

**An evaluation of the impact of
public involvement and engagement
in the Connected Health Cities
Programme**

TwoCan Associates

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Foreword

As a large data-intensive initiative, Connected Health Cities (CHC) has been unique in that one of its main aims, to work with and gain the public trust, was only achievable using patient and public involvement and engagement (PPIE). As a result, PPIE has underpinned all the work that we do across our city regions. 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. We have already begun sharing our successful approaches, both between the regions and nationally, and we are identifying ways that we can improve them. We recognise that building successful PPIE requires time to mature and we acknowledge that some of what we have achieved has still got some way to go before it is embedded in our routine practice. We also recognise the need to continue to evaluate the impact of what we do.

However, we are immensely proud of the co-production and wider contributions that the public have made to CHC. This report would not have been possible without the input from so many different experiences, opinions and viewpoints. The body of work that has created this report will continue to have an impact, not only through the defined outputs, but through the change in mind-set of those who have performed the research and those who will lead research in the future.

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Thanks

Thanks to all the people who generously gave to their time to be interviewed and/or take part in the final workshop. We are very grateful to them for sharing their experiences of PPIE and their views on the work of CHC.

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Executive Summary

Introduction

This report summarises the findings from an evaluation of public involvement and engagement (PPIE) in Connected Health Cities (CHC). CHC is a £20m Department of Health funded programme which aims to transform healthcare by gathering data, experts and technology in secure data facilities. The project is being delivered across four regions in the North of England, working with a regional coordinating centre. The programme began in January 2016, initially for three years, and was extended to the end of March 2020.

Methods

The PPIE team commissioned TwoCan Associates to assess the impact of their activities as part of an internal exercise. Semi-structured telephone interviews were carried out with ten CHC staff and involved patients/ members of the public. The findings were used to develop five case studies illustrating some of the most successful PPIE projects as well as drawing out lessons for the future. These were discussed at a workshop with CHC staff in order to develop a final set of conclusions and recommendations.

Findings

The five case studies of successful PPIE illustrate how this work has made a significant difference to the CHC Programme by:

- Improving communication with 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

The factors that have contributed to this success include having senior level support and leadership in PPIE, appropriate levels of staffing and budget, and being able to draw on the skills and experience of the central PPIE team.

The challenges CHC staff have experienced in taking PPIE forward are similar to those experienced by many other PPIE projects and include:

- Setting up public panels – since these require considerable time and resource to become effective and may not enable all patients/ members of the public to contribute.
- Recruiting people to involvement roles – finding ways to recruit people that are open to all and also identify people with the essential skills and experience for any role
- Partnership working – in particular defining the boundaries of expertise and responsibility for decision-making in professional-public partnerships
- Practical issues – finding ways to develop and enhance current practice in ways that reflect expected standards
- Defining the public – in ways that are not exclusive and involve all stakeholders in health data research, including front-line health and social care professionals

Conclusions and recommendations

The PPIE work across CHC has led the field in terms of engaging and involving the public with the issues around the use of health data in research and service development/ improvement. There would be great value in CHC sharing its findings nationally with other health data related projects, both in terms of PPIE practice and in terms of the outcomes of their public consultations.

It is important to note that CHC is a 'network of networks', operating on a 'hub and spoke' model. Each region has allocated different levels of resource to PPIE, and employs PPIE staff with differing levels of skills, experience and capacity. This means that each region has been successful in different ways, and experienced different kinds of challenges.

If CHC is to continue, then each region may need to develop its own bespoke PPIE strategy, reflecting local interests, and their specific learning to date. Any central PPIE facility will need to be flexible enough to respond to diverse needs for support, as well as identifying where collaboration could avoid duplication of effort and ensure efficient use of resources.

Some options for future development include:

- More detailed attention on clarifying the purpose of each PPIE activity in terms of how it supports the mainstream CHC agenda i.e. making PPIE a mechanism by which CHC can enhance all aspects of its work, not only increasing public trust
- Increasing the extent of patient/ public influence e.g. by enabling patients/ the public to prioritise topics for research and service development or by involving patients/ the public in the interpretation/ analysis of health data
- Training PPIE staff and others working directly with patients/ the public to help them clarify boundaries in terms of roles and responsibilities, manage people more effectively and select the 'right' people for different involvement roles
- Developing flexible and responsive approaches to PPIE to support the involvement of a diverse group of patients/ the public
- Involving other end users of health data research/ service development, in particular front line health and social care professionals, to enable their perspective to influence the work of CHC
- Developing plans for evaluation at the same time as planning any PPIE activity so that lessons can be learnt in real time to influence policy and practice

As well as gaining considerable expertise in PPIE in the health data field CHC staff have supported and developed a pool of well-informed and highly-skilled patients/ members of the public. These people therefore represent a highly valuable resource. Some thought should be given as to how to further develop or maintain this pool in future, whether CHC continues or new health data related programmes emerge in the CHC regions.

1. Introduction & background

- 1.1 This report summarises the findings from an evaluation of public involvement and engagement in Connected Health Cities (CHC). CHC is a £20m Department of Health funded programme which aims to transform healthcare by gathering data, experts and technology in secure data facilities. The project is being delivered across four regions in the North of England, working together with a regional coordinating centre in a hub and spokes model. The programme began in January 2016, initially intended for three years, and was extended to the end of March 2020.
- 1.2 Patient and public involvement and engagement (PPIE) is directly relevant to the second aim of CHC, which is to work with, and gain the public's trust that CHC is using health data responsibly, safely and to improve services for the benefit of all patients.
- 1.3 The PPIE team commissioned Dr Kristina Staley from TwoCan Associates (www.twocanassociates.co.uk) to assess the impact of their activities as part of an internal exercise. TwoCan is a small consultancy specialising in developing policy and practice around patient and public involvement in health and social care.
- 1.4 The aims of this evaluation are to:
 - Capture and summarise evidence of the impact of the PPIE work to date
 - Identify ways to enhance future impact
 - Identify a strategy for evidencing future impact

Structure of the report

- 1.5 **Section 2** describes the methods used to carry out this evaluation. **Section 3** includes five PPIE case studies from CHC. These have been selected to illustrate the range of different approaches to this work, and the many different kinds of positive impacts. The input from the public has had immediate benefits for CHC projects and identified where there may be added value from further PPIE in future.
- 1.6 **Section 4** describes the challenges that CHC staff have faced in undertaking PPIE, and the views of patients and members of the public on their experience of being involved in CHC. These findings suggest ways in which the PPIE might be further developed in future to extend its influence and enhance its impact.
- 1.7 **Section 5** draws out a series of conclusions and recommendations for future PPIE strategy development. This section was written with input from CHC staff, following a workshop run by Caroline Doherty and Kristina Staley from TwoCan, to ensure that the recommendations are practical and grounded in CHC staff's experience.
- 1.8 It is important to note that this evaluation was carried out while some of the PPIE activity was still relatively new. The findings represent a snapshot in time, based on short, telephone interviews with a small number of stakeholders. The impact and extent of the influence of PPIE in CHC is likely to increase over the final year, as everyone continues to enhance their skills and confidence in this new way of working.

