

Connected Health Cities – End of Project Report:

Patient and Public Involvement and
Engagement in the North West Coast



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ABSTRACT:

The Connected Health Cities (CHC) programme linked health data to develop a learning health system to improve care for people in the North of England.

To ensure the residents of the North West Coast (NWC) that we were using data safely and securely, the NWC CHC developed a robust programme of patient and public involvement in order to create a civic partnership to engage, educate and establish the trust of people whose data we use.

Stimulating debate with the wider public regarding consent and use of data, the NWC CHC established an active Public Involvement and Engagement Senate (PIES). The role of the Senate was to ensure that the patient's voice was represented in the region's health improvement projects and provide feedback on our areas of clinical focus – COPD, epilepsy and alcohol-related illness.

The NWC CHC team supported the Senate to get involved in a wide range of projects including a patient and public survey, co-development of voting polls and a health information preferences consent app.

As well as establishing trust, this inclusive approach enabled us to explore issues of consent to share data, to gauge public perception of data sharing and the issues surrounding how these decisions should be made in an informed way, to ensure we promote effective communication of data at local levels and enabling access within and between services and teams and the wider community.

INTRODUCTION:

Patient and public involvement (PPI) played a key role in the development and delivery of the Connected Health Cities programme.

CHC uses data provided by patients and collected by the NHS as part of their care and support. Patient data should be kept safe and secure, to protect everyone's privacy, and there must be safeguards to make sure that it is stored and used responsibly. Everyone should be able to find out how patient data is used.

During the CHC programme, it was important to establish public trust and to instigate an effective dialogue with people in the region about how we use their data across a range of agencies, both NHS and public sector.

A model for connecting and engaging people from various sectors, including the public, was developed to inform our work on turning health information into knowledge to improve health services. As a result, PPI underpinned all the work across CHC's city regions.

PPI activities were co-ordinated by the central CHC Hub in Manchester with each CHC region developing its own programme around the key objectives which were consistent to the project.

The Innovation Agency, the Academic Health Science Network for the North West Coast, led the PPI programme for CHC in the North West Coast.

Patient and Public Involvement Lead, Debbie Parkinson, created a programme of engagement over the four year project to enlist the trust and active involvement of people throughout the North West Coast. The approach taken followed three key principles:

- a) To develop a group of 'critical friends' who were educated about the programme and would be given the opportunity to advise on the project and its activities
- b) To engage, reach out and educate the public about data sharing, whilst identifying public concerns and exploring issues of consent
- c) To get patients and public involved with bespoke work relating to our three areas of clinical focus - COPD, alcohol-related illness and epilepsy.

METHOD:

CREATION OF A PATIENT INVOLVEMENT AND ENGAGEMENT SENATE

The NWC CHC created a patient and public forum to advise the programme and ensure that the patient voice was heard and acted on throughout the project.

Referred to as the Patient and Public Involvement Senate (PIES), members represented a diverse cross-section of people including professionals, retired people, patients and healthcare workers.

The Senate enabled CHC workstreams to gain access to relevant end-users to ensure that their designs and deliverables were realistic and relevant to the public.

Education in data-sharing and its uses was vital to enable members of the public to make informed choices of consent to share their healthcare data.

The Senate members were upskilled on aspects of healthcare data use, aspects of information governance and work in the consent model for opting in and opting out of sharing healthcare data both within direct care and outside it.

Senate members helped to spread and adopt the concept of data-sharing within their communities and with networks which included Age UK, Breathe Easy Groups, hospital governance boards, University of the Third Age and Patient Participation Groups within GP practices.

The Senate was kept fully informed of all aspects of the project to enable members to talk confidently at events and to the media, and helped to produce case studies and other communications for the wider public.

PIES also worked with other CHC areas and members attended events, helping to raise awareness of CHC and explain the project to others in their communities, as well as instigated discussions on the potential use of health data for research.

We encouraged Senate members to feel empowered to speak confidently at large events, giving the patients' view on data-sharing which helped to inform not just CHC but other regional projects.

Senate members took part in video interviews which were uploaded to YouTube, helping to spread information and provide additional resources to CHC.

Opinions and insights informed all of the work of the CHC project and led to the Senate co-producing a 'wizard' for consent to share data for iOS and Android platform apps. They worked with nationally recognised and industry partner ORCHA to develop this into a wire-frame format ready for delivery with the Share-to-Care programme.

The Senate was invited to collaborate on many projects, such as the creation of a survey to discover people's views on sharing their health data. This led to a larger number of members of the public and patients being aware of the impacts of data sharing and local dashboards for care pathways now being used. The Senate designed the survey, ensuring that the questions asked were those which they would want to be asked if consent to share their data was sought.

A dashboard produced for alcohol clinics in hospitals was developed with patients' views and opinions on their pathway of care, elicited by Senate members.

Dashboards for use to reduce unplanned emergency admissions in hospitals in the care pathways were developed using patient insights from the Senate and other interviews with patients and members of the public as described above, ensuring that it meets the needs of both clinicians and patients.

