

GREAT NORTH CARE RECORD PUBLIC ENGAGEMENT REPORT

Authors: Stephanie Mulrine, Professor Madeleine Murtagh, Dr Joel Minion

Published: July 2018



THE GREAT NORTH CARE RECORD

The Great North Care Record is a project currently being developed by the Connected Health Cities in the North East and North Cumbria. Connected Health Cities is working in collaboration with local health and social care providers, academic institutions and the community as a whole.

What is the Great North Care Record?

The Great North Care Record is a new way of sharing medical information across the North East and North Cumbria which is accessed by health and social care practitioners to provide direct care for patients. It means that key information such as diagnoses, medications, details of hospital admissions and treatments can be shared between different healthcare services including hospitals, out of hours and ambulance services.

Sharing information to support patient care is already available across the North East and North Cumbria since the introduction of the Great North Care Record. The project is exploring opening up healthcare data to more groups such as social care providers, healthcare planners, public health teams, and researchers.

Healthcare records are a rich, but untapped source of information which, in the hands of researchers could bring new insight and discoveries about treatments and diseases. This has not been achieved on a large scale before as obtaining permission from the public to use their information in this way is very difficult.

This is a challenge the Great North Care Record is seeking to overcome.

Who can access the Great North Care Record?

Currently, accident and emergency departments, ambulance service, 111 services and out of hours in the North East and North Cumbria can access a read-only version of GP records for most of the 3.6million people living in the North East and North Cumbria – with their permission. Access to health information is highly protected and safely stored. Only clinicians who have the right level of clearance are able to access health information and their access is fully auditable.

In the future, more services could potentially access the Great North Care Record. This is one of the areas that this research explores.

How does the Great North Care Record benefit citizens?

Historically, each organisation involved in providing care such as GPs, local hospitals, physiotherapy departments or the ambulance service has held limited information about individuals– but no one has had an overall view of someone's medical or social care history. This is one reason why health

and care practitioners often ask patients the same questions over and over, or repeat the same tests.

With the Great North Care Record, the more health and social care teams will have access to detailed information to help them provide better care. This information will only be accessed with an individual's permission.

With the Great North Care Record, these details are available securely, electronically and in real time.

The ambition of the Great North Care Record is to improve information sharing between healthcare services to improve the level of care. Furthermore, by sharing information in a consent-rich, secure environment, making the region one of the best places to do research.

Controlling how your information is shared

Not everyone is comfortable with their information being shared. Currently, the public can opt out of their information being shared within the NHS. Identifiable information can only be shared with researchers with the patient's permission. More information about the Great North Care Record is available at www.greatnorthcarerecord.org.uk.

Engaging citizens

Engaging citizens in developing the Great North Care Record is crucial to making sure it is acceptable and meets the needs of all citizens.

Why is citizen engagement important to the Great North Care Record?

- Citizen engagement in the North East and North Cumbria is a cornerstone of the success of the Great North Care Record.
- The Great North Care Record will continue to be co-produced and co-designed with citizens and aim to meet the obligations that all systems and practices are transparent, fair and commensurate with citizens' expectations and has the ongoing support of the majority of the population.
- Citizen co-production of the Great North Care Record will allow citizen engagement with and public support of efforts to share health and social care data for care delivery, service evaluation and planning, and research.

Connected Health Cities worked with Teesside University and local Healthwatch groups in the North East and North Cumbria to bring together citizens across the region. The aim of engagement sessions was to identify citizens' hopes, concerns and expectations about the Great North Care Record.

Citizens were invited to take part in engagement sessions to learn more about data sharing and the Great North Care Record and to discuss their hopes, concerns and expectations about this new

initiative. Twenty three engagement sessions took place between May 2017 and December 2017. 314 citizens were involved in these sessions.

As part of the engagement sessions, a Teesside University researcher led group discussion about the Great North Care Record and the sharing of electronic information and data. Some of these sessions were recorded, with the permission of participants, to enable independent analysis. Recording and analysis of the group discussions provides the enduring evidence of citizen perspectives and values.



This evidence will continue to underpin ongoing development of the Great North Care Record. This report of findings was prepared by researchers from Teesside and Newcastle Universities. Academic articles and presentations will also be produced from this work. These publications will be accessible through local Healthwatch websites.

