingly strict in the involvement of users in events such as these.

A number of specific developments have been pursued, including an app for goal setting and food and mood tracking in eating disorder services, and a shared decision making digital platform in mental health rehabilitation and recovery services.

MEDTECH

What is it?

This work concerns the desire in Leeds to support the development of a cluster of companies developing and manufacturing health and care products and devices. The focus of the engagement strand of this work is on the involvement of patients and users in the development of new products, which is an under-developed area of activity.

Who is involved?

Partners from industry, Universities, the NHS and patient groups have been meeting over the last year to explore the potential use of Medtech simulation facilities in the city to accelerate learning on the application of technology to selected clinical pathways and explore the implications of this for skills and education

What has happened?

This is an area in which community engagement is at an early stage, but there are some encouraging examples of service user input to product development. Examples include the use of compressed stockings and orthotic supports and dash board development for mobile technology with and for older people. A Medtech expo event was delivered in July 2014 helped to demonstrate the benefits of collaborative approaches

This strand of work has sought to explore how all key partners can change their expectations concerning the involvement of patients at all stages and levels of product development, from discovery through to implementation.

THE INNOVATION EXCHANGE

What is it?

This project was originally conceived with a long term objective to create a real and virtual space in which experts, innovators, financiers and members of the community can interact.

What has happened?

An initial phase of activity involved the opening of the top floor of Munro House in the city which now hosts the Open Data Institute, the Leeds Data Mill, Leeds Civic Lab and the Leeds Impact Hub.

Who is involved?

The membership of the Open Data Institute is growing and Munro House is increasingly being used as an innovation space particularly for open data related initiatives focused on the community, professional collaboration and health services.

ASSISTED LIVING LEEDS

What is it?

Assisted Living Leeds is a major service development which has built a new one-stop centre that houses a range of assistive technology and related services to support older and disabled people to live safely and independently.

What has happened?

The project is split into two phases:

Phase 1 - Bringing together and enhancing Leeds' Assistive Technology services (including community equipment and telecare) in one

building.

Phase 2 - Developing the rest of the building for a range of options aimed at further improving the assistive technology services available in the building, including a retail unit, a Smart House and a product incubator/Innovation Lab.

Phase 1 completed in early 2015. Work is underway for Phase Two to identify potential commercial partners and funding streams to create a sustainable business model of development.

Who is involved?

The project is a joint project between the NHS and Leeds City Council and partners including Universities and User Groups.

Community engagement is particularly important in the second phase, both in order to inform the shape and nature of the development and to secure user involvement in the innovation and product

development process. The aim is to enable the health and social care community to act in new and enterprising ways by engaging with the private sector and creating innovative partnerships to further improve the services on offer.

An exploratory event has been held with potential public and private partners. It confirmed commercial interest in pursuing the initiative and further discussions are now underway on further potential involvement through an "innovative partnership" or "competitive dialogue" group.

The model is being tested this year through establishing a 'pop up' Innovation Lab.

Leeds Involving People have worked with an existing user group to develop their role to focus pro-actively on engagement with business.

THE LEEDS CARE RECORD

What is it?

Leeds Care Record is a new confidential computer record that will over time include a range of health and social care information to help improve the care a patient/service user receives.[23] The care record is intended for use by professionals and the individual or patient themselves.

Who is involved?

The Leeds Care Record is run by Leeds Teaching Hospital Trust under the leadership of the Leeds Informatics Board, a partnership group between the hospital, clinical commissioning groups and social care. The Care Record is developed in partnership with technology suppliers.

The project has required extensive communications and engagement. This has been conducted with patient groups and the general public using a

number of communication tools and partner agencies.

What has happened?

To date, the Leeds Care Record has been rolled out to 88 of the 109 GP Practices in Leeds. The project is currently in rapid implementation of electronic patient records at Leeds Teaching Hospital Trust and is developing integrated records between the community and mental health trust in Leeds. A city-wide deliberative enquiry and communications exercise with the public has been undertaken about how patient records should be used across health and social care.

The project is a crucial part of the city's ambitions for integrated working across health and social care

professionals. Work in Leeds is

LEEDS CARE RECORD
Shared information. Better care for you.

a pioneering example of interoperable health care records, which is a national priority.

.

Key Themes and Findings

Interviews with each of the project leads had focus on what their key learning points were for future work in their own project, and also what could be transferred to other work across the city. The following key themes and findings summarise the main areas which were identified. A common theme across all projects was that learning could be better shared across projects in Leeds and also that much good practice and innovation is already available, but the health and care sector could improve how quickly this is adopted. Therefore, there are best practice case studies and existing methodologies included alongside the 3 themes and 10 learning points.

THEME 1: COMMUNICATIONS, CONSULTATION AND ENGAGEMENT

Language is important

Timing is everything

Form follows function

THEME 2: INNOVATION

This is about developing products, not just commissioning and delivering services

Learn from design principles

Understand people's everyday lives

Remember who you are designing for

Innovation is about long term change

THEME 3: KNOWLEDGE SHARING AND LEARNING

Different groups have different expertise. Use them all.

Learn from Europe

THEME 1: COMMUNICATIONS, CONSULTATION AND ENGAGEMENT

Language is important

In all projects the use of clear language can be seen to be important. Language must be reflective of the audience that it is aimed for. It should be centred on the needs of users, and not driven by internal process or technical language.

Health and social care in particular, can be prone to the use of terminology and jargon. When this is combined with language associated with new technologies and innovation, there is potential for language to become almost impenetrable to a lay audience. At times this has been the experience of some elements of the URBACT project. Successful use of language has been evident in the mHealth project, where communications have fulfilled a clear purpose and language designed with the audience at the forefront.

If it is a priority for innovation and community engagement in health to play a role in reducing health inequalities, then particular focus needs to be paid to how language is used. 16% of adults in the UK have a reading age at or below those expected of an 11-year-old. If these people are to be active participants, then communications from public sector bodies need to be designed accordingly.

Timing is everything

Communications should take place at a stage which is most useful and appropriate for its audience. Too soon, and the message is unclear and not relevant. Too late, and the opportunity to incorporate the voice of communities can be lost. Relationships of trust between organisations and communities, where changes are happening through co-creation are much more likely to lead to well-timed communications.

Case Study: The Leeds Care Record

The Leeds Care Record is an innovative project about sharing patient data across health and social care organisations. Because it is a project about how key aspects of a person's health and social care information is used and shared, it requires a significant amount of communication and consultation with people. The project has used a number of different forums through which to communicate with people, including user groups, mainstream media, social media, through GP practices and events. During the management of these communications it has been crucial to engage with people when there is a need for them to be a part of the project, where communication results in mutual benefit and when the project is mature enough to gain credibility. Engaging too soon would result in a lack of credibility and trust, which is crucially important for a project which is about medical records.

As a default, the communications in the project are open and transparent. All reports are available for the public to view on the website and promoted via social media. This openness has meant that the project operates from a position of trust and accountability with the general public.

Being open by default has helped with timely communications.

Form follows function

For public projects, there can at times be a temptation to communicate as a 'tick-box' exercise in order to fulfill consultation requirements, or to promote work. In user-led innovation, however, engagement is an integral part of the process so communications must always be designed in order to fulfill a specific function. This will lead to clearer, simpler communications which have direct and useful benefit. In the mHealth and Assisted Living Leeds projects for example, the user contribution adds significant value throughout the development process, which has meant that the form of engagement has been designed to obtain maximum value from its function. For some of the projects, for example the Leeds Care Record, this has meant starting with small scale communications which are focused on specific items and allow trust and understanding to develop, before undertaking larger, city-wide communication messages.

Methodology: The Engagement Cycle
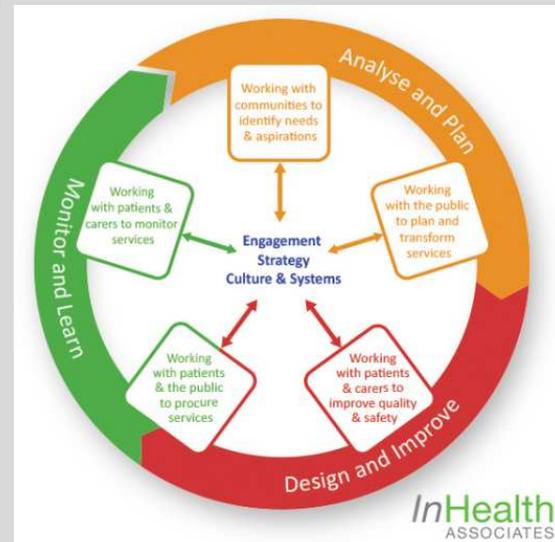
The Engagement Cycle[24] is a tool that helps commissioners of health and social care to understand who needs to do what, in order to engage patients, communities and the public at each stage of commissioning. It was designed by *InHealth Associates,* a network of patient and public engagement practitioners and has been used by people across all of commissioning. It is built on clear reasons for engaging and identifies five stages where people should be involved. Commissioners can use the Engagement Cycle as the basis for thinking through overall strategic direction, or focus on a particular stage to think through what needs to happen for a particular engagement purpose. A benefit of the Engagement Cycle methodology is that each stage of engagement has a very clear purpose, and is set within the context of an overall method.

THEME 2: INNOVATION

This is about developing products, services and approaches, not just commissioning and delivering services

Many of the solutions involved in health innovation are about technological change involving people's ability to manage their own health and care needs. Involvement and self-management of care is a key part of health care strategy in Leeds. People are therefore more often in direct control of their health care than they may traditionally have been. This is combined with a potential reduction in the direct, generalised commissioning of services by health and social care organisations. As a result, much of the innovation in health and social care now requires a focus on product development in new technologies, specific and personalised to an individual's needs. There are consequently many lessons to learn from product development techniques which are well established in the digital sector.

Remember who you are designing for

The design of public services must start with user needs. There are times when public sector organisations can create services which are too focused on delivering organisational need, or when private interests can be put ahead of user gain. However, for a sustainable, innovative future there is a place where returns on investment can be complementary and not mutually exclusive. Methodologies such as Social Return on Investment can help to broaden the perspective on what and whose outcomes are valued, and they can be

Case Study: mHealth Habitat

Mobile health is an area of development across health and social care, and Leeds has established a successful 'mHealth Habitat' programme. Within its various activities, the programme is involved in app development for self-management solutions. The work has used agile project methodologies and service users are at the centre of the design, testing and implementation phases of new solutions.

The project does not associate with traditional public sector models on consultation and engagement, but instead uses an approach of participation and involvement, in which public sector organisations take a brokerage role between industry, academics and patients. All ideas start with the perspective of the service user's everyday lives, and new products are created by undertaking an iterative process of frequently testing and changing solutions.

utilised more effectively across partnership projects.[25] Public health and social care organisations can play an important role in brokering relationships between users and providers, and advocating maximum social benefits. Having communities at the centre throughout the innovation process helps to priorities user needs.

Learn from design principles

There are principles from design methodologies which are common to all the Leeds projects. Good design is about developing innovative solutions which work for people as a result of a creative process.

As a result there are many principles from design that health and social care organisations can apply, whether the end product is a physical solution or a policy response.

Methodology: Design Council – Design in the Public Sector

The Design Council's report 'Design for the Public Good' showed that design thinking offers a complete end-to-end problem solving method, which can be applied to product development and policy making.[26] Design offers a basic three step process which can be transferred to innovation and user involvement in health care:

1. Research User Needs – Good design is about what works for people. Capture and understand people's needs.

2. Visualise Solutions – Visualisation enables communicates to a wide variety of people. It encourages empathy and understanding and makes designers focus on people's everyday lives. It also put a focus on outputs and gives a genuine understanding of how systems and processes work.

3. Prototype and Improve – Design provides tools to test the right ideas, to see what does work and what doesn't work as quickly as possible. Prototyping test ideas at an early stage before significant resources are committed to implementation.

Innovation is about long term change

Many of the ambitions in Leeds about health innovation are about long term systemic change. Medical technology is a good example of an industry whose traditional relationship with communities has been about income generation, economic outputs and job creation. In a new era of personalised medicine and local solutions, there is more of a need across health for innovators to tailor their work to the needs of communities and individuals, and shift more of a focus to health creation in addition to wealth creation. This requires a more participatory approach with evidence of local impact. Whilst individual innovations can be a quick process, system-wide change at scale will be a long process. Leeds can increase the scale and pace of patient led innovation by increasing the number of projects that are happening in the city, and increasing the scope of these projects.

Understand people's everyday lives

When designing new products or new services, the starting point should be the needs of the user. In order to understand the needs of the user, how they actually experience services and use products must be clearly understood. User-led design processes, where the genuine experiences of users of observed and adaptations made incrementally have been particularly effective in the mHealth Habitat project. Simulation and participative events can provide a key platform for product development which is based on an in depth understanding of people's respective needs. The principles in this approach can be adopted elsewhere across the design of public services.

Methodology: Ethnographic Research

Ethnographic research is a type of social science research which involves observing people in their real-world environment. It involves faithfully reporting what is observed. It can be used to gather information on how people live, what choices they make and how they use products. It can be used to identify needs which are not currently met by existing services or technologies. Its principles can be useful for product design (design ethnography) because it helps to identify any differences between how manufacturers intend things to be used compared to how they are actually used.

THEME 3: KNOWLEDGE SHARING AND LEARNING

Different groups have different expertise. Use them all.

Innovation requires the combination of various different people with different types of expertise. Knowledge and insights from different sources are all as valid as each other for designing useful solutions. Health care is a complex environment, and innovation is more likely to happen when users, professionals and policy makers bring their individual perspectives. This does not mean that all decisions and innovation will arise from committees with a wide variety of experiences. Instead, where individual and communities can provide unique expertise, they should have opportunity to provide this alongside professional practitioners.

Learn from Europe

Engaging with partners in Europe provides the opportunity to get out of the city to gain new experiences and learn new things. Whilst this can come with additional administrative burden, European engagement will open up new opportunities for inward investment and learning. If Leeds is to be a global city for health and innovation European partnerships and projects should continue to be pursued. This should be done so with specific purpose and deliverable outcomes.

Case Study: Assisted Living Leeds

Assisted Living Leeds is a new building, run in partnership between the NHS and the City Council which houses the Leeds Community Equipment Service, Telecare service and Blue Badge Parking Scheme. It is managed within adult social care, for which a traditional model of service development has been through commissioning and consultation.

In the current financial climate for health and social care, the public sector does not have the funding to be able to traditionally commission services. This means that there is a shift away from consulting with service users to instead engaging with users and businesses in finding innovative solutions.

As a result, the Assisted Living Leeds project is working with different groups with their own unique expertise. Service users are experts by their experience, occupational therapists bring professional expertise and businesses provide technological and product development expertise. By exchanging the knowledge and priorities of these different groups the project has been able to discover what developments are needed by the various parties, and establish a business case for implementing these solutions.

This approach has been successful for the completion of the Phase 1 of the project to open the new building, and will continue to be used during the development of Phase 2. For Phase 2 a number of options are in development for how additional space in the building can be used. An innovation partnership group is to be established to undertake competitive dialogue and appreciative inquiry between users, the private sector and the public sector for the design and development of options for the space.

Conclusions: What Next for Leeds?

Engaging communities in health and innovation is important

For the reasons outlined throughout this report, it is clear that the topic of engaging communities in health and innovation will increase in importance over the coming years.

First, the context of the current situation for health and social care gives prominence to these themes.

Financial pressures, the rise in the number of people with long-term health conditions, need for integrated working and emergence of new technologies all require a response which involves and designs around individuals and communities.

Second, current policy across health and social care gives strategic focus to pursuing these themes

Locally, nationally and internationally there is recognition that the value of communities has been underutilised in our professionally driven health systems. Strategies such as the NHS Five Year Forward View consistently refer to how the involvement of communities is crucial for creating sustainable health systems.

Third, the evidence for the benefits of community engagement in health is widely accepted.

There is a substantial amount of evidence that communities which are connected and involved are healthy communities. National Institute for Health and Care Excellence guidance endorses community engagement as a strategy for health improvement.[19] The experience from projects in Leeds has shown that involvement of the public and communities adds unique and significant value to the quality of work and outcomes that are achieved.

Fourth, the experience in Leeds has seen the trialing of new models and application of existing methodologies which have had practical benefits to projects.

Leaders of each project have reflected upon the value that approaches which involve people throughout have on the benefits which projects produce. It is pertinent that models and methodologies are often already in existence elsewhere and that Leeds has been able to apply them to a wide range of projects.

The nature of engaging communities in health and innovation is changing

Leeds' experience of deploying approaches to community engagement across the five pilot projects has shown the development of a significant shift in the nature of engagement in several different ways. Across all projects it should be concluded that there is not a one-size-fits-all approach to innovation, and effective engagement is organized around a set of principles rather than a number of prescribed models. Some concluding observations show that there has been:

- A shift from consultation on service changes to active involvement in new service design and product development;
- A progression from engagement with traditional service providers to co-design and collaboration with businesses and product developers;
- The start of a process by which citizens are involved in identifying areas for innovation as well as participating in projects that have been initiated by a local authority or health provider.

The work has identified four areas which must be addressed in future approaches to community engagement in innovation in health and care.

First, it is essential to be clear with users, patients and citizens about the nature of the engagement in each project.

This raises issues of power and decision-making. In short, it is important to be clear about whether users are being involved in the decision-making process. Questions which must be addressed in order to establish this clarity include:

- Are the people involved being treated as consumers or co-producers?
- Is this market research or co-design?
- Who has decision-making responsibility? Are the participants in the engagement being involved in the decision-making or are they being consulted?

Linked with this is the value of considering whether there is an appetite to enable and encourage patients, users and citizens to initiate innovation in health and care (as well as to engage with innovation initiated by businesses, academics, clinicians and officials).

Second, the importance of adopting an inclusive approach to engagement and making sure that every voice counts.

This means actively seeking out hidden voices, where appropriate accessing experts by experience and the importance of providing timely feedback to people who have participated in the process.

Third, there is a need to be alert to the challenge of creating a relationship of trust between business and patients, users and citizens in the context of engagement and innovation.

The relationship with businesses in innovation is very different to the more traditional relationships in commissioning and procurement processes. More thought needs to be given to further developing user, patient, citizen and community engagement in product development by companies in the health and care sector. There are issues for both sides of the relationship, including:

- Demonstrating the benefits to business partners;
- Ensuring that the city benefits from the value produced as a result of the engagement.

Fourth, adopting a flexible, learning approach to replicating innovation and scaling-up is important.

Not all approaches are replicable. It is important to use existing networks wherever possible and build bridges between them, with a way of enabling learning between one group and another. Continuous evaluation and knowledge sharing is important for this.

Leeds has a unique role and opportunity as a centre for health, innovation and community engagement

With the wealth of assets in the city and pioneering projects across health and social care, there are clear opportunities for Leeds to be recognised as a leading city on the themes of health, innovation and community engagement. Reflecting on the URBACT project provides some recommendations for the city.

First, Leeds should be **Ambitious** in what it wants to achieve across these themes. This means being recognised as a global leader, and therefore participating in more European and international projects. This also means having genuine and lasting impact across its communities and bold strategy to reflect a shift to community-based approaches across health and social care partnerships.

Second, Leeds should continue to **Build on its Assets** when developing its approaches. The city has a wealth of assets across industry, community networks and public sector organisations. The new models evident in the URBACT-affiliated projects are positive, practical ways which have evidenced how to build on these assets to work for shared outcomes and produce positive results.

Third, practitioners and decision makers should continue to **Learn, Adapt and Adopt** from best practice. There is creative and innovative work happening across the city which can be translated into other projects in Leeds. There is well established good practice in other areas of the country and other sectors which have useful application for innovation in health. Also,

disseminating learning from Leeds to elsewhere will attract interest and potential investment in work that is happening in the city.