2. Methods

- 2.1 The public engagement and involvement team and the independent evaluator consulted the staff with responsibility for PPIE within CHC to identify a short list of projects to include as potential case studies. The lead staff member linked to each project was interviewed about the PPIE within their projects. The questions were adapted to suit the specific context, but generally aimed to find out:
 - What had been done and who had been involved?
 - What difference the PPIE activity had made?
 - What lessons had been learnt about PPIE?
 - What could be done to improve PPIE in future?
 - What lessons there might be for CHC going forward?
- 2.2 Where possible and appropriate an involved patient or member of the public was interviewed about their experience of being involved. They were asked similar questions about what had worked well, what had been the impact, and where there might be improvements in future. The public engagement and involvement team reviewed and agreed the interview questions.
- 2.3 All ten interviews were conducted by phone at a time to suit the interviewee and lasted 30-45 mins. With the interviewee's permission, the discussion was recorded and transcribed. The transcripts were used to write the case studies along with previously published information about the projects. They were further analysed to identify key themes and the main points in Sections 3 and 4 of this report. All recordings and transcripts were deleted at the end of the evaluation.
- 2.4 The workshop was held in April 2018 and was attended by PPI staff and senior managers from across CHC. The participants discussed the findings of the report and initial conclusions. Their views informed the final recommendations.

3. The impact of involvement and engagement in CHC

- 3.1 Even within the short time frame that PPIE has been taking place within CHC, it has made a significant difference to the Programme by:
- Improving communication with 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
- 3.2 Different parts of CHC have involved patients and public in different ways for different purposes, leading to a wide range of outcomes. This section first describes five case studies illustrating these different approaches and impacts of PPIE as well as summarising the lessons learnt to date. The case studies are:
- (A) The #datasaveslives social media campaign
 - (B) CHC public engagement events
 - (C) The Great North Care Record
 - (D) Citizens' Juries
 - (E) A Wizard app for consent to use health data collected via healthcare apps
- 3.3 The final part of this section discusses the more general benefits of PPIE that have been reported across all parts of CHC and the factors that have contributed to this success.

Case Study A: The #datasaveslives social media campaign

Background

The #datasaveslives social media campaign aimed to bring balance to the debate around the use of healthcare data, to counteract much of the negative media coverage of general data misuse. **Stephen Melia**, Communications and Public Engagement Lead at CHC Hub, was interviewed about the aims of the campaign and its achievements. **Kay Gallacher**, an involved member of the public, was interviewed about her views of its impact.

To date, the #datasaveslives campaign has:

- resulted in over 15,000 posts on Twitter ('tweets') sent in the last 3 years using the hashtag
- been adopted by CHC, the Farr Institute for Health Informatics and NHS Digital
- become a partner in the Wellcome Trust's, Understanding Patient Data programme
- received support from influential stakeholders including MPs (e.g. Jo Churchill MP), Lemn Sissay MBE (Chancellor of The University of Manchester), Lord O' Shaughnessy (Parliamentary Under Secretary of State at the DH) and Dame Fiona Caldicott (National Data Guardian)

At the start of the CHC Programme, Stephen recognised there was a need for an awareness raising campaign to address public suspicion about the use of medical data. The concern was that this suspicion could potentially undermine many of the e-health projects aiming to improve people's health as well as NHS services. With colleagues in the CHC Communications Team, Stephen developed the '#datasaveslives' title for the campaign, which aimed to bring all the stakeholders together in support of a common purpose. Initially the campaign was used to engage researchers working within The University of Manchester, as Stephen explained, *"We wanted academics and the people we work with to understand that they had a role to play in raising awareness of how data is used. They liked it, and were supportive of it, and once we had some of the senior 'thought leaders' on board, it really gathered momentum."*

#datasaveslives has since developed into a very effective brand, becoming a headline for subsequent public engagement activities in schools, festivals, science fairs and hospitals. It has been used to create an online resource of information about research that uses patient data, and a number of important health organisations such as the Wellcome Trust, NHS Digital, the Farr Institute and the World Health Organisation have signed up and added their support. Having multiple organisations' on board, particularly the Farr Institute (a Great Britain-wide network of 21 Universities) helped the campaign to grow exponentially. Stephen believes it acted as a catalyst for all those people with shared interests to work together more closely and to feel more confident about promoting research using health data. Importantly, he explains *"It's also proved a good way for us to start our conversations with the public. Once you say 'data saves lives', people immediately ask 'How?' "*

Starting the debate with the public with this positive outlook is seen by some as a strength of the campaign. It's a 'conversation opener' that encourages people to want to find out more and to ask questions. Kay supports this view, *"If you're making the statement "Data*

Saves Lives” my initial questions are, ‘Why does it save lives?’ and ‘What’s that got to do with me?’” If the conversation started with the concerns, this might have only served to shut the discussion down.

However, there are some clear limitations to the campaign. For example, Kay has questioned the use of the word ‘data’ and whether the public actually understand it. *“Most people out in the public domain call the data ‘medical records’. There’s a different language being used. Someone needs to make that ‘data’ real, so the public understand why researchers want to use it and what it is that they are trying to get from it.”* The CHC communications team are aware of these concerns and in response they endeavour to be very clear in their conversations with the public. They take great care to explain what information the University researchers want to use and the exact processes they follow to ensure they use the information responsibly. As Stephen explains, *“We are open and honest about we are actually doing and what we’re not doing, so that people have clear information and understand what we’re doing and why. We are trying to explain the benefits of data research, but we’re not trying to convince anybody with a hard sell, we just want to enable people to make up their own minds.”*

Another limitation to the campaign is that it only reaches those people who are social media savvy, who understand the word ‘hashtag’ and are willing to seek information online. For this reason, Kay concludes that the campaign needs to be supported by other forms of outreach that can target the people who aren’t linked into the technology. This may include many older people, who are also the biggest users of the health service.