Summary of findings

Citizens expressed clear values and expectations about sharing the data held on them. Fundamental to these values was an expectation of respect.

- *Reciprocity:* Citizens recognised the benefits of sharing data for improving health and social care for themselves and others in the community. Citizens said they would like to have access to data held about them, both to see what is said about them and to add additional information like organ donor preferences.
- *Fairness:* Citizens expected communication and making decisions about data sharing (including information about what data they are happy to share) to be accessible to all regardless of class, education and literacy, disability, ethnicity or capacity. They expected an even higher level of care for data sharing about potentially sensitive or stigmatising issues like mental health, reproductive health and sexuality.
- *Agency:* Citizens said they want a say in how data about them is used, by whom and for what purposes. Control of information use and access was not only an individual issue. Citizens expected to be involved in the oversight and governance of information sharing and the Great North Care Record.
- *Privacy:* Citizens expect their privacy to be maintained, except where they have specifically agreed to share personal information. They recognise privacy as central to preservation of

an individual's sense of self (identity) and that it should not be violated. Citizens wanted to know that data about them is secure and that their choices and preferences are upheld.

- *Transparency and Trust:* Citizens expected to be informed about how data about them is or may be used. They wanted to be able to access further information on Great North Care Record and data sharing as and when they needed it. Citizens expected institutions handling data about them to act in a trustworthy manner. They said healthcare institutions are the most trusted. Research institutions were felt to require more information to give clarity and lead to greater trust. Concerns were raised over agencies such as police. Commercial and for-profit organisations the least trusted.

Findings

Citizens were asked to give their thoughts, feelings and opinions on data sharing and the Great North Care Record. A clear ethical framework for data sharing emerged from analysis in which five key values were seen as being central to the successful establishment of the Great North Care Record, (1) reciprocity, (2) agency, (3) privacy, (4) transparency and trust, and (5) fairness. The foundation of these values was an expectation of respect.

Reciprocity

Citizens recognised the benefits of sharing data for improving health and social care for themselves and others in the community. Citizens said they would like to have access to data held about them, both to see what is said about them and to add additional information like organ donor preferences.

Citizens were asked to reflect on how the proposed Great North Care Record may benefit them and others, or the NHS more widely. They were able to give examples of how such an initiative could or would have directly benefitted them. Not having to repeat themselves to Healthcare Professionals (HCPs) was often seen as a benefit. Participants felt that this could potentially benefit the NHS and make the jobs of HCPs easier.

"I think the advantage we can all be aware of, if you have had any experience of going to A & E in the middle of the night, not on my own behalf but because my husband had broken his hip and fortunately I was with him and I could keep repeating the information which spared him. If I hadn't been with him, it would have been worse."

There was support for data held by the Great North Care Record being used for research purposes. Research was seen to benefit the wider community and society as a whole, as well as the individual and the NHS. Though "research" meant different things to different people. Concern was raised that if the research purposes and uses of the Great North Care Record are not communicated well to the population that could undermine trust and buy-in.

"I should probably mention our Daughter in Law has a very rare autoimmune disease, now this would put forward a lot information to the research which is being done [...] Every university is doing but to get more of the information they need from individuals maybe would push forward something that would eventually produce a cure for some you know."

Fairness

Citizens expected communication and making decisions about data sharing (including information about what data they are happy to share) to be accessible to all regardless of class, education and literacy, disability, ethnicity or capacity. They expected an even higher level of care for data sharing about potentially sensitive or stigmatising issues like mental health, reproductive health and sexuality.

In order that trust of citizens can be established and built upon the Great North Care Record needs to demonstrate fairness in how it is governed, secured, implemented, and reported upon.

Participants highlighted throughout a range of discussions that to willingly sign up to an initiative such as Great North Care Record there would need to be reassurances, not only for oneself, but for those who might be vulnerable, particularly people with:

- A sensory impairment (blind, deaf, etc.)
- English as a second language
- Mental health issues
- Learning difficulties

Participants felt that if they were to gift their information that it should be handled sensitively and be used to the benefit for society. Ensuring that data is accessed, handled and potentially examined in a manner that avoids prejudice, discrimination and abuse was key. Communicating and demonstrating that this continues to be recognised and adhered to was important to citizens.

