

A large, stylized graphic in shades of green. It features a vertical line that divides a large circle into two halves. The left half of the circle is a lighter shade of green, while the right half is a darker shade. The circle is set against a background of a light green, rounded rectangular shape that tapers to a point at the bottom, resembling a stylized letter 'D' