On behalf of:



NHS Leeds North Clinical Commissioning Group NHS Leeds South and East Clinical Commissioning Group NHS Leeds West Clinical Commissioning Group

Sharing Healthcare Records

An overview of healthcare data sharing in Leeds

Healthcare organisations across Leeds are working together to further improve health and social care across the city. Health and care professionals have a duty to share relevant information between themselves if they are involved in providing you with care. For example, in Leeds you have your own Leeds Care Record. This leaflet describes how else we share your information.

Following some independent research conducted in the city called Joined Up Leeds, it is clear that people want to understand the benefits of sharing data. In this leaflet we are providing information to help you understand these benefits. We also explain how you can opt out of sharing if you so wish.



Personalised Care

Personalised care management, known also as population health management, pro-active care management or risk stratification, is a process that helps your family doctor (GP) manage your health.

Your GP regularly uses information from their records and those held in hospital to ensure that you get the right personalised care and have access to the right services. This would include looking at any recent hospital treatments along with any existing health conditions that you might have. This may alert your doctor to the likelihood of a possible deterioration in your health. The clinical team at the surgery will use the information to help you get early care and treatment where it is needed.

The information will only be seen by qualified health workers involved in your long term care. NHS security systems will protect your health information and patient confidentiality at all times.

Right to opt out

Patients have a right to opt out of their information being used for personalised care management. For more information and/or to opt out please speak to your GP.



Leeds Care Record

What is the Leeds Care Record?

At the moment, every health and social care organisation holds a different set of records about you. Information in different records may be duplicated or incomplete.

Leeds Care Record is a confidential computer record that will over time include a range of health and social care information to help improve the care you receive directly.

If you live in Leeds, a Leeds
Care Record will be created for
you automatically. Records will
be held on a secure computer
system where access is strictly
controlled and will include
key health and social care
information about you. The
information is compiled from
medical records you may have,
like GP records, hospital records
and social care records, to form
one complete care record.

"Rolling out the Leeds Care Record is an exciting time for health and social care professionals across the city. As a GP it will be really helpful to see complete, up to date health records from across all organisations involved with patients in my care. It will allow for a more joined up approach with the ultimate aim of providing an even better service."

Dr Jason Broch

Clinical chair of NHS Leeds North CCG





What kind of information will be shared?

- List of diagnosed conditions

 so health or social care
 professionals have a complete
 record of your care
- Medications so everyone treating you knows what medicines you've been prescribed
- Allergies to make sure you aren't given medicine that might give you an adverse reaction
- Test results to speed up your treatment and care
- Referrals, clinic letters and discharge information – to make sure the people caring for you have all the information they need about other treatment you're having elsewhere
- Address and telephone number – your up to date contact details

Why do you need to share my information?

The Leeds Care Record will provide health and social care professionals directly involved in your care access to the most up to date information about you. Information is already shared by phone and paper records and the Leeds Care Record will allow this to happen more efficiently. It does this by sharing appropriate information from your medical and care records between health and social care services in Leeds.

Can I opt out?

Yes you can choose not to have a Leeds Care Record. It is your choice but sharing your medical and social care information through a Leeds Care Record will make it easier to provide the best quality care and support for you now and in the future.

Summary Care Records

The Summary Care Record aims to further improve the safety and quality of patient care. It is an electronic record that gives healthcare staff faster, easier access to essential information about you anywhere in the country, so that you can be given safe treatment during an emergency or when your GP surgery is closed.

For example, a person who lives in Leeds is on holiday in London. One evening, they're knocked unconscious in a car accident and taken to an accident and emergency (A&E) department. Without the Summary Care Record, it would be difficult for A&E staff to find out if there are any important factors to consider when treating the person, especially as their GP surgery is likely to be closed.



If healthcare staff cannot get key health information quickly, such as information on allergies, some patients may be at risk. A Summary Care Record is an electronic record, it does not contain detailed information about your medical history, but important health information, such as:

- if you're taking any prescription medication
- if you have any allergies
- if you've previously had a bad reaction to any medication

Access to your Summary Care Record is strictly controlled. Only healthcare staff who are directly involved in your care can see your records using a special smartcard and access number (like a chip and pin credit card). Staff will ask your permission every time they need to look at your record and if they can't for example because you're unconscious, then they may look at your record without asking you. However, they must note this on your record.

Do I have to have a Summary Care Record?