"I'm a bit worried about the bit more vulnerable in our society. If you have somebody who's got a long enduring mental health problem, somebody with early onset dementia, somebody with language difficulties. I'm only bringing this up as devil's advocate. Having [an] intervention based on equality, so that people are more able to actually use this and understand it better. Can actually go through and make informed decisions. But more vulnerable people find it more difficult so you're generating inequality by doing it.

"And its people filling it in for them, isn't it? [There's] a safeguarding [issue] here."

Agency

Citizens said they want a say in how data about them is used, by whom and for what purposes. Control of information use and access was not only an individual issue. Citizens expected citizens to be involved in the oversight and governance of information sharing and the Great North Care Record.

Mostly citizens supported a move away from paternalistic medicine and care and towards person-centered care. Citizens wanted to be reassured that they would have a choice about sharing information about them and that they could control *what information is seen, how much of it, by whom and in what circumstance*. They expected to be given control over their decisions about information sharing and did not think that health care professionals should make decisions on behalf of patients or citizens.

"I think that people should be given a choice."

"Yeah because there's a lot of people who don't want anybody to know their affairs, you know even though it's to do with their health. So, I think people should have the choice."

Citizens said that access to the Great North Care Record and making decisions about sharing information about them should be made user-friendly and accessible to all. They expected support to be available for people with visual impairment, who were hard of hearing or deaf, for whom English is a second language and that particular support was needed for children and young people to make informed decisions. Supporting choice and for those who lacked capacity and who may struggle to make an informed decision was identified as important.

"I think it would be interesting to do a piece of work with carers in terms of, for the people who are interested, to see what the plan is for people who don't have the capacity to be able to sign up and sign out and things like that. To be able to, and even if they do have the capacity, maybe to be working with carers who can maybe help. [Be] the middle man a little bit. And if they're being educated on what's going on, maybe they can [make choices]."

There was concern that setting preferences and recording choices about information sharing in the



Great North Care Record would be exclusively online. Citizens argued strongly that other avenues for accessing the Great North Care record needed to be made available - via post, in the GP surgery, at outreach community events, by provision of drop-in sessions so people could ask questions, via an advocacy service. Otherwise older, vulnerable or poor members of the community could potentially be excluded.

"I'm actually more concerned at this point that it's IT by default. If you've got people who can't see people with brain injuries. The more complex the thing is the more likely it is they'll just tick any box. They might end up consenting to something that they haven't really [understood]."

"It's frustration more than anything else. They might understand but give up because it's too complex."

“There are several technophobics around as well because some people don’t have computers.

“So, don’t leave us behind that’s the message really.”

Citizens said they thought people should be able to change their decisions and permissions with changing circumstances or opinions. Being able to change preferences was seen as a way of increasing confidence and trust in Great North Care Record.

“I think if something happens in your life or happens in your personal life or in your medical life you might reach a stage when I don’t really want that to be published anyway. They should have that facility to just say I’m opting out.”

Controlling how information was shared was not only seen as an individual issue. Participants felt strongly that there should be mechanisms in place to protect against misuse or breaches. Citizens expected strong oversight of the Great North Care Record, particularly if sensitive information was to be shared outside of the NHS. They expected citizens as well as professionals to be involvement in ongoing oversight of this process in order that citizens feel reassured. A citizen’s governance panel was discussed as one possibility for ensuring citizen’s expectations are met.



Privacy

Citizens expect their privacy to be maintained, except where they have specifically agreed to share personal information. They recognise privacy as central to preservation of an individual’s sense of self (identity) and that it should not be violated. Citizens wanted to know that data about them is secure and that their choices and preferences are upheld.

Privacy was an increasingly important concept for citizens. They thought privacy issues needed to be taken very seriously, particularly where information was sensitive or potentially stigmatizing. The sensitive nature of mental health and continuing stigma or taboo in wider society meant that many felt it would have to be treated differently from physical health data.

"I think that's why it's a very personal thing. I know a lot of people told us when we were doing our work around mental health that for them sharing their story with several professionals at different times was really distressing so it is a very personal thing isn't it. Some people may be quite happy to say it once and then people can, other professionals can see it but then of course other people in some respect it should be very confidential to them and that one individual and it shouldn't go anywhere else.

"Again, that's about being able to make the decision on what you share, who you share with on what level."