Case Study B: CHC stakeholder engagement events

Background

PPIE staff from across the different CHC regions have taken part in events to raise awareness of the Programme and the potential use of health data for research amongst the general public and other stakeholders. **Stephen Melia**, Communications and Public Engagement Lead at CHC, was interviewed about engagement activity in the CHC Hub, **Jo Hobbs**, Public Engagement Researcher, discussed her engagement work in Greater Manchester and **Debbie Parkinson**, Patient and Public Involvement Lead at the Innovation Agency (the Academic Health Science Network for the North West Coast), discussed her public engagement work. **Kay Gallacher**, a member of the public, was interviewed about her involvement in planning these types of event. **Kuldeep Sohal**, Programme Manager, Connected Yorkshire, was interviewed about the engagement of professional stakeholders, involved in providing data to the Programme.

The CHC Hub used an existing Public Forum (created for the Health e-Research Centre at the University of Manchester) right at the beginning of the Programme, and subsequently formed a sub-group of Forum members who were interested in public engagement. Stephen works with the sub-group to plan and deliver various engagement activities. The sub-group members have provided valuable feedback on initial ideas and helped to determine whether the public are likely to be engaged. This has been a new way of working for Stephen, but he quickly saw the value if it, *“It’s one thing for me to think up an idea in the office, but I don’t have the lay perspective. Forum members act as a helpful sounding board. Sometimes it means the ideas get scrapped, but they also help shape the ideas. They’re good at helping us to break things down into bite-size activities, and also understanding what’s going to be relevant and accessible to the public.”*

Stephen gave an example of an activity where the Forum members had helped to shape the design. *“We were developing a health data jigsaw and one person suggested putting ‘My data’ on one of the jigsaw pieces, keeping that piece back and then offering it to the person completing the jigsaw with the question ‘Do you want to contribute your data to the bigger puzzle?’. This would get them to think about how their data becomes part of the whole picture. This worked well, particularly with younger and teenage audiences, and proved to be a valuable conversation starter.”* It was this kind of feedback from members of the public, which helped to make many of the activities more engaging and the messages much clearer. For the staff involved, it is sometimes challenging to be on the receiving end of what may feel like criticism of ideas that ‘won’t work’, but Stephen recognised that often the discussions with Forum members were providing valuable learning.

One of the key lessons for Stephen has been to avoid over-engineering engagement activities, as he explains, *“Sometimes the best ideas are the simplest ideas. We have developed activities that have 3 or 4 stages, and actually people just want a 5-minute conversation - they don’t want to think through what a learning health system is! At a lot of public engagement events, people aren’t necessarily coming because they want to learn about health data - they’re coming because they’ve got children and they’re looking for something fun to do on a Sunday afternoon. So it’s about thinking through from their perspective, about what their expectations are, or how willing they are to spend time and effort learning about what we do. Sometimes, the public have basic, fundamental questions,*

and a lot of the detail that we'd gone into, wasn't really appropriate."

Forum members have also been involved in giving talks and running activities at public events. From Stephen's perspective this involvement adds credibility to CHC's messages, enhancing their impact, *"It's not me saying 'I'm paid by The University of Manchester and here I am telling you what I think'. It's more, 'Here is an actual member of the public and they are really enthusiastic and passionate advocates'. Ultimately people are willing to listen to what a patient or a member of the public has to say, much more than a professional."*

Kay also highlighted this added-value of involving the public in giving talks at events, *"We put a public face on it all, rather than a University face, which is a real benefit... We're not talking researcher speak, we're explaining it in ways that anybody in the street can understand. That's our benefit, we simplify things. Hopefully the public can relate to us. I've long used this phrase, 'people like us', because I think, if you can relate to the person that's giving the message, it means a lot more."*

When patients share their stories of how linking up data could impact on their health and care, these can be very powerful as Debbie has experienced, *"My COPD patients who have been involved from the very beginning, have a good understanding of CHC, so much so that one of them came to a conference last week and gave a talk as one of the guest speakers. At conferences you often hear the experts giving their opinion, but we always include a patient speaker where we can. It is refreshing and convincing to hear a patient speak, which makes it 'real' for the audience."*

Getting people to the point where they feel able to give talks requires developing their skills and knowledge, so that they feel confident talking about the work of the CHC and how the data is used. Often this means training and briefing patients/ members of the public, supporting them to develop their presentations, and sometimes co-presenting with them. Some staff have found this required a lot more time and resources than originally envisaged.

From Jo's point of view her engagement work has been more effective from going into community spaces and reaching different audiences, *"We've been going to libraries and leisure centres, places where the University doesn't traditionally have a presence. The University has a strong focus on the Science Fairs and Festivals, but I've gone to the smaller community hubs where you have people from very different backgrounds."*

Kay believes this is where the public involvement in planning events has made an important difference, *"People in our group have brought in ideas for different kinds of events to attend, and also identified where not to go. Often people inside the University don't have this type of information simply because they aren't living in the sort of communities that we live in. We've encouraged them to engage with a broader part of the community, not just the people who go to Science Fairs, who tend to be people who are already into that sphere of thinking. We also want to engage the people who think science and research have nothing to do with them."* More work is still to be done, to engage the groups that may be harder to engage.

The other key stakeholder group that has been targeted is the professionals involved in providing data to CHC. Kuldeep explained why it has been so important to work with this

group, *“If we didn’t have professional stakeholder engagement we wouldn’t have the support from all the data source organisations. All 88 GP practices, three Trusts, two Local Authorities and two charities in our region have signed up to CHC, but that would not have happened, if we hadn’t worked with a professional Steering Group, that included representatives from those organisations. I’m an unknown person, but by having that group of professionals supporting us, there is always someone from that group who can liaise with any professional to address any queries or concerns. Our Steering Group members are well-known, well-connected and respected locally, so they have been instrumental to getting buy-in into the project.”*

The key factor that led to the success of this professional engagement was establishing trust in CHC. From Kuldeep’s perspective, *“Although the Steering Group members have been involved in CHC from the outset they had some misgivings. The Group wanted to make sure that processes and procedures to request, store and analyse data from the GPs adhered to the highest standards of information governance and security and would not result in the GPs being fined millions of pounds! So we did what they asked, making sure we had consulted information governance consultants, and informed the Information Commissioners Office of our work. We also asked the organisations we work with about their priorities for service improvement across the region using this linked data model, and are developing projects to reflect those ideas. So we are working collaboratively, which means the professionals are willing to endorse and promote the Programme.”* As end-users of the results of CHC research, health professionals are also people who can usefully influence decisions about what service improvement and research gets done, so the outputs are genuinely relevant and can promote positive change in their practice.

