Patient & Public Involvement (PPI) in a Digital Age

An overview of AHSN activity and learning

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Foreword

We live in a digital age. Our every day is being made remarkable by the ways in which digital technology is helping us to live, work and lead healthier lives.

We have untold health information at our fingertips. We can book appointments online to see our doctor. We can wear new technology to measure our blood pressure, heart rate and our footsteps. This and other data we share about ourselves can help health researchers devise new treatments and interventions to help family, friends and our community.

This digital revolution in health and social care is at the heart of the Academic Health Science Network (AHSN) agenda to drive forward technology and innovation over the next five years. An agenda that it will be taking forward with industry, the third sector, academic organisations and local authorities in partnerships that will also help ensure the adoption and spread of innovation so it makes a real difference to people's lives.

But the most important partner in this endeavour will always be patients, carers and the public. Their early and ongoing involvement is essential to good research design. It will be their insights, experiences and ideas that will help drive forward innovation. They will be important agent provocateurs in ensuring innovation is adopted. Their challenge will also be important in reminding us that the future is as much about empathy as it is about coding.

Against this background I am delighted to commend this guide to you. Intended for use by the public, designers, clinicians and others, it will help colleagues and partners think through the different ways they can involve patients and the public in driving forward innovation: what is relevant and appropriate. It includes examples from AHSNs around the country who have involved the public in different ways. It aims to encourage and disseminate good practice.

I am excited to see what will unfold in the AHSN Network in the future. I have no doubt this guide will be helpful. The possibilities are endless, as they say.

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Acknowledgements

1. Introduction

With NHS England's relicensing of Academic Health Science Networks (AHSNs) in 2018, it is timely to review the opportunities provided by digital technology for public involvement in both our work and our networks. As part of a broader discussion, this paper aims to identify how we can strengthen the voice of the citizen and patient in our current digital activities and embed co-production with the public as 'the way AHSNs do things'. It also aims to provide a useful guide to the different ways AHSNs around the country are involving the public in innovation based on technology.

In this document, the terms 'citizen' and 'public' are used interchangeably to denote someone who is not a paid member of staff but has a general interest in getting involved with our activities because of their experiences of health services as a patient, carer or resident in the UK. The term 'patient' is used for someone who is interested in getting involved because of a specific health condition they have experienced.

In an age where more and more of the population are using digital technology to manage various aspects of their health, the role of the public is vital in helping to shape and develop this medium. Science and technology have revolutionised clinical practice, particularly in hospitals, enabling the kind of surgical interventions that would have been unimaginable 50 years ago.

Now that technology has the potential to revolutionise how people manage their health themselves, in their homes and in their communities, it is imperative that patients and the public are helping to drive the digital agenda forward. Whilst young people will be the main beneficiaries of such developments, particularly as they get older, the 'baby boomers' and 'silver surfers' also have the potential to benefit.

The document 'The NHS belongs to the people: a call to action' (NHS England 2013) describes clearly the role of technology in giving citizens and patients control over their health. The role of technology in health is a vast and rapidly growing field, which is constantly changing. I find it useful therefore to view patient control within what I identify as three main functions of technology. These functions are not rigid and may sometimes overlap. I suggest they are:

1. Technology for bringing together patient data. This includes patient data sharing and interoperability activities (when multiple computer systems or

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software can exchange and make use of information) that have a similar aim but around the country have different names. Their main aim is to make patient data more accessible across the health economy. Bristol has Connecting Care for instance, whilst Manchester has Datawell as part of its DevoManc initiative.

2. Technology for connecting directly with patients. This includes technology which assists patients to manage their health and wellbeing (eg diabetes apps), potentially release nursing time and extend clinical reach (eg telehealth, online counselling) or which patients use for self-diagnosis.

3. Technology for communicating and engaging with citizens. Used for service improvement, generation of ideas, product development and so on. This includes crowdsourcing techniques and other forms of citizen science.