The Great North Care Record represents a departure and change from currently established protocol. There were concerns around the potential abuse, exploitation or leaking of sensitive information that could subsequently lead to discrimination. Issues of transparency, trust, fairness and informed choice became even more important where sensitive or stigmatizing information was involved. Given high profile malware attacks on the NHS, citizens were understandably concerned with the security around sharing their data. This included the potential for hacking into NHS, abuses by the HCP access to information, negligent use of confidential information, potential 'leak' or creep of information outside of NHS.

"You see data get lost every week. Authorities and government have been in situations where that information has gone, so it's about protecting that information. That is our personal information, which is sensitive to me and others in this room.

"I think [the Great North Care Record] is a good thing. I think that the reservations are what everybody felt with the National one [care.data]. That there is a security issue and I think it's been proven that they've hacked into the health service and hospitals in the recent months, and that their computer data wasn't up to date with protection. I think the public's main concern is anybody can hack into this information. I mean I don't care, but if you had had an abortion or you had mental health issues, it's not everybody who wants to give that information out to anybody, perhaps."

Transparency and trust

Citizens expected to be informed about how data about them is or may be used, and by whom. They wanted to be able to access further information on Great North Care Record and data sharing as and when they needed it. Citizens expected institutions handling data about them to act in a trustworthy manner. They said health institutions are the most trusted. Research institutions were felt to require more information to give clarity and lead to greater trust. Commercial and for-profit organisations the least trusted.

As a new initiative, citizens wanted clear and unambiguous information about the Great North Care Record.

"It should be clear just what organisations can access. So you've got to get that clear because, if you don't get that clear, you're going to have a terrible job to get people to give consent to that."

"... You've got to build up trust with the public. If that trust hasn't got the right foundations, it isn't going to work."

They wanted to know:

- Who will be able to see my data? GP? Nurse? Receptionist? Researchers? Police?
- How will this be secured from hackers?
- What if I wish some of my medical data to be kept private? Can that be done?
- When will I be able to set my permissions and preferences?

Citizens also suggested that to make a properly informed choice there would need to be sufficient detail and tailoring to individual needs and circumstances.

"I think an understanding of what the Great North Care Record entails at the person's level rather than this generic 'we're all going to read this form, this is what it means'. That might not mean anything to that person if they don't grasp all those concepts or the jargon or the language. [Information] needs to be personalised to each individual so it truly is an informed choice."

"So, they know that you'll get chapter and verse since the moment I took my first breath. Or actually, you'll know all about my appendix and my cervix and my sore throat and my ear infection, but my mental health is in a box over there. And only that lady is going to access that because she's the only one working with me on that. I think it's about informed choice rather than a generically implied consent. Because lots of things seem to go down an implied consent route because people don't shout loud enough."

Healthwatch members expected access be restricted to authorised people only. And when asked, raised particular concerns about some organisations having access to their data, particular the police and commercial organisations. There was significant skepticism about the motivations of these organisations for using information about them. Most citizens were quite vocal in their opposition to commercial uses of information about them. One or two "played devil's advocate" to suggest ways in which commercial access might be beneficial to citizen or NHS, but would not sign up themselves. The strong opinions about non-NHS uses of the Great North Care Record underscores the need for transparency and ongoing engagement about these issues.

"I would not want to think that anybody, Tom, Dick and Harry can go into your records. To me it should be the GP, emergency services at the hospital if necessary."

"What would the police – researchers yes – but what would the police need your medical record for? They're not medically trained."

"What are [commercial companies] going to do with your information? I would imagine it wouldn't be for the best of interests. It's not going to directly benefit you, is it, by them knowing?"

“If it was for research purposes you can see the benefit because overall potentially if you’re in that situation it’s going to benefit you. Because research has found out X, Y and Z. But for commercial, what’s the benefit?”

To ensure that citizens feel comfortable and confident in Great North Care Record, transparency should be an ongoing duty. Given that many citizens had not heard of the Great North Care Record they discussed how there would need to be significant promotion and awareness raising, though they also recognised this would have cost implications. Communication and engagement with individuals and communities over time was seen as necessary to ensure transparency and create a recognisable and trusted initiative.



Questions for Connected Health Cities and the Great North Care Record from citizens

Participants had queries and concerns regarding the GNCR that could not always easily be addressed during the engagement sessions. In order to highlight the range and specificity of these questions, examples are highlighted below.