The Senate has also:

- Helped to advise The Royal Liverpool University Hospital on alcohol-related liver disease and alcohol-related brain research, which has led to receiving National Institute for Health Research (NIHR) grant funding for research.
- Helped PhD students to carry out interviews on how COPD patients self-manage their condition and how their data was used, which educated them on COPD lived experience when they were developing their research.
- Written mission statements and helped to draft a Citizen Charter so that it spoke with relevance to the public.
- Attended and advised at industry-NHS hackathons, for example, two PIES members attended a hackathon hosted by Amazon web services and expressed that they wanted to use Alexa to support their medication regime and this project has subsequently been developed with the team.
- Advised the Pathway Profile team at the University of Liverpool to write a questionnaire for patients on their experience of their pathway and how data would and could be used which was instrumental in recruiting participants

- Given insights on developing dashboards for use to reduce unplanned emergency admissions in hospitals in the care pathways to ensure that they met the needs of both clinicians and patients.
- Reviewed and gave feedback on regional consent issues which informed activities such as Share to Care – Local Health and Care Record Exemplar (LHCRE).
- Worked with a composer at the Royal Northern College of Music to create a piece of music to tell the story of how CHC is improving care for patients in the NWC.

*More detail on specific PPI projects can be found below.

EVENTS ENGAGEMENT

As part of the work to engage and educate the public on CHC, the PPI team at the Innovation Agency attended several events, including two Health Melas in Preston and Leyland, the Merseyside and Cheshire iLinks Conference, the NHS EXPO, the Innovation Agency NHS-Industry ECO Events (12 across the lifespan of the project) and two specific NWC CHC events.

Over the course of these events, PPI staff spoke to hundreds of people – both staff and the public, who wanted to find out more and express their views on information sharing. This played a big role in raising the profile of the programme and gaining visibility with stakeholders.

From our initial work, it was clear that patients and their carers did not understand that GPs could not see their hospital records or access clinic letters. Most assumed that the NHS data was a 'joined-up' service between providers.

The team also attended events in other areas, engaging with members of the public to raise the profile of the work of the CHC project with exhibition stand leaflets and marketing goods – inviting them to share their views via a voting box to the question: "Would you agree to share your health care data for research?" Overwhelmingly, over 80% of people who voted said "yes".

Involvement of patients and public members also focused in our key pathway areas to gather views and preferences on sharing data. The PPI team:

- Interviewed patients with alcohol-related illness and their carers at the Royal Liverpool Hospital to learn about their patient journey and gain their opinions on

how and with who their data could be shared. A focus group was formed at Genie in the Gutter in Liverpool for those who were recovering so that their views could be obtained.

- Attended COPD 'Breathe Easy' groups in Chester, Sefton, Morecambe, Leyland and Darwen, educating, informing and gaining opinions of those with the condition. Some members also took part in a trial of a self-care app, 'How are you today,' provided by local company, Intelesant, to trial the data-sharing process and give an insight into how the system could work. This app is now being used by clinicians in Lancashire.
- Used technology as a vehicle for engaging the public, e.g. introducing a COPD app, which is now being prescribed to COPD patients for self-management.
- Several patients shared their stories and experiences in case studies which were published on the CHC website.

PATIENT AND PUBLIC SURVEY

An online survey was developed focussing on gaining insights from citizens in the North of England and gained traction across the country through social media. Insights were gained into how and what data patients would be prepared to share.

Patients and members of the NWC Senate were asked what questions they would want to be asked in order to consent to share their data.

The questions, written by the Senate, formed the basis of the survey and informed the production of an app for consent to share healthcare data.

The survey was used when engaging with patients and citizens including in hospital clinics, GP surgeries, breathe easy groups and more public events such as iLinks Innovation Conference, NHS Expo and shopping centres. The survey took place over three months in 2018.

Findings from the survey included:

- 79% of those questioned had registered for access to their electronic records at their GP surgery, but of these, only 21% had used it and reported that it was simpler to order their prescription in the surgery or to ring for appointments. On explaining that both of these

could be done online saving the constant redialling when trying to book an appointment, most said they would try and use it in the future.

- There were differences observed between the views of patients with long-term health conditions and those of members of the public not currently accessing healthcare.
- 82% of those asked said they would readily share their healthcare record for research but would prefer to remain anonymous with only 18% refusing to consent to share their data. When asked if they would agree to be identified in research this figure dropped to 70% agreeing to share their data.
- When asked if they would share their data with commercial companies including dentists and opticians, only 61% said they would consent to share their data. When it was explained that companies may include professionals such as dentists prescribing antibiotics, most of the respondents changed their minds but stipulated that they did not want insurance companies or the police to have access to their data.

“I just want to stop my family from suffering as I have”

(survey participant responding to the value of sharing their healthcare record for research)

VOTING POLLS AT LARGE EVENTS

Coloured counters were used in events and conferences for ‘Happy to share my data’, ‘Would not want to share my data’ and ‘Not sure if I want to share my data’.

The voting polls were used in 21 events including universities, festivals, shopping centres, iLinks conference, NHS Expo, Blue Dot Festival, Innovation Agency events, as well as local health melas.