Case Study C: The Great North Care Record

Background

The goal of the Great North Care Record (GNCR) is to make real-time health information available to health and social care practitioners, so that patients' data can inform decisions about their treatment and care. By fostering a local culture of information sharing, and ensuring public trust in the systems and processes, the project also hopes to gather public support for making such data available for service improvements and research.

In the first stage of GNCR, patient records within the GP system were made available to emergency care departments and out-of-hours services across all the acute trusts in the North East and North Cumbria. Now work is underway to extend the availability of the data to other hospital wards and departments and social care organisations. **Mark Walsh**, Operations Director, CHC North East, was interviewed to report on the PPIE work that has underpinned these developments.

From the start, public engagement has been an integral part of the GNCR, to ensure transparency and to build public trust. Mark believes that other such programmes have ultimately been unsuccessful, because they didn't take measures to ensure there was public understanding and support for how their data was being used. PPIE is therefore seen to be essential to the success of the whole project.

CHC North East has worked extensively with the 12 Heathwatches in their region and with Teesside University, to consult people from a range of backgrounds and affected by many different health conditions about the use of their health data. They first ran three pilot sessions with their neighbouring Healthwatch in Darlington, which proved invaluable to the roll-out of the remainder of the consultation, as Mark explained, *"Because we live and breathe health data, sometimes we can get quite technical, or very clinically focused, so we wanted to be sure we were describing what we're doing and asking our questions in ways that are easy for people to understand. Our Healthwatch and academic partners were really good at helping us develop the presentation material and the language we used to explain the concepts behind what we were doing"*.

The other 11 Healthwatches subsequently used the pre-prepared presentations and information packs to run additional sessions in their local area. Each session was branded by the relevant Healthwatch at the same time as being clear they were contributing to the wider GNCR consultation exercise. This approach proved highly successful in engaging a diverse range of people within a relatively short space of time. *"In three months, we ended up running 24 sessions, involving about 340 people across the North East. Liaising with the Healthwatch network helped to open doors, because we could tap into many of their existing group meetings. These included minority groups and people with certain health conditions, who would have otherwise been harder to engage."*

One of the factors that helped some of the sessions work well was to involve a local clinician in delivering the initial presentations. Mark believes this gave the project credibility and relevance to real-life. After the introduction, the presenters left the room to allow participants to express their views freely and honestly in a discussion facilitated by independent researchers from Teesside University. The experts returned at the end of the session to answer any outstanding questions. Involving the clinicians in these presentations

also proved to be effective in building clinical support for the GNCR.

The questions asked in the consultation focused on people's preferences for how their data should be used and who should have access to the information. The options included making the data available to NHS staff providing care, researchers in universities, and/ or other sectors such as the police, social care and voluntary organisations. This required educating people about current data sharing, because many assumed that health professionals already had access to patient information. Mark emphasised that *"A key aspect all the way through was making sure that we educated people to begin with, so they understood the current state and why we thought things should be done differently. That was really important."*

The sessions also explored how individuals could take control of the different types of data usage. Mark and his team are already making use of the findings to shape their ongoing work, *"We are developing an app that allows people to set their own preferences on how their personal data is shared, so they can establish their own privacy settings. The consultation exercise revealed a lot of resistance to the police having this information and so this option hasn't been included with the first version of the app, although we will continue to test this idea with people."*

Another important lesson was around the diversity of needs and interests that will need to inform how the GNCR works, as Mark explained, *"We didn't really appreciate the scale of the diversity amongst the groups, in terms of enabling people with different disabilities to participate, such as hearing difficulties or learning difficulties, as well as using different languages for the various ethnic minority groups, and being sensitive to their cultural concerns. It certainly opened our eyes and has influenced our thinking about all our communications going forward, how to present our materials, everything."*

The public groups also indicated their support for further public involvement in the next stage of the GNCR. In particular, they favoured the idea of establishing a public forum to be part of the formal governance structure. Mark hopes that such a forum could be consulted on any proposals to increase the content of the Care Record or expand its availability, informing decisions about what's acceptable. Members could additionally be involved in co-developing any new technology, for example by testing and giving feedback on the new preferences app.

Prior to the consultation exercise, CHC North East had concerns that people might go to the press with complaints about the use of health data, which could have potentially damaged the brand and the wider Programme. They therefore commissioned a local company who specialise in handling the media, to be ready to manage such a situation. In the end these services weren't required, a testimony to the fact that the exercise had been managed well and sensitively and that genuine consultation had taken place.

As well as analysing the findings from the public sessions, Teesside University also evaluated the process. They are running a You.Gov poll to provide quantitative data from a broader cross-section of the public that will complement the qualitative findings. It is hoped the combined results will be relevant to other UK health record projects, particularly in terms of understanding the diversity of the public's views. However, Mark believes that every project will still need to work with their local communities in order to establish trust, *"That is absolutely fundamental. People really welcomed the fact that we were going to talk to them before any changes had been made, rather than telling them about it afterwards."*

Case Study D: Citizens' Juries

Background

Two citizens' juries, one in the North West and one in the North East of England, explored whether the planned and potential uses of health data by CHC were acceptable to the public. The 36 jury members were selected to broadly represent the demographic mix of the north of England (according to the 2011 census). The volunteers selected had no experience working in the NHS or with medical records. Over four days, the citizens heard from and asked questions of expert witnesses, and carried out group exercises. They reached conclusions together, and were polled on their individual views at the start and end of the jury process. An independent community interest company, Citizens' Juries c.i.c., were commissioned to design and run the juries, working in partnership with the Jefferson Center, the founders of the citizens' juries' method. Mary Tully, Director of Public Engagement, CHC Hub, who led on this project, was interviewed about its impact.

The goal of the Citizen's Juries was to ask an *informed* group of citizens about their views on acceptable uses of health care data. Mary explained that the jury approach was chosen because it filled a gap in current knowledge about the public's views, *"A lot of the work in this field has been done by surveys, doorstep surveys or street surveys, without giving people any prior information. If people don't really understand the issues, undoubtedly they'll give you an opinion, but it may not be a particularly informed opinion. We liked the Jury method because it allowed time for learning and reflection, and importantly it plays close attention to avoiding bias."*

The professional companies which ran the juries ran them to a very high standard, following agreed best practice in the use of this approach. The detail of the processes has been made transparent on the CHC website, along with the participants' experiences of taking part and the final outcomes.