Records Management: Creation, distribution, use, maintenance and disposition of information

- Where is the information held?
- Who actually owns the information?
- Who updates the information on the record? The doctor’s secretary, or a data input specialist?
- Is this view-only or can healthcare professionals update it with immediate effect?
- How long will it take for any updates to the record to appear? A lot can happen health-wise even just in 24 hours.
- How long will the record be kept for?
- Could this record my organ donor preferences?
- What happens to the information when someone dies?

Process: How will the system work?

- How will you ensure that you capture everyone? Many people don’t use their GPs for years or might not see any advertisements.

- How will you ensure that this is accessible for all? Deaf? Blind? Colour blind? English as a second language? Learning difficulties? Carers and guardians?
- If this is currently only regional, what happens if I fall ill in Liverpool, London, or abroad?
- I live near the boundary of the GNCR region and have to choose between two hospitals that are covered by different system. How will my information be shared?
- I don't want to be called up every other day, how will researchers contact me?
- Who decides which researchers are allowed to contact me?

Content and Access: What is held, who can use it, how and when?

- How will I know what can be seen about me and my health by those accessing it?
- Will I have to give consent each time I interact with a healthcare professional?
- Will anyone with an NHS Smartcard be able to access my information?
- Will social care be kept separate from accessing this as NHS primary care do?
- Will there be an audit trail of who, when and why someone has accessed my information?
- If the government are funding this I am worried they will have access to my data. Is this the case?
- What will be in place to ensure this isn't abused by professionals accessing it?
- How can police use this information as first responders without it being misused or adding to their workload?
- How will access for research be kept separate from access for healthcare purposes?
- Will researchers have access to my medical record?

Patient Control: Powers retained by citizens

- How can I decide which parts of my medical information are shared?
- Can this let me see what the doctor has written about me and correct any mistakes?
- Will this give me the ability to edit my own medical record and input my perspective?
- Can I update my preferences at any time if my circumstances change or I become worried about the scheme?
- Could a GP overrule a patient and decide to share information?
- Can the record be made available to the immediate family to track genetic conditions?

Data Security

- If data used by research is anonymous, how can I be sure I am not identifiable?
- How will this be secured from hackers?
- Last year hackers were able to get into the NHS records, what will stop them from being able to shut down this record?

Legal Framework

- Will this fall in line with existing laws on power of attorney?
- Will a court order supersede the GNCR and allow access to those I wish to keep out?
- How can I be sure that this information won't lead to discriminatory care of those with sensitive issues?
- What happens for children or teenagers?

- What if things change in the future with government policy or NHS funding and the option to consent for this disappears?

Current Systems

- Hasn't this already been done? I was asked for my consent by my GP years ago.
- Has this been done elsewhere? If so, how did it work for them?
- Why is this not being done nationally altogether?
- Could I not just have all my information on a USB stick, a QR code or a microchip implanted under my skin and choose myself who I give access to?

Other questions

- I haven't heard of Connected Health Cities or the Great North Care Record, who are they?
- How will this all be promoted?
- What do you mean by research? What type of research? Statistics? Clinical trials? Focus groups?
- How do I know that the research being carried out is in my and the communities best interest?
- Will there be fine print that is hidden that means my data can be sold off to private companies?
- Is this information going to be sold off to insurance companies?

This list of questions is by no means an exhaustive list, but indicates several things. Firstly, that the public have a great deal of interest in how their health information is used. Secondly, people have experience of the NHS and wider society from which they draw upon to help inform their decision making. This means that to ensure that all those asked whether they would like to sign up, may have different understandings and so need some informational and education work in order to allow them to make an informed decision. Lastly, it indicates that there is further work to be done as the GNCR is tested and adapted in order to give additional insight into the public opinion.

Recommendations - citizen expectations

For the Great North Care Record to be successful it would need to operate in a manner that satisfied the expectations of citizens. These expectations include that:

- Citizens have a say about how information about them is shared.
- Citizens are able to update their preferences as and when suits them
- Citizens are able to access further information on Great North Care Record as and when required
- The Great North Care Record is a site for citizens to record their wishes (e.g. organ donation) and experiences (e.g. self-monitoring of diabetes)
- Accessibility is for all citizens
- Great North Care Record is promoted widely
- Governance of the Great North Care Record is by experts *and* citizens

- Privacy and security is understood as important and not static
- No companies or individuals make a profit from citizens health and social care data
- Those wishing to access data be held to account for their usage
- Vulnerable groups are protected from misuse or abuse of data to avoid discrimination or stigma
- As it progresses the Great North Care Record continues to meet the needs and expectations of citizens and that these will change as society, laws and policies change.