The degree to which these developments are being patient/public led is questionable. Although some apps have been designed and produced by patients in response to an observed gap in the treatment available to them, the systems and processes that lead to the adoption of technology tend to marginalise the voice of most patients and the public. In addition, we must not forget the 10%, often those that are the most vulnerable in society and in greater need of health services, that have been identified as never using the internet.

This guide seeks to make it easy for AHSNs to reflect on and choose the kind of involvement suitable for the activity they are planning. It includes a number of case studies that illustrate successful examples of approaches from across the Network. Wherever possible, the case studies have been drawn from the AHSN Atlas of Solutions in Healthcare, our online collection of high impact innovations. Other sources have been drawn on where necessary. The guide tries to draw out the learning from this work, both what has worked and what has not. It is not an exhaustive list, but a sample drawn from the information available, with case studies selected based on the extent to which they illustrated good practice.

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2. Technology for bringing together patient data

The perception amongst many members of the public is that health services already share information and many cannot understand why, in this day and age, a hospital or GP cannot track an individual's care through a patient's computer records. The National Data Guardian, Dame Fiona Caldicott, recommended in her 2016 report that "there needs to be a much more extensive dialogue with the public about how their information will be used".

The degree to which the public has been engaged in this dialogue seems to vary across the country. In my experience, interoperability projects are nervous about involving the public, and are worried about adverse publicity, particularly in the wake of the Care.data scandal. However, there are examples where involving the public has led to positive and constructive outcomes. In Greater Manchester the AHSN, Health Innovation Manchester, has set up a Datawell Accelerator Board, which includes Public Experience Group (PEG) Members as part of its membership.

Case Study: Health Innovation Manchester's Datawell Project

Datawell is a platform for sharing NHS health data in the Greater Manchester area. Developed by Health Innovation Manchester, it provides essential infrastructure for direct care and health improvement initiatives, and enables patients to access their shared records.

From the outset, the project recognised that publicly funded streams of work in the NHS and affiliated organisations should be accountable to the public. To support this, the Health Innovation Manchester Public Experience Group (PEG) was formed. The group comprises nine members of the public, drawn from across the region, plus two professional members of AHSN staff. Health Innovation Manchester defines 'public' as anyone not already actively involved within health and social care in a professional capacity.

This new technology will bring benefits for patients and clinicians but also raises issues that require public debate and discussion, such as what the platform might be used for and which organisations might participate. For example, there was a discussion about whether the general public would support sharing some components of their records with the police or social services. Another discussion was around the appropriate information governance arrangements for direct care and secondary uses, and what people thought about accessing their own shared record.

It was felt that the views of PEG members were important in influencing the design and policies of the programme. To this end, PEG sits within the Datawell Programme

Governance with a direct link to the programme's Senior User Group. The project also recognised the importance of ensuring the technical complexities of the programme did not act as a barrier to the public voice being incorporated into the work. Early group meetings were spent discussing the technical approach and exploring commonly used terms in information governance. This enabled a shared understanding and language.

The PEG has guided the project's approach to communicating with the wider Greater Manchester population, helping with the selection of an external communication agency, and reviewing and editing the public narrative. Group members have become advocates of the Datawell programme, sharing their own stories and reasons for wanting their health records to be shared.

The project has also set up the Datawell Oversight Board to consider any technical and information governance issues presented by new uses. Members of the PEG are represented on this Board. Their role will be to encourage new projects to include the patient and public voice and involvement activities. They will also scrutinise use of the platform and ensure this is being used appropriately and for the benefit of the Greater Manchester population. More info: www.healthinnovationmanchester.com

Other examples of technology for bringing together patient data can be found in the North West and the West of England AHSNs.

The Innovation Agency (AHSN for the North West Coast), North East & North Cumbria and Yorkshire & Humber AHSNs are supporting the Connected Health Cities (CHC) project. This unites local health data and advanced technology to improve health services for patients in northern England. 'By making better use of the information and technology that already exists in our health and social care system we can make sure services are more joined-up and improve the health of patients.' This interoperability makes sure patients are able to access their medical records, personal care records, online test results, email consultations with individual clinicians and so on.

In the West of England, Bristol Health Partners and the University of Bristol are creating a health data inventory in collaboration with the Connecting Care[1] partners across the greater Bristol area, mapping out what health and care data is being collected and kept throughout the city. Public contributors from the West of England AHSN supported by People in Health West of England (PHWE) have been involved in shaping the project from the beginning. This will be the first step in a data strategy that will see the digital health and care partners of the Bristol, North Somerset, South Gloucestershire Sustainability Transformation Partnership (STP) develop an 'Information Engine', designed to underpin future care delivery, service transformation and research.

The role of the Health Innovation Manchester Patient Experience Group provides a clearly thought out model of public involvement which can easily be replicated by other AHSNs. Not only has the group offered public accountability to the project, as they have increased in confidence, they have contributed to the development of the project as partners.

1 Connecting Care is a digital care record system for sharing information in Bristol, North Somerset and South Gloucestershire. It allows instant, secure access to your health and social care records for the professionals involved in your care https://www.connectingcarebnssg.co.uk/

3. Technology for connecting directly with patients

This is a fast growing area, which includes technologies that help patients self-manage their own health and wellbeing, extend clinical reach to manage long term conditions, and support patients to self-diagnose. Included here are telemedicine, online counselling for mental health and apps to manage long-term conditions.

a) Helping patients manage their health and wellbeing

There are now a huge number of examples of these technologies. The Lincus example below from the Innovation Agency (AHSN for the North West Coast) demonstrates the importance of bringing together health organisations, industry and the charitable sector. The final product is an app that helps vulnerable people manage their health, while helping health professionals to support them to do this.

Case Study: Lincus - an app and web browser service to improve self-care and wellbeing

Lincus is a simple to use web based application, enabling users to record their wellbeing data, providing a holistic picture of their health. It is proving to be a useful tool to support those who have learning difficulties, are homeless or have diabetes to manage their health.

Lincus was co-designed by Rescon Technologies, and drew on the experiences of a range of individuals; from athletes through to those with complex health needs. The device helps track and improve the health and wellbeing of individuals, producing data that can be shared with care professionals.

The service was commissioned across six local authorities. Initially progress was slow. This was due to a number of factors. There was resistance amongst service providers in recognising the benefits of the device. It also became clear that there had not been enough engagement with local communities and stakeholders before commissioning took place. Finally the lack of IT infrastructure for the programme, including the difficulty of sourcing tablets on which to use the app and record data, presented practical and logistical challenges.

A breakthrough came when the charity Person Shaped Support (PSS), who provide services to vulnerable people on behalf of Liverpool Clinical Commissioning Group (CCG), saw the benefits. They provided a team of health trainers who worked with

community groups and individuals, encouraging them to use the devices.

The support of the Innovation Agency was pivotal to the further spread and adoption of Lincus as the 'app of choice'. They introduced Rescon to potential collaborators such as the learning disabilities charity Hft, Liverpool FC Foundation, Riverside Housing, and Liverpool City Council. These relationships helped to develop the app further. The first 'on the street' trial for multiple and complex service users was launched by Rescon's Lincus team in collaboration with the YMCA Liverpool. This captured information about mental health, alcohol and substance abuse, and homelessness issues and how well interventions work in improving service user wellbeing over different time frames. 12 service users with complex issues took part in the trial.

A grant from the Innovation Agency in 2015 supported Liverpool City Council to commission Lincus as a tool to improve the health of people with mental health issues and learning disabilities. This was followed by a project to help identify high blood pressure while educating people on the importance of blood pressure checks. Lincus now supports 300 individuals across six city region boroughs through the Liverpool 'Innovating for Improvement' programme. The web and app service has 3,500 users and Rescon has contracts which will lead to another 20,000 users by mid-2018. Over 1,600 people have been screened and educated about blood pressure.

The savings offered by the device are impressive. Phase 1 of the blood pressure screening programme achieved savings of over £750 per person identified with hypertension, showing an overall cost saving of £253,500. A 75% saving in the time spent on care was shown in other work where Lincus was used as a care management platform. Previously up to two hours would have been spent per patient. Using Lincus reduced this to 15 minutes.

This project has highlighted the change in culture and attitudes amongst clinical staff needed to support the spread of apps as tools for improving the health and wellbeing of the local community. It has also demonstrated the vital role the charitable and community sector play in enabling this to happen successfully. More info: atlas.ahsnnetwork.com

b) Extending clinical reach

Technology is increasingly being used by health professionals to provide clinical care to patients. This enables patients to monitor their condition under the supervision of clinical staff.

For many patients it is a welcome development. It saves them the travel time that is required for routine monitoring, which may sometimes feel unnecessary if treatment is progressing to plan, and they can carry out basic health checks in the comfort of their own home. For many patients this gives them a sense of control over their treatment.

Case Study: Flo Simple Telehealth: various AHSNs

Technology-enabled care services (TECS) can transform the way people manage their health and reduce use of health and care services.

One example is Florence Simple Telehealth (Flo), an interactive texting service, free to patients and used across healthcare settings. Flo Simple Telehealth uses SMS text messages on mobile phones to communicate with patients. Flo actively supports the model of patient self-care management and compliance, while also delivering productivity gains for services, enabling larger caseloads to be managed within existing resources. Flo is owned by the NHS, and was created in Stoke-on-Trent CCG. It is cost-effective to administer and free for patients.

It is in use within the North East and North Cumbria, East Midlands, West of England and West Midlands Academic Health Science Networks, and nationally it's reaching over 70 health and social care organisations with 33,000 patients registered for a wide range of conditions using clinically approved pathways.

Flo combines the expertise of the patient's healthcare team and the convenience of their own mobile phone, giving prompts and advice. If the patient needs more assistance, Flo helps monitor vital signs such as blood pressure, pulse, and oxygen levels. Evidence suggests that Flo increases levels of adherence through education and creating good habits in users, and health professionals have noticed a reduction in consultation time.
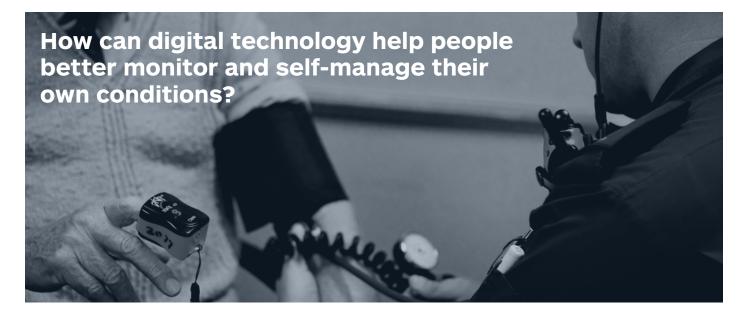
The UK population is increasingly diverse. Language, age and other factors mean methods of communication between clinician and patient are changing. Telehealth, telecare, telemedicine, telecoaching and self-care apps transform the way people engage in and control their own healthcare, reducing valuable clinician time to take basic readings. More info: atlas.ahsnnetwork.com

Other examples can be found in the field of psychology, where digital technology has really taken off. Being able to access counselling services remotely is for some patients a great relief. It can be carried out at a time and place that suits them and some people prefer the anonymity of not being in personal contact.

Several AHSNs are drawing on the digital expertise of Inhealthcare to develop the technology for clinicians and patients to work together to manage a number of different conditions, such as atrial fibrillation and the prevention of falls. Modern technology is increasingly able to take on routine monitoring tasks, freeing up clinicians to concentrate on providing expert medical intervention where and when it is needed.

A model of technology extending clinical reach, supported by Kent, Surrey and Sussex AHSN, is the NHS study being carried out by Surrey and Borders Partnership NHS Trust. Called TIHM (Technology Integrated Health Management) for dementia, it aims to transform support for people with dementia and their carers. Here, a whole systems approach to dementia is being piloted, connecting hospitals with the patient's home.

Individuals living with dementia and their carers are being provided with sensors, wearables, monitors and other devices, which will combine into an 'Internet of Things' to monitor their health at home.

The aim is to reduce the need for GP visits and unplanned admissions to hospital, prevent or delay the need for costly long-term care in nursing homes, and reduce demands on carers. Patients can be monitored and kept safe within their own homes through a number of methods such as heat sensor equipment and tagging. It is currently one of the Test Beds, a way of bringing together the NHS and industry to test out new ways of doing things. Successful innovations will then be available for other parts of the country to adopt and adapt to the particular needs of their local populations.

How can digital technology help people better monitor and self-manage their own conditions?

c) Enabling patients to monitor their condition and make their own diagnosis

The internet is making it possible for people to access and buy specialist equipment that can help them monitor their condition and make a diagnosis as to whether they need professional healthcare. There are signs that the medical profession is not yet prepared for this.

For example, there is equipment available for people who have atrial fibrillation or heart valve disease that enables them to monitor their blood clotting time and adjust their medication accordingly. Despite a Cochrane review that found outcomes from self-monitoring and self-management to be equally (if not more) effective, this is not readily available across the country, leaving individuals to identify sympathetic clinicians and buy the equipment themselves.[2]

The following case of someone who learned how to take their own National Early Warning Score (NEWS), which came to the attention of the West of England AHSN, illustrates a growing trend. Names and other identifying details have been changed to protect confidentiality.

2 This was brought to my attention by two patients self-managing their condition. For more information see http://www.cochrane.org/CD003839/VASC_self-monitoring-and-self-manage-ment-oral-anticoagulation-therapy and http://www.acsma.org.uk/

Case Study: Tom takes control of his NEWScore

Tom suffers from a long term condition that makes him prone to sepsis and cellulitis. He was going in and out of hospital several times a year, whenever he felt unwell and had a high temperature, regularly drawing on the emergency services to take him to the Emergency Department of his local hospital. During one such attack, the health professional who was treating him told him about the National Early Warning Score (NEWS). He showed him the equipment to use, the link to the website where NEWS can be calculated and how to measure his score.

Tom felt inspired. He went on to the internet and researched how he could get hold of the equipment. Some he got from Boots and some online. He explained that he went for the high end of the market, as he wanted reliable equipment. He said that cheaper equipment was available but he wanted the score to be as accurate as possible. He spent about £150.

The moment he starts feeling a little bit 'poorly', he takes his NEWScore. He explained that his condition can deteriorate very, very quickly.

"Even in a 15 minute period, things can change," he said. "I don't bother with 101. If my score is over 3, then I know I need an ambulance. When you dial 101, you are waiting and waiting for a call back to speak with a doctor. Meanwhile the infection is worsening. If your temperature is over 40, you will be in a poorly state in hospital for longer."

The call centre and ambulance crew recognise the score and respond immediately, rushing him to hospital. They told him that he had made their job much easier as they can see the urgency straightaway. "Every time I tell the call handler my score on the phone, they come round and scoop me up."

Because he can now take his own NEWScore, he can take action early. From hospital stays of one to two weeks, he is now only in for two to three days. He used to go in very ill and needed much more supervision. Now, he says, "I'm getting early warning to make that call and get treatment when it is needed, and more quickly. Now I get well quicker and am not in hospital so long." He has used it three times over the past year. Tom has his own supply of antibiotics and starts taking this as soon as he has taken his NEWScore to get a 'head start' in fighting the infection. "If I get the shakes, then I'm in trouble."