The evaluation showed that people did change their minds after hearing the evidence, and their opinions did become more measured over time. From initially being sceptical, some of the Jury members moved to being more supportive. From Mary's perspective, one of the key factors that influenced people's opinions was whether any particular use of health data was likely to genuinely benefit the public. In response to this finding, CHC has since placed greater emphasis on explaining the public benefits of any of their planned research in all their communications. A strong likelihood of public benefit meant Jury members were even willing to accept a commercial use of NHS data, as Mary explained *"So if a company were to use data to improve the way that it ran clinical trials for diabetes, for example, that was fine, because you could see the public benefit. But if a potential use only benefited the company, then that was considered to be totally unacceptable."*

However, the overall conclusion from the jury work was that there is no simple definition of what the public believes to be an acceptable use of health data and that each proposal may need to be assessed on its own merit. For this reason, the CHC intends to set up an independent assessment panel in future, to look at potential data uses. Mary explained that the initial idea for this panel is that, *"It would be made up of specialists and lay people working together to make recommendations. The panel could set some criteria, and if a project fitted with those and was not seen as particularly sensitive, it might be able to just go ahead. The panel could also advise researchers about specific proposals, if it felt there were some concerns associated with that particular data use."*

As such a panel has yet to be established, the public forum at Greater Manchester CHC was recently asked to comment on a new proposal for CHC to work with industry. The decision to involve the panel was a direct response to the lessons from the Juries, as Mary explained, *“Given what we’d learnt, we didn’t think we could assume the proposal would deliver a public benefit, and we therefore asked the group to make a judgement on this. Their input really helped finalise a few ideas and ensured we added some additional points to the contract with the company - because the public felt that there were points that needed clarification, these ended up being part of the contractual negotiations.”*

The Juries have had a wider impact across CHC by informing other public consultation exercises and by Jury members joining local panels. Some members, along with other CHC public panels, have been involved in drafting a Citizens’ Charter. This is a series of statements outlining CHC’s commitment to abide by certain ethical standards in the use of people’s information. As Mary described, *“The Charter explains who we are and our principles, how we will use data in a trustworthy way, how we will talk to the public to understand how they want us to use data, and what standards of practice that we follow.”* This Charter will be made available on the CHC website by June 2018.

Importantly, the Jury work has also raised the national profile of the CHC Programme. Mary has been invited to speak about the Juries at both national and international conferences, *“It’s been seen as an exemplar of citizens’ juries, for example it’s one of the highlighted examples of public engagement on the Wellcome’s Understanding Patient Data website, so lots of people have wanted to hear about it. I was also interviewed for an article in the British Medical Journal. So I think it has helped enormously to enhance CHC’s standing and reputation. It demonstrates how public involvement has been a core part of what we do, not an add-on. It is very much a core part of the entire endeavour.”*

Case Study E: A Wizard app for consent to use health data collected via healthcare apps

Background

The Patient/Public Involvement and Engagement Senate (PIES) at the Innovation Agency (Academic Health Science Network for the North West Coast) has developed a standalone Wizard for consent to share data from health self-management mobile phone apps. After testing, the Wizard will be made into an app that can front any other app. Members of PIES thought this would be the best way to gain consent from the health app users, and have been instrumental to its development. **Debbie Parkinson**, Public Involvement Lead at North West Coast CHC and the Innovation Agency, was interviewed to provide an overview of the project and the planned next steps.

Debbie set up PIES at the beginning of the CHC Programme, so the group have been working together for nearly two years. She recruited 25 patients, carers, advocates and members of the public, some with experience of epilepsy, COPD (chronic obstructive pulmonary disease) or alcohol misuse, as these were the priority topics for research in her region. She provided a series of briefing talks for the PIES members to ensure they were fully informed about the different CHC work streams. At one of these talks, the speaker highlighted the potential of using data from self-management apps for research into long-term conditions. The PIES members were enthusiastic about this idea and suggested using the same technology to obtain consent for use of this data. *“They didn’t want it to be a long list of terms and conditions that you would just swipe through. They wanted something that was clear and direct, which enabled the individual to set limits on who could use their data, and to be informed of who was using it and how it was being used”*, Debbie explained.

PIES members then started work on developing a list of questions that could be used in the app, to guide users through the decisions they would need to make about the use of their health data. They went out to consultation asking local researchers and clinicians, as well as a wider group of patients and carers for their views on the questions. Debbie believed that it was essential that they were collaborative, *“It’s got to be co-production with clinicians and everyone else involved, so that everyone gets what they need from the final product.”*

To ensure that a range of patients and carers had their say Debbie visited nearby clinics, talking to people in the waiting rooms, *“I targeted the Centres where I could get feedback from patients with alcohol problems, because we were conscious that the COPD and epilepsy patients/ carers had had that opportunity, but people affected by alcohol misuse hadn’t become full members of PIES.”* Patients and carers from other CHC regions were also consulted and the general public involved via a survey using social media. However, it was the PIES members who had the final say on the questions approved for use in the app.

This testing and evaluation revealed an important difference between the views of the 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 any other reason. Although members of the public will 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 on consulting widely on issues relating to the use of health information and

being clear about whether patients or public are being involved.

With the final list of questions agreed, Debbie collaborated with ORCHA (the Organisation for the Review of Care and Health Applications) and EMIS Health (a provider of healthcare software) to create a stand-alone Wizard app for consent to share data. In order to pilot the concept of the Wizard, she is testing it in connection with a self-management app for COPD that is currently being prescribed in Lancashire. *“We worked with a company called Intelesant that provides an approved COPD App called ‘How Are You Today?’. It’s been through all the rigours, so we thought that was an ideal one to start with. They agreed to give our Wizard App for free to people that we identified as using their app, provided that we got consent from their GP to ensure these patients were capable of self-managing their condition. So far we’ve recruited seven people to take part and have more in the pipeline.”*

Currently the aim is to test how well the consent process works and whether the Wizard app is easy to use. No one’s health data is yet being collected or analysed. The results of this pilot weren’t available at the time of writing this case study, but Debbie feels confident that the app will work well, because it’s been designed and developed by the actual end users, *“This is so different from the typical consent processes, where there’s pages of small print and you don’t always know what you’re signing up to. Our app is short. There are only 12 questions, and they are written in a language that’s easy to understand, and in big enough font so you can actually see it and read it. Patients will understand it because they wrote it!”*