Yes. Your GP will have informed you at the time by letter which contained details about your choices and how to opt out of the scheme. If you opted out, you can re-join the scheme at any time.

More information about Summary Care Records including 'how to opt-out' is available at:

www.nhscarerecords.nhs.uk



Care.data

Care.data is a national initiative which aims to increase the range and detail of information collected across all NHS funded services

This programme of work is led by NHS England and the Health and Social Care Information Centre (HSCIC), the trusted national provider of high quality data and IT systems for health and social care. It will securely link all of this information together and make it available to those who plan NHS services, researchers, medical charities and businesses that support the NHS to make services better.



So why does the NHS in England need to collect and connect this data nationally?

At the moment, the NHS in England only has detailed information about the care that you, and patients across the country, receive in hospital. The NHS in England needs to see the full picture of the care you receive in GP practices, the community and other care settings so it can see where improvements can be made.

The NHS in England wants to collect information about the care you receive outside of hospitals, such as when you visit your GP. This is part of a new programme of work in the NHS called the 'care.data' programme.

Specific information needs to be collected from your GP record so it can be accurately linked to the information HSCIC collect about the hospital care you receive.

Your NHS number, date of birth, gender, postcode and ethnicity will be collected in order to connect the information held by your GP Practice to information from other parts of the NHS where you have had treatment. Once your information has been connected, the information that could identify you will be removed or reduced to make them less identifiable, for example, using age, instead of date of birth.

In addition the information from your GP about prescriptions, referrals and diagnoses will also be collected. GPs already record this information using a series of codes. Only this coded information will be collected.

Can I opt out?

Yes, you can opt out of your identifiable GP data being used for purposes beyond your direct care. This opt out will include both local and national uses of your GP information and one of these is the care.data programme. If you need more information you can call the dedicated patient information line on 0300 456 35318*, email datasharing@nhs.net or visit www.nhs.uk/datasharing

^{*}Calls to 0300 numbers will cost the same as calls to geographic numbers (starting 01 or 02), and may be included as part of any inclusive call minutes or discount schemes in the same way as geographic calls provided by your provider.

Patient Online

What is Patient Online?

With Patient Online you can access GP services from your computer, tablet or mobile phone, as well as through your local GP practice to:

- book GP appointments online
- view a summary of your health records online
- order repeat medications online

What is the benefit of Patient Online?

Online services will allow you to book and cancel appointments or request repeat prescriptions at a time that is convenient to you – day or night. It will help you to take greater control of your health and wellbeing by increasing online access to services.

Evidence shows that patients who are informed and involved in their own care have better health outcomes and are less likely to be admitted to hospital.

How can I get access to my GP Record?

Generally, you will need to fill in a short form and bring proof of your identity into your GP surgery so that they can provide you with logon details and with a password. Please speak to your practice who will advise you how to do this.



Key facts

Personalised care management/ risk stratification

- takes certain personal, confidential data from GP practice systems
- alerts your GP to any likelihood of a possible deterioration in your health
- the information will be used to get you early care and treatment if needed
- you can opt out if you wish to, please speak to your GP

For more information www.leedsnorthccg.nhs.uk /about-us/informatics

Leeds Care Record

- provides access to health and social care records to healthcare staff in Leeds so that they may offer you the best and safest integrated care possible
- your information will be stored securely
- helps care professionals directly involved in your care access to the most up to date information about you
- you can opt out if you wish to, please speak to your GP

For more information www.leedscarerecord.org

Continued





Summary Care Record

- has been used by healthcare professionals for a number of years
- records a summary of key health information
- these records enable healthcare professionals to treat you safely
- if you need urgent care anywhere in the country, staff will be able to access information critical to your care
- you can opt out if you wish to, please speak to your GP

For more information www.nhscarerecords.nhs.uk

Patient Online

- book GP appointments online
- view a summary of your health records online
- renew prescriptions online
- no requirement to opt out, you opt in

For more information www.england.nhs.uk/patient-online

Care.data

- aims to increase information collected across all NHS funded services to monitor and improve patient care
- will link GP and hospital data to provide a complete picture
- every appropriate step will be taken to protect your privacy
- if you don't want GP information that relates to you to be used for purposes beyond your direct care, you can opt out. Please speak to your GP practice

For more information please call the patient information line on **0300 456 3531*** or visit **www.nhs.uk/datasharing**

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