Being able to take his own NEWScore means Tom feels much more in control over his condition and reassured that he is not using emergency services unnecessarily. His partner also knows how to take it, so if Tom is too unwell to take it himself, she can take it. This is reassuring for both of them. More info: atlas.ahsnnetwork.com

There is clearly an appetite by some patients to take more control over their health, which needs to be balanced by the evidence available. We need to be ready to respond and support patients to understand the benefits and limitations of taking control and what to do when things go wrong.

4. Technology for communicating and engaging with citizens

In the health sector, public involvement has evolved with the purpose of engaging with patients and the public as equal partners to improve services. It has used a range of interactive methods, often drawn from community development and qualitative research methods. These have included conferences, discussion or focus groups, surveys, citizen juries, telephone interviews, and other.

Alongside this, citizen science methods have been used by academia and others to carry out mass observation studies to harness the enthusiasm of individuals to gather volumes of information that would not be possible through the limited resources of most organisations. The annual RSPB bird counting day is one example.

With social media having a more prominent role in communication, especially amongst young people, it is important to review the opportunities this brings to public involvement in the work of AHSNs. Through Twitter, Facebook and YouTube, it is now possible to reach millions. Any individual can set up a crowdsourcing site to test out ideas or raise funds for a cause. Alongside this growth in communication technology, a range of methods have developed that have exploited this ability to reach out to a wide range of people. There is an opportunity here for the AHSNs to embrace these methods and reach out to a wider public.

There are a number of online methods we can use:

a) Online crowdsourcing

Crowdsourcing is a useful method to consider when reaching large numbers of people is a key objective. It has been used by academia for monitoring the natural environment (counting bees, butterflies etc) and it is tempting to consider using these methods to engage with large numbers of people, to get feedback on service design or new developments.

Two AHSNs drew on these methods to test out how they could work in the AHSN context. One was 'Design Together Live Better' by the West of England AHSN and the other was the Health Innovation Network's (AHSN for South London) 'Early planning for dementia' project. They both provide lessons we can learn from and build on.

Case Study: Design Together, Live Better

This project set out to find new ways for individuals, innovators and health professionals to come together to co-create new products and devices for those with

challenging health conditions to improve independence and quality of life.
The West of England AHSN works hard to keep citizens at the heart of this process and has been exploring ways of co-creation and co-production of ideas.

The first phase was led by the West of England AHSN in partnership with Designability, a research and product development organisation.

More than 100 members of the public took part in the Design Together, Live Better initiative online, via a dedicated phone line or through workshops across the region. Participants included people living with a long term health condition, carers, family members, health professionals, volunteers and support workers. At the end of the programme, Designability reviewed all the product ideas and selected ten concepts for further exploration.

This led to three final ideas being developed into prototypes: a seat harness that can be fastened with one hand, a 'companion' trolley and a portable bidet.

There were three elements that made this approach particularly innovative.
Firstly there was the mix of backgrounds, bringing together product designers, members of the public, health professionals with their range of skills, knowledge, experience and perspectives not normally found in the same room.
Then there was the use of crowdsourcing to reach out to people with challenging health conditions and people who might not normally take part in more usual 'engagement' activities.

The third key element was the commitment to co-creation. Design Together, Live Better was a genuine exercise in the co-creation of ideas to improve the quality of life of those living with a health condition, bringing together patients, public, and health professionals, as well as both design and business skills.

The mix of disciplines (enterprise, design, media and public involvement) was exceedingly fruitful and gave our work a dynamic edge, while drawing on the concept of crowd-sourcing had the potential to democratise involvement. It reached out to people who may not normally engage with the health sector, may have a disability and therefore have mobility problems or may be too shy to attend meetings. On the other hand, it can potentially exclude those who don't use digital media, so needs to be used in conjunction with other forms of outreach.

The co-production approach provided a value-base and ideology for the project that brought citizens, designers and others together in a creative partnership of equal co-creators, which led to design ideas that may not have been identified otherwise.

The learning derived from this project has led to the West of England AHSN developing a new online platform called hyvr, bringing together innovators and the public. We are hoping that this will bring us into contact with a much wider audience. More info: www.hyvr.co.uk and www.weahsn.net

Case Study: Crowdsourcing as part of the early planning for the dementia theme

The Health Innovation Network (HIN), South London AHSN, launched a crowdsourcing initiative with Clever Together in January 2014 to precede and inform a clinical launch event. Here crowdsourcing is defined as an online conversation forum, which enables a virtual, workshop-style, discussion. The intention was to identify initiatives that were improving dementia services, the challenges, possible solutions and any opportunities to improve health outcomes, care experience or reduce costs. This information was then shared at the Dementia Launch Event in February where the programme priorities were further explored and prioritised.

115 people across South London were invited by email to take part, along with some nominated national stakeholders. 30 people joined the conversation and generated 113 contributions.

A shadow exercise was completed by Innovations in Dementia. People with dementia and those who care for them were invited to small group and individual discussions and asked similar questions. Their views were then shared alongside the crowdsourcing ideas at the launch event. It gave the audience a starting point to consider what the HIN programmes could focus on and where the energy was for improvement work.

HIN decided on the workshop questions, invite targeted groups of people to participate and then encouraged ideas, online voting and discussion about HIN projects. Clever Together supported HIN to design, deliver and evaluate the campaign strategy as well as providing the technology to reach a large number of people for facilitated discussion.

The HIN programme team saw it as an opportunity to reach out to networks in a planned way to seek their views on clinical themes, insight on and validate planned activities and identify best practice. It complemented the face-to-face stakeholder events and enabled people to engage with the work in their own time.

Clever Together provided statistics on how representative a conversation was, the most discussed and voted areas and supported action planning. The discussions were anonymous, which encouraged people to share ideas and make comments. However, the participants could also opt to be contacted and that meant that HIN could also recruit people who had supported the development of particular ideas. More info: healthinnovationnetwork.com

Both these examples demonstrate the pioneering and tentative use of crowdsourcing by health organisations to reach out and engage with large numbers of the public.

It is interesting to note that in both examples personal contact was an important part of the methodology as organisers were anxious to make sure that the process did not exclude the more marginalised sections of society.

b) Online Citizens' Panels and Forums

These are different ways of engaging and creating discussion online. There are numerous ways of doing this. For example the term Citizens' Panels can be used to describe a number of different models. In some cases it can refer to bringing people together face to face. For the purposes of this paper, the Citizens' Panel set up by the Scottish Health Council is of interest. This is a demographically representative online group of people who are periodically asked to comment on a range of health and social care questions. For more information see www.ourvoice.scot/citizens-panel. Online forums and support groups that provide information and support, often on specific conditions also fit into this category.

c) Online Platforms

Online platforms cover a wide-ranging set of activities such as marketplaces, online advertising platforms, social media, search engines and more. Well known examples include Amazon, Ebay and Uber. They share a number of important characteristics.[3]

For AHSNs they are of interest as they have the ability to organise new forms of participation based on collecting, processing and editing large amounts of data where the value of the service increases with the number of users. They bring consumers and producers together, relying on information and communication technologies to reach their users instantly and effortlessly.

Whilst there are some caveats to relying solely on this method to communicate with the public, online platforms have the potential to enhance citizens' participation as they facilitate access to information, in particular for the younger generation. They clearly have a vital role to play in the health economy and bringing health innovation to citizens and patients.

The hyvr digital engagement platform, detailed in the case study on page 14, is designed as a way for citizens to collaborate online on ideas and the creation of new healthcare products. It is a natural extension of the Design Together, Live Better project insofar as it takes the original concept and moves the creation of ideas away from face-to-face engagement and places it in an online, virtual environment.