If successful, the Wizard app will also be tested in combination with an epilepsy self-management app at a local neurological hospital. It will then be made available for more general use. The PIES also has plans to be involved in the development of other apps as Debbie reported, *“We recently had a meeting about with the North West Ambulance Service about a new app to identify stroke centres for rapid treatment. What that does is help para-medics to identify people who are having a stroke, and when appropriate, directs them to the nearest stroke specialist centre rather than just a local A&E. So people get the best treatment and avoid being sent to the wrong place. We’ll be involving our patients with that, because once the app is working for stroke patients, you can use it for COPD and other conditions, and that’s where our patients and carers can make a useful contribution.”*

General benefits of PPIE in CHC

- 3.4 The different parts of CHC have approached PPIE in different ways. Some have set up new panels of patients and/ or members of the public. Others have worked with existing groups. Some have done both. All have invested a great deal of time and energy into supporting these groups to get them to the point where they feel confident and sufficiently informed to make valuable contributions. This preparation work is very time-consuming, so the impacts may not be felt until at least a year after any new group has been established. The staff and patients/ members of the public involved in CHC have therefore achieved a great deal in working with these groups through to the point of seeing significant change and improvements in the first two years of the Programme.
- 3.5 The case studies above illustrate how the PPIE has influenced the development and outcomes of specific projects. The patients/ members of the public who have been involved to date now provide a well-informed and highly-skilled group of people who can offer insights and feedback on an ongoing basis. They continue to help improve CHC's communication with the public and to provide their perspective on different projects, as one panel member describes:

We're a conduit between the academics and the medical profession and the public. We comment on what they're looking to do and help them interpret their work in a way that the general public will respond to, but we also give a view on what the general public may feel about a particular aspect of their work. So that's what our role is. **Member of the public**

Factors that have contributed to the success of the PPIE

- 3.6 The success of the PPIE projects are undoubtedly due to the efforts of all the staff involved, but PPIE leads reported that the support from the central public engagement and involvement team at the CHC Hub had been invaluable, particularly in explaining the significance of this work, and equipping people with the skills and know-how.

The engagement team explained how important public involvement is to everyone. So they've led the way and then I definitely, quickly saw that value for myself. We work together as a team and I feel really comfortable to ask questions and to get feedback from them. There have been loads of opportunities to develop skills on the job, and for us to hear from other organisations about what they're doing and how they're doing it. So we've been able to learn and develop, and I've been happy with that. **CHC staff**

- 3.7 The CHC Hub was able to build on PPIE work from previous projects at the Health Research Centre in Manchester, and was thus able to bring in experienced staff, draw on existing PPIE networks and rely on tried and tested ways of working. The Hub was able to share its experience with the regions, supporting those staff to borrow, adapt and build on what had been done at the centre.
- 3.8 Another key factor contributing to success has been the leadership from the top. This has ensured public engagement has been a central part of the work of CHC, and has

been well-resourced. The budget included money for public engagement and the Director of Public Engagement was a member of the senior management team, ensuring that all top level decisions included consideration of patients and the public.

4. The experiences of staff and involved patients/ members of the public

4.1 This section reports on some of the challenges staff have experienced in undertaking PPIE and some of the ways involved members of the public have suggested the involvement processes could be improved in future. These issues are discussed in relation to the following topics:

- Setting up public panels
- Recruiting people to involvement roles
- Partnership working
- The practicalities of involving people
- Defining the public
- Evaluation of PPIE
- Preparing for the project to end

Setting up public panels

4.2 Patient/public panels have become a common way of supporting PPIE in health and social care research. However there are some limitations to their application. In the first instance, not all people are willing and able to participate in this way, in particular people with certain health problems (e.g. drug or alcohol misuse), people whose first language isn't English, and people with little or no experience of this way of working. One way to overcome this issue is to recruit people who can advocate for these groups, but these individuals may not have direct experience of the issues, and may not be able to speak with an authentic voice. Their contributions may be of equal value, but different to those of people who are directly affected.

4.3 The experience of CHC staff suggests a more effective way to involve people from these groups is to go out into the community and talk with them in their own settings. This helps people to feel more willing and able to engage. While undoubtedly effective, such approaches are resource intensive and may not always fit well within a research organisation's existing working culture.

“The biggest challenge I've had is trying to find minority groups to work with. I've spoken to a couple of the community leaders and their suggestion was to go out to places like their art groups in community centres, and to go to them. Not medical groups, but coffee mornings! It is my intention to go out to the groups, to the temples, to the mosques, and talk to groups in their own environment rather than expecting them to come to ours. I think that's the learning.” **CHC staff**

4.4 Another common challenge is equipping people with sufficient knowledge about the context in which they are working, so they are clear about why and how they can contribute. In the context of CHC, the involved patients and members of the public have been on their own learning curve, and some are only now getting to the point where they can effectively influence and add value.

“It was a real eye-opener for us how little the public understood about how the NHS currently uses data. We never covered that because we never thought of it really, and it became clear that people had quite varying understandings about how you would actually run a health service and therefore how you would use

data to change how you would run a health service. That really made us realise that we needed to be very clear in our public activities about what currently happens, why care pathways have been run that way up until now, and therefore why you would want to do it differently using data.” **CHC Staff**

- 4.5 While everyone involved may need this type of induction and briefing, the needs may be even greater when patients/ members of the public take on roles to speak on behalf of the project. Some staff felt that they had not had sufficient time and resources to address this issue.

“While there’s been a commitment on paper to training [public contributors], it hasn’t been prioritised. The priority has been more on what the public can do for CHC as quickly as possible, rather than taking the time to upskill them for a longer term investment. This may be OK for a pilot project, but it’s been a challenge.” **CHC staff**

- 4.6 When a panel is first established, there is always a tension around how much to set the direction of its work and how much control to give the members. CHC staff wanting to show respect and to demonstrate that they valued the panel’s input, sometimes chose to give the panel more of a free rein right from the start. However, as discussed above, panel members needed time to understand the Programme and their place within it, which meant they felt unable to steer their work at first. This suggests new panels may need more input from staff when they first get going, and would welcome stronger direction.

