

Connected Health Cities North East and North Cumbria response to Great North Care Record Public Engagement Report

We welcome the feedback we have received from the Great North Care Record Public Engagement Report.

It was commissioned by Connected Health Cities North East and North Cumbria to explore the attitudes of people in our region to sharing their medical information within the NHS and beyond. The Connected Health Cities team oversees the implementation of the Great North Care Record. The Great North Care Record is a way of sharing medical information between health and care professionals. We want to give the public the choice whether to share their information with researchers.

We are grateful to everyone who participated in this piece of research.

The insight that this report provides us, has given us a clear steer from the public which is being used to inform how we continue with the Great North Care Record.

The reports clearly articulate that people want to be in charge over how their information is or isn't shared. We want to be able to put the mechanisms in place so that people living in our region can choose whether they share their information, and with who.

What we are doing next

Based on the feedback we have received, we have developed a plan of action to take the development of the Great North Care Record forward.

Keep asking – have we got this right?

As a direct result of the outputs from the engagement sessions we have arranged the next round of workshops which will explore the development of a tool which captures peoples' data sharing preferences. This will look at the language being used, the questions we will ask and the process. The feedback from participants will be used to inform the next version of the preference tool.

This work is ongoing, and we will continue to share our work with Healthwatch groups to ensure that the services we design, meet their needs.

Further issues we want to explore with public focus groups include what supporting communications people need to make informed decisions about how they choose to share their information.

Raising our profile

Most people who attended the workshops had very little prior knowledge of the Great North Care Record. We will spend the next 12 months or so, using a number of techniques to spread the word about the programme and communicate its benefits. This includes regional press and social media.

We will go to regional events to showcase the Great North Care Record. Taking our team to where people already gather and to begin raising awareness about the programme. This will help us to gather feedback to ensure that we continue to meet the needs of citizens in the North East and North Cumbria.

Ensuring we get governance right: Public panel

We will set up a citizen panel who will perform several functions including approving requests to access data from researchers, be a 'critical friend' to assess and evaluate our communications and to be the 'voice of the patients and the public' in our governance structure.

We will answer your questions

The report raises several questions which have taken on board and will form the basis of our public communications campaign. These common questions and issues have helped us understand what is important to the participants of the research, so we can ensure we address these in our public messages.

We won't leave anyone behind

We know that not everyone wants to use online services. We will design the Great North Care Record so that no one is excluded from registering their information sharing preferences.

Engaging with the public is not a tick box exercise for the Great North Care Record. We need to design a service that meets their needs. We can only achieve this by continuously talking and listening to the public as the programme continues to develop.