Fourth, there is a need for people to **Be Realistic** about the achievements to date and the scale of challenges which are ahead. The URBACT project has shown that approaches are developing, and there is a long way to go before communities are fully engaged in their health care and innovations in the health system. Whilst it can be said that the project has witnessed the beginnings of a shift in the nature of engagement, there is much progress to be made before the health and social care system in Leeds can be said to be positively agile, creative and fully engaged with its communities.

Fifth, there is a need for projects and strategy to **Be Practical, Focusing on Outcomes**. The main impacts and learning points that this report has reflected upon have been from projects that have had recognisable deliverables and clearly defined project scopes. The clear outcomes produced from the Leeds Care Record, mHealth Habitat and Assisted Living Leeds projects gave them focus and clarity. All the principles and learning points that have emerged in Leeds will be best developed when incorporated within practical projects which can deliver clear benefits to all partners involved. Partners in Leeds should have benefits and deliverables at the forefront of their minds for designing strategy and projects.

Bibliography

1. Leeds and Partners (2014) *Health and Innovation* (Leeds City Region) Available at: http://investleedscityregion.com/system/files/uploaded_files/HEALTH INNOVATION PROSPECTUS.pdf.

2. Leeds City Council (2011) *City Priority Plan 2011 to 2015* (Leeds City Council).

3. Leeds Health and Wellbeing Board *Leeds Joint Health and Wellbeing Strategy 2013-15* (Leeds).

4. Leeds City Council (2012) *Commission On The Future of Local Government: Final Report* (Leeds) Available at: https://civicenterpriseuk.files.wordpress.com/2012/07/final-commission-on-the-future-of-local-government-electronic2.pdf.

5. Hampson M, Baeck P, Langford K (2013) *By Us, For Us: The power of co-design and co-delivery* (Nesta).

6. NHS England, et al. (2014) *Five Year Forward Vew* (NHS England).

7. National Voices, Think Local Act Personal (2013) A Narrative for Coordinated Care. Available at: http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf.

8. Department of Health (2013) *The NHS Constitution* (Department of Health).

9. Department of Health, NHS Improvement & Efficiency Directorate, Innovation and Service Improvement (2011) *Innovation, Health and Wealth* (NHS).

10. Office for Life Sciences (2011) *Strategy for UK Life Sciences* (Department for Business and Skills, HM Government).

11. World Health Organisation (2012) Health 2020: the European policy for health and well-being. Available at: http://www.euro.who.int/en/health-topics/health-policy/health-2020-the-european-policy-for-health-and-well-being.

12. World Economic Forum (2013) *Sustainable Health Systems* (Switzerland).

13. Tritter JQ, McCallum A (2006) The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy* 76(2):156–68.

14. South J (2014) Health promotion by communities and in communities: current issues for research and practice. *Scand J Public Health* 42(15):82–7.

15. South J, Stansfield J, Mehta P (2015) *A guide to community-centred approaches for health and wellbeing* (Public Health England, NHS England).

16. Hibbard J, Helen G (2014) *Supporting people to manage their health: an introduction to patient activation* (The King's Fund).

17. Boyle D (2014) *Turbo charging volunteering: co-production and public service reform* (Centre Forum).

18. Boyle D, Coote A, Sherwood C, Slay J (2010) *Right Here, Right Now* (NESTA).

19. NICE Local Government Briefings (2014) *Community Engagement to Improve Health* (National Institute of Health and Care Excellence).

20. Foot J, Trevor Hopkins (2010) *A glass half-full: how an asset approach can improve community health and well-being* (Improvement and Development Agency).

21. Wanless D (2002) *Securing our Future Health: Taking a Long-Term View Final Report* (HM Treasury).

22.   mHealth Habitat (Leeds and York Partnership NHS Foundation Trust, Leeds Community Healthcare NHS Trust and North Leeds Clinical Commissioning Group) Available at: http://mhealthhabitat.co.uk/.

23.   Leeds Care Record (Leeds) Available at: http://www.leedscarerecord.org/.

24.   InHealth Associates *Engagement Cycle* Available at: http://engagementcycle.org/.

25.   The Cabinet Office, Office of the Third Sector (2009) *A Guide to Social Return on Investment* (HM Government).

26.   The Design Council (2013) *Design for Public Good* (European Commission).