So in terms of the project, that felt like a slow start... what I picked up was frustration in the early days that, well what are we doing? I don’t think it was actually very clear what we were there to do... But it was a funny meeting, it wasn’t like ‘this is what I want you to do’, so we could come away and feel like we’d done something. People found that frustrating, and I felt that this group has got to form before it can make a cohesive contribution. **Member of the public**

The panel was given its own autonomy, so that we were making decisions about how the meetings would run, but I think that might have been a bit too early. Certainly I was expecting to be told how it would be, at least initially, then to have the opportunity to change it perhaps later in time. We needed more direction. I honestly wouldn’t have minded being told this is how it’s going to be.

Member of the public

Recruiting people to involvement roles

- 4.7 When involvement roles become available often these are offered openly to everyone on a panel or in a group, with the aim of ensuring equal opportunities and avoiding bias in the selection. While these are honourable objectives, there can be downsides to such an approach. The first is that people may be reluctant to put themselves forward because they are uncertain whether they are the right person for the role. It can also mean that the same few people put themselves forward repeatedly, allowing others to hang back. A Panel member explained that they expected the staff involved to make an assessment of who has the most relevant experience and skills and to invite those people to take part.

At the meeting, the staff member would say 'I need somebody to do this, this and this' and we'd all sit and look at her. And I'd think, well, basically I'll do anything, so I'd look at everybody for a while and then I'd say, 'Yes, I'll do it.' But then it's only me and that's not right, so I'll not say anything the next time! I found that difficult, to strike that balance as to when to wade in or not wade in...I need their guidance to tell me what they think I'll be best suited to, because I might volunteer to do X project but actually there's somebody in the group who's got better experience and skills than me to deliver on that project. I'm not going to take that personally. **Member of the public**

- 4.8 The second problem that can arise is that people put themselves forward for a role that is not suitable for them, because they haven't the necessary skills or aptitude. This can create difficult situations to manage, when people may need to be encouraged to consider a different role or require additional support. This requires sensitive handling and can be very challenging for the staff with overall responsibility for the outcome.
- 4.9 Selecting people for specific roles may be one way to overcome some of these challenges, but this often needs to be balanced with commitments to encourage people to learn and develop new skills.

It's difficult where you've got a group of people that are all trying to learn about a subject that's not that easy to understand. You're trying to be balanced and impartial and equal and allow people to learn at the same pace, but some people are always going to be better at some things than others. **CHC Staff**

You've got to factor in that you're aiming to develop the individuals on the panel as well, so perhaps sometimes the job needs to be given to someone who isn't the most experienced at it. This matching thing is a problem isn't it, because you've got a project and it's the project that's important at the end of the day, that's why we're there. And we've got to find the best way to deliver the outcome on a particular task, whilst balancing that with who's actually the best person on the panel at that time, and who could learn something from it and thus make a contribution in the future. **Member of the public**

Partnership working

- 4.10 Working in partnership with patients and members of the public is often a new way of working for staff and it takes time to learn the boundaries around who has the power in decision-making, and individual roles and responsibilities. With good intentions, staff may want to demonstrate that they are willing to listen and respond to other perspectives and to show respect for the public's views. Much of the PPIE guidance also emphasises the importance of being 'patient-led'. However, there is a risk that this can result in the professional voice being lost or unheard, which may not foster effective partnerships. Good partnership working is based on mutual trust and respect, and ensuring everyone around the table has an equal voice.

In future it may be useful to set clearer boundaries of what the role public involvement should be... it has evolved organically, but with the lessons we have learned, we could perhaps take a bit more ownership over the work that's done, rather than allowing everything to be patient-led. Being clear about expectations

would have been helpful. **CHC staff**

The practicalities of involving people

4.11 The issues that involved patients/ members of the public raised around how involvement might be improved in future, mainly related to the practicalities of working with them. Their suggestions included:

- Being more flexible around frequency of meetings, rather than meeting quarterly, meeting more often at the start to allow the group to bond and then arranging meetings according to the demand for work to be done, rather than at fixed time points.
- Giving more notice about meetings and about opportunities to be involved, people are busy and concerned about missing opportunities without sufficient notice to schedule other activities around their involvement.
- Enabling panel members to meet outside of formal meetings e.g. to go to events, conferences etc together to encourage bonding, and similarly allowing more time for socialising and networking amongst group members.
- Better preparation for meetings with pre-circulated information about the topics that are going to be discussed.
- Feedback on the impacts of any involvement activity so panel members know what's happened in response to their input and what difference it has made.
- More detailed information on the different components of CHC and where their group or panel fits into the bigger picture.

Defining the 'public'

4.12 As with many research Programmes, CHC aims to include patients and the public, but these terms are sometimes contested and not always clearly defined. For example, not all members of the public define themselves as citizens:

*The NHS insists on calling people citizens and I've been challenging that because patients and public don't like being called citizens, and the ethnic minorities don't think it includes them, if they're not British citizens. **CHC staff***

4.13 There is also some confusion about whether professionals can be counted as public, when they are sometimes the main end users of some of the CHC research. It is not clear whether there has been an expectation that professionals could also have their voice heard in the consultations on CHC projects.

*"Where does public stop? I've been talking to professionals, because they are also the public. They might not be lay, but they're still public. Some professionals we've consulted have raised concerns about research projects, but didn't have much influence on the outcome. The consultation was part of the 'yes, we've consulted', but if it didn't come back with what the researchers had already decided they were going to do, then it's been allowed to drift away." **CHC staff***

Evaluation of PPIE

- 4.14 Many of the PPIE staff are capturing information about the PPIE activity that is taking place, and asking involved patients/ members of the public to provide feedback on their experiences. However, it is not clear how this information can be used to evidence impact, or how it can support learning and improved practice. It was suggested that evaluation is built into the planning of PPIE to provide learning in real time, as well as capturing impacts at the end.

“Evaluation, it’s got to be at the forefront when you’re developing your project... we need to learn some lessons about putting evaluation in. It has to be formative as well as summative - it may be short-sighted to leave it all to the end. You should be learning as you go.” **CHC staff**

Preparing for the project to end

- 4.15 The initial CHC Project was for three years and it has since been allowed a no cost extension through to March 2020. This has meant some of the public engagement work has come to an end and some of the PPIE staff will not be kept on beyond the original end of the contract. Any further work will depend on whether the program can be refunded, or whether a similar project is funded. This has caused some frustration for staff and involved patients/ members of the public who feel like they are only now reaping the rewards from their investment in setting up Panels. It will be important to consider how to enable the Panel members, who are now highly skilled and knowledgeable, can continue to influence research in the health data field, either as part of refunded CHC or another related project.