Based on the voting polls, 92% were willing to share their data, a higher proportion of people as compared with the online survey.

It is important to note that there were discussions at the voting polls (prior to voting) on the use cases for shared data and the potential value as part of improving own and wider population health.

This is aligned with the general CHC finding that it is imperative to hold conversations on what they are consenting to with both patients with long term conditions and members of the public.

DEVELOPING AN APP-BASED CONSENT TOOL

The Senate worked closely with ORCHA, an industry partner, and co-produced a wire-frame, or 'wizard', for an app as part of gaining consent to share healthcare data for research and other uses.

This is essentially a set of carefully curated questions written by the Senate with a guide on how it is presented (the wireframe) in any digital app used in healthcare which requires consent.

Patients and members of the public will be able to easily complete the consent process by selecting the data they would like to share, how to share it and can also select or decline the companies with whom they wish to share their health data.

A series of workshops, meetings and working sessions were held with participation from the patients, citizens, healthcare professionals and stakeholders such as NHS Digital. The development phases and review points included the wireframes, early-stage prototypes and trial versions.

Following successful completion of the project, the wizard has been adopted as part of the consent process for two regional projects with a view to further roll-out in the region.

The Local Health and Care Record Exemplars (LHCRE) Programme, Share2Care in the North West Coast, is using this wireframe to trial consent in two areas including tele-dermatology and breast cancer post-operative patients.

The Senate also contributed to early-stage feedback on the NHS App. The wireframe is free for app companies and others to use as they work with researchers to gain consent for their projects.

Subsequently, interest was shown by NHS Digital who are looking to incorporate the questions written by the patients in the new NHS app which was trialled in Liverpool and has now gone 'live' nationally.

Following these successes, a Senate Member has been made an NHS App Ambassador for NHS Digital from the work done within the CHC programme with patients and members of the public.

IMPACTS:

In the North West Coast, the CHC team invested a lot of time and energy into supporting the Senate to become a well-informed and highly-skilled group of people who feel confident and informed to make valuable contributions and can offer insights and feedback on an ongoing basis.

The Senate continues to help improve the Innovation Agency's communication with the public and to provide their perspective on different projects.

We found that when patients share their stories on how linking patient data could impact on their health and care it can have a powerful effect on making people think about the benefits of sharing their health information.

The PPI team's work in gauging opinion on health information sharing preferences revealed important insights – mainly the difference between the views of patients and those of members of the public.

As Debbie explained: "It was quite eye-opening. It became very apparent that the majority of patients with a long term medical condition would share their data with anybody, for research or for any other reason.

"Although members of the public are happy to share information about themselves on Facebook and with their Tesco Clubcard etc., they don't want to share their medical data."

This emphasises the importance of consulting widely on issues relating to the use of health information and being clear about whether patients or public are being involved.

MONITORING AND EVALUATION

Engagement was continuously monitored for effectiveness to inform both planning and delivery as the project developed.

This took the form of honest appraisal of sessions and of progress, learning what was working and what was not and to provide evidence of impact.

The CHC Hub PPI team commissioned Dr Kristina Staley from TwoCan Associates (www.twocanassociates.co.uk), a small consultancy firm specialising in developing policy

and practice around patient and public involvement in health and social care, to assess the impact of PPI activities.

This independent evaluation was commissioned to help us collate, organise and present evidence of the impact of our public engagement and involvement and identify a strategy for enhancing and evidencing future impact. The findings from this evaluation have shown us how much we have achieved in each of our city regions.

Impacts of PPI on the CHC programme included:

- Improving communication with and educating the public about the use of health data in research and health service development
- Increasing CHC's understanding of the public's views on acceptable uses of health data
- Increasing CHC's understanding of the public's concerns and informing measures to address these issues
- Developing processes of obtaining consent for the use of health data in ways that are clearly understood and meaningful to the public
- Ensuring good governance through the involvement of the public and other stakeholders in policy and practice decisions

CONCLUSION:

The CHC programme was launched at a time when public trust in the reuse of healthcare data was at its lowest.

CHC developed an innovative approach to public involvement that set a new benchmark and has been widely adopted.

The very fact that this has been delivered with patients and members of the public as our central partner is what has made CHC truly transformational.

As a result of PPI activities for the NWC CHC, patients and their carers are now more aware of the use of their data within the healthcare system and how giving consent to share their data can not only help with research for future patients but also improve their own care pathways.

Our work has demonstrated overwhelmingly that patients and the public, do trust the NHS with their information, are willing to share information but want to be informed, have agreed that a process or app to gain consent and seek information sharing preferences for secondary uses, is acceptable.

Through our programme of discussion, education, collaboration and dissemination, most now know the importance of giving consent to share their data and how it benefits their own care.

Nationally, patient involvement and participation has been recognised with more patients being able to 'have their say' and understand the need for data sharing.

Going forward, the CHC methodology and approach to PPI will be used as a model for other areas of care.

We are immensely proud of the co-production and wider contributions that the public has made to CHC.

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