

GREAT NORTH CARE RECORD PUBLIC ENGAGEMENT REPORT

SUMMARY FINDINGS

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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.

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

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