5. Conclusions and recommendations

- 5.1 This section draws up a series of conclusions and recommendations from the interviews with staff and involved members of the public, as well as discussions with CHC staff at a final workshop.
- 5.2 It is important to note that CHC is a 'network of networks', operating on a 'hub and spoke' model. The central hub hosts the CHC PPIE team who have provided support to staff working in the four CHC regions. Each region is following its own programme of work, has allocated different levels of resource to PPIE, and employs PPIE staff with differing levels of skills, experience and capacity. For example, some staff in the regions work full-time on PPIE, while for others it is only part of their role. This means each region has developed its own approach to PPIE, which has been appropriate and relevant to their local context. This also means that each region has been successful in different ways, and experienced different kinds of challenges.
- 5.3 If CHC is to continue, then each region may need to develop its own bespoke PPIE strategy, reflecting local interests, and their specific experience and learning to date. Any central PPIE facility will need to be flexible enough to respond to diverse needs for support, as well as identifying where collaboration could avoid duplication of effort and ensure efficient use of resources.
- 5.4 Given this diversity across the networks within CHC, it proved difficult to reach a consensus on the way forward in the workshop. Each region may wish to develop and expand their PPIE in different ways in future. The conclusions and recommendations in this final section may not therefore uniformly apply across all parts of CHC. Instead it offers a number of options for consideration, which may be more or less relevant in different contexts.
- 5.5 The conclusions and recommendations are discussed in relation to the following:
 - Sharing successful approaches to PPIE
 - Expanding and enhancing PPIE in future
 - Evaluation of PPIE
 - The legacy of CHC

These will be discussed in turn.

Sharing successful approaches to PPIE

- 5.6 The PPIE work across CHC has led the field in terms of engaging and involving the public with the issues around the use of health data in research and service development/ improvement. There would be great value in CHC sharing its findings nationally with other health data related projects, both in terms of PPIE practice and in terms of the outcomes of public consultations. There was also some enthusiasm for developing toolkits. The goals of this work would be to enable others to:
 - avoid re-inventing the wheel, learning from CHC staff what they would do again and what they would do differently if they were to start from scratch

- using the outcomes from CHC consultations to inform their own policy and practice around health data governance
- develop new questions to ask the public, building on the lessons from CHC consultations in order to support further policy and practice development
- adopt CHC approaches to working with the public to gain their trust, at the same time as adapting these approaches to reflect their local context

5.7 Some CHC regions may wish to learn from what other regions have done to set up similar successful PPIE projects. However, PPIE projects do not always easily transfer from one location to another, because success is so often dependent on context – in particular, the level of resource invested in the activity, the skills and experience of the PPIE staff leading the work, and the availability of suitably experienced patients/ members of the public. Understanding the contextual factors that have contributed to success is essential to support any attempt to replicate a PPIE project elsewhere. Furthermore, given that there may be different purposes for PPIE work in different contexts, it is not always necessary or appropriate to try to standardise PPIE across a network like CHC. It may be more important to ensure all approaches are fit for their particular purpose, and are tailored to reflect the local need.

Expanding and enhancing PPIE in future

5.8 Having taken PPIE to an advanced level, some CHC staff have experienced challenges in their work that are commonly experienced across many current PPIE projects beyond CHC. In future, some staff may therefore wish to consider whether:

- the purpose of each PPIE activity could be made clearer to all involved, in terms of how it supports the mainstream CHC agenda i.e. making PPIE a mechanism by which CHC can enhance all aspects of its work, not only in terms of improving public trust in the use of health data
- the extent of patient/ public influence could be enhanced e.g. by enabling patients/ the public to help shape decisions about prioritising topics for research (or priority areas for service development and improvement) or by involving patients/ the public in the interpretation/ analysis of health data
- PPIE staff and others working directly with patients/ the public could be trained and supported to be better prepared to work in effective partnerships e.g. to be able to clarify boundaries in terms of roles and responsibilities, to manage people more effectively and to select the ‘right’ people for different involvement roles
- more flexible and responsive approaches to PPIE could be developed, to support the involvement of a diverse group of patients/ the public
- more attention could be given to involving other end users of health data research/ service development, in particular front line health and social care

professionals, to enable their perspective to influence the work of CHC as well as patients/ the public

Evaluation of PPIE

5.9 There was limited time in the workshop to discuss evaluation of PPIE beyond a general overview. We discussed how:

- there can be a tendency to leave thinking about evaluation until the end of a project or piece of work
- evaluation needs to be an integral part of the planning of any PPIE activity. Once the purpose of the activity is clear, it becomes easy to identify what needs to be evaluated. For example, if the aim of involving the public is to comment on a poster for use in GP surgeries advising the public about the use of health data, it follows that what could usefully be captured is what patients/ public specifically recommend in terms of the design and content of the poster, whether this makes the poster more appealing and easier to understand, whether this changes patients/ public's views on the use of their data in this context etc. In summary an evaluation plan needs to be bespoke and reflect the specific aims of each PPIE activity.
- the purpose of the evaluation also needs to be clear. The aim might be to generate evidence of impact, to assess how well the activity is meeting the needs and interests of involved patients/ members of the public, and/or for staff to improve their practice. There is always more that could be evaluated than is practically feasible. Once its purpose(s) is clear, the evaluation becomes more focused, which is essential to shaping and prioritising what is going to be assessed and how.
- assumptions are always being made about what works and how this will bring about change over time. Planning an evaluation in detail at the start, helps to surface these assumptions. It is then possible to design strategies for testing them. The learning from this process often provides valuable information for future PPIE work.
- as part of the planning, it is often helpful to consider who will use the findings from the evaluation and what they might be expected to do with those findings. Defining the target audience(s) and the objectives of informing them of the outcome, can usefully shape the final dissemination strategy.

The legacy of CHC

5.10 As well as gaining considerable expertise in PPIE in the health data field (see above), CHC staff have supported and developed a pool of well-informed and highly-skilled patients/ members of the public. These people could potentially develop leadership roles in future, both regionally and nationally. They are also people who could be immediately involved in any new projects, to ensure PPIE is integrated into new work from the very beginning, rather than waiting for any new PPIE structure to evolve and mature. They therefore represent a highly valuable resource. Some

thought should be given as to how to further develop or maintain this pool in future, whether CHC continues, or whether new health data related programmes emerge in the CHC regions.