



Yorkshire & Humber
Care Record

Use My Data LHCRE

Rebecca Nichells – Communications and Engagement Lead
Fiona Fylan – Director at Brainbox Research Ltd

Local Health and Care Record Exemplars – LHCRE

We are 1 of 5 LHCRE

Receiving £7.5m over 18 months national investment which is locally match funded

Building on existing local shared care records with new technologies to provide a long term

Leadership from health & social care professionals and citizens is key to success of a LHCRE



Yorkshire & Humber Care

Record

will improve a citizens' health, wellbeing and care by allowing clinical and care staff involved in a person's care access to up to date and relevant information.

- will ensure the best care is offered, improve safety through helping clinical and care staff work seamlessly together.
- will reduce unnecessary tests
- will reduce need to provide the same information again and again.

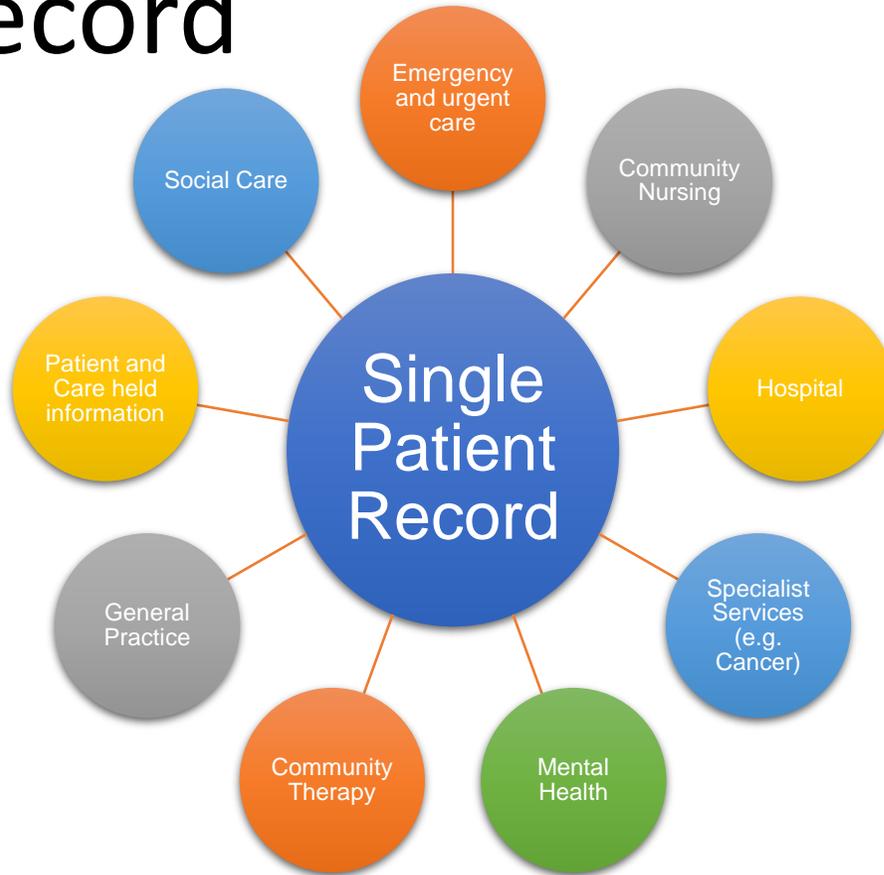
In the future:

- we will also be better plan how to deliver healthcare in a local area and promote wellbeing by actively supporting our citizens.
- we will have the ability to make people's health data available to them on their own devices.

Right information, Right person, Right time.



Yorkshire & Humber Care Record



- A Local Health Care Record provides a single view of the patients record from the 74 organisations and 725 GP practices in Yorkshire & Humber.
- Made up on the following;
 - Rapidly Improving Care
 - Systems of Systems
 - Data Ark
 - Person Held Record
- Concentrating on cancer pathway, emergency & urgent care



JoinedUp Yorkshire & Humber



What is Joined Up Yorkshire and Humber?

- An exchange of information – “conversation” – between organisations who want to share and use health and wellbeing data and individuals who live in the region.
- People discussing how their health and wellbeing data could and should be shared, the benefits of sharing, the concerns they have, and how data could be used to improve population health.
- Deliberative research using case studies to generate interest and enthusiasm in the conversation and to enable people to have an informed discussion about data sharing.
- Co-creation activities to develop a set of principles that form the basis of how data should be collected and shared.



Three approaches

1. Community-based conversations:

- Focus groups generate insight into how people imagine data sharing could work successfully and the “showstoppers” that lead to people opting out
- Showcards containing short case studies ask people if they would allow their data to be used in this way.

2. Media-based conversations:

Invite comments on willingness to share data, trust, and commitments that would reassure people about data sharing

- Online survey
- Twitter hashtag

3. Co-creation workshops:



Who is taking part?

- Many and diverse people across Yorkshire and Humber
 - Humber Coast and Vale
 - South Yorkshire and Bassetlaw
 - West Yorkshire and Harrogate
- We're talking to people rather than patient groups
- Three focus groups in each of the three areas
- Showcards in at least three public spaces in each of the three areas
- Online survey and twitter hashtag shared by CCG staff and partners
- Four co-creation workshops attended by the public and at least one NHS data expert

Let's give it a go.....

- Is this a good use of information?
- Would you be happy for your information to be used in this way?
- What are the benefits?
- What are the dangers?
- What should the rules be?

Sheila's Story

Sheila is 83 years old and lives alone. Her health is good but she is unsteady. Sheila received a visit from a charity worker, who explained that the local health and care record system had flagged her up as being frail and at risk of falling.

"I was surprised they knew I was worried about falling. The grab rails help me get up and down the stairs and in and out of the shower. I feel much more confident now"

The charity worker arranged for grab rails to be fitted in Sheila's home to reduce her risk of falling, and for physiotherapy appointments to strengthen her muscles. These changes should help Sheila to stay living independently in her home.





A little bit different.....

- Is this a good use of information?
- Would you be happy for your information to be used in this way?
- What are the benefits?
- What are the dangers?
- What should the rules be?

Mohammed's story

Mohammed is 42 years old and has recently been diagnosed with diabetes. During a review of people's health records, the NHS found that there were a lot of people with diabetes in Mohammed's area. They set up a local diabetes group to support people with diabetes. It provides information about diabetes, advice about exercise and healthy eating, blood tests and medical treatments.

"I probably wouldn't go to the diabetes group if it were in the hospital but because it's local I go every week"

The NHS used information from the healthcare records of everybody in the region to find out where new healthcare services are needed.



A different use.....

- Is this a good use of information?
- Would you be happy for your information to be used in this way?
- What are the benefits?
- What are the dangers?
- What should the rules be?

Saffi's story

NHS researchers looked at information from everybody's medical records to find out what makes it more likely that somebody will develop cancer. They searched the records to find people who are more at risk and shared this information with local health clinics. Saffi's records showed that she is at higher risk so her local health clinic wrote to her to invite her for screening.

"I was surprised to get a letter from the clinic. At the appointment they explained why I am more likely to get cancer and they gave me lifestyle advice and offered me a screening test"

Saffi can have a screening test every year. By using information from everybody's medical records, the NHS aims to detect cancer sooner and treat it more successfully.



Are you different?

For health professionals: Do you feel different thinking about this as a professional to when you are a patient or carer?

- Why is it different?
- Benefits (green), Dangers (red), Rules (orange)

For the public: Why might you be keener than others to share your data?

- What has made this difference?
- Benefits (green), Dangers (red), Rules (orange)





JoinedUp Yorkshire & Humber