Citizens demonstrated a high regard for the NHS and a wish that the Great North Care Record be beneficial for those working in healthcare settings. The NHS is seen as a fundamental part of UK society and one which many citizens gave detailed accounts of how they or their family and friends had benefitted greatly from.

Citizens should be viewed as critical to the process, but also critical by nature. Their participation and willingness to appraise the Great North Care Record was detailed and nuanced. If asked, citizens will freely give their opinions and expectations. As the Great North Care Record will adapt and change over time to reflect societal and policy change, citizens' assessments should be continually sought.

Healthwatch's influence on the Great North Care Record

Even before the findings of this research were completed, the engagement sessions and focus groups were making important contributions to the development of the Great North Care Record. The Connected Health Cities team who attended the sessions came away understanding the very clear message from citizens that they expected to have a say in how their data was used, by who and for what purposes.

The development work of the Great North Care Record has put this expectation at the centre of its work. The social aspects of developing the Great North Care Record (how it affects citizens and front-line staff) are seen as being just as important as the technical aspects. The influence of engagement with Healthwatch is seen in Professor Joe McDonald's statement recently about the Great North Care Record. Joe was present at many of the Healthwatch events and has taken to heart the discussions of citizens. He said:

"The shared aim of our project is a culture of care where information about a citizen is available to professionals wherever and whenever that person is being treated, regardless of location or provider."

"We also want the public and professionals to understand the power of data and for citizens to make an active choice to gift their information to the project, so that it can be used, with consent, for planning and research as well as individual care and self-management."

"We want to build trust so that the whole community is working towards a shared goal. We will develop an eco-system of collaboration and innovation across health, social care and academia and we will do this whilst protecting and respecting the individual's choice about their data."

"We call this the Great North Care Record and we think it can change lives and transform care."

What's next?

Public engagement does not simply end with completion of the engagement workshops and focus groups. Whilst the discussions were able to give great insight into the how the principle of the Great North Care Record might be received but more is needed to ensure that the implementation of the Great North Care Record accords with citizen expectations.

Across the focus groups citizens struggled to describe what they would like a sign-up process and registering their consent to look like due to the lack of visual or interactive model to engage with. One of the important next steps is to work with citizens, including citizens to co-design a range of practical applications of the Great North Care Record, for example information sharing permission and preference setting tools and tools to enable citizens to become involved in research.

Recruitment through Healthwatch ensured that those who participated in the engagement sessions and focus groups were keen to share their opinion and engage. However, we know that many citizens are not involved with Healthwatch. This may be because they are not currently concerned about their health data. We also need to also capture the perspectives of these individuals and groups to ensure that the Great North Care Record is respectful of all North East and North Cumbria citizens.

Thank you Healthwatch!

We could not have done this without you! Thank you to all the local Healthwatch teams for their tireless work to arrange the engagement sessions, and particularly to Healthwatch Darlington for coordinating the work. Organising over 20 workshops with catering, room bookings, and getting the right people there was by no means a small task. The Healthwatch teams actively promoted every session, and all were well attended thanks to this support.

The biggest thank you goes to all the participants. They gave up their time to come along, listen to the presentation and provide valuable feedback. They gave their views and often shared personal experiences both positive and negative and have provided a wealth of information.

IF YOU WOULD LIKE TO DISCUSS THIS REPORT WITH THE AUTHORS OR
THE CONNECTED HEALTH CITIES TEAM, PLEASE CONTACT THEM DIRECTLY

Stephanie Mulrine

Newcastle University

Stephanie.mulrine@newcastle.ac.uk

Professor Madeleine Murtagh

Newcastle University

Madeleine.murtagh@newcastle.ac.uk

Dr Joel Minion

Newcastle University

Joel.minion@newcastle.ac.uk

Mark Walsh

Connected Health Cities North East and North Cumbria

Mark.walsh@connectedhealthcities.org