It aims to encourage citizens to self-organise into different communities where health-related issues can be discussed and peer support offered, and from which concepts for healthcare product improvements can grow, evolve and be developed by innovators in the health and life science space. The products could be digital apps/sites or physical devices. This is a pioneering venture for the West of England AHSN, which will provide much learning for the AHSNs as a whole.

3 For more on this see Online Platforms and the Digital Single Market Opportunities and Challenges for Europe http://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1466514160026&uri=CELEX:52016DC0288

5. Summary of key points of good practice

AHSNs need to be at the cutting edge of health innovation and to do this they need to draw on the benefits that technology brings. The issue is not whether we should be working with technology, but how we do this in a way that involves citizens and patients. AHSNs can demonstrate a multitude of examples where this has happened.

- We have seen how public involvement eases the way for interoperability of health data to be accepted by the wider public.

- The experience of Lincus reminds us that without public involvement, in this case with a voluntary sector organisation, there is a risk that innovative devices fail to get used by clinicians and patients.

- Section 3c raises the issue of how digital technology enables individual patients to proceed faster than the services are ready for. There is an appetite from individual patients to have greater access, autonomy and control over the use of technology to manage their health. This appetite offers a challenge to AHSNs as to how ready they are to support the public to do this safely.

- Section 4 provides some reflections on how we are moving forward in using online methods of engagement.

- A final issue is that of inclusion and equality. One of the concerns about digital health is that it excludes those who, for a variety of reasons, may not be able to use this technology to manage their health. It is important that digital technology is offered alongside more conventional forms of health care and communication channels.

The AHSN Network is fortunate to be able to draw on these experiences and models from around the country, giving it a strong public base from which to go forward in the next phase of its new licence.

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We are at the beginning of a digital revolution in healthcare, with the opportunity to make sure emerging digital projects in the AHSNs talk to each other and build on the knowledge and experience we have between us.

6. Ways forward

The wealth of experience already existing amongst public involvement leads across the AHSN Network provides an opportunity to share knowledge and ensure a coherent approach to involvement. We are at the beginning of a digital revolution in healthcare, with the opportunity to make sure emerging digital projects in the AHSNs talk to each other and build on the knowledge and experience we have between us.

The alternative of not working together creates a risk to our public reputation and to our effectiveness. To address this, there are a number of possible actions:

1. Review and map how the AHSNs involve citizens and patients as we adapt to a constantly changing digital environment.

2. Bring together AHSN staff who are using digital technology or who have the interest and expertise, to meet and share information and learning about our digital activities and different methods of public involvement.

3. Set up a reference group of citizens/ patients who have knowledge and experience of digital health to provide a continual source of support and ideas and who can guide the AHSN Network going forward. They can be drawn on for short term projects as well as longer term, and will be able to provide an on-going source of support.

4. Add a new section to the online AHSN Atlas of Solutions in Healthcare that draws out the role of public involvement in the featured innovation case studies and what difference it made. This will describe how innovation can benefit from the different ways of involving the public, as patients, as individual citizens and through charitable sector organisations.

5. Produce a statement of good practice for the AHSN Network, affirming our commitment to public involvement at all stages of project/product development:

- Ideation and testing stage – when ideas are not fully formed and being bounced around is when involving citizens with the appropriate skills and perspectives is vital. This helps them grow with the thinking of the group and develop their understanding of the language and the issues so that they can contribute effectively.
- Implementation stage – staff would be expected to get on with the 'doing', but it can be helpful to have involved those citizens from the ideation and testing phase to continue bouncing ideas around when needed.
- Steering of project – it is always good practice to include two people who can represent the 'lay' view to the steering group of any project or activity.
- Ad hoc testing with focus groups etc - these can be with condition specific support groups or mixed groups.

6. Encourage staff in AHSNs to develop their skills in public involvement through training and action learning sets.

7. Continue the discussion

This paper is intended to be the start of a discussion. Please feel free to comment on this document, share your ideas and suggest further case studies. You can contact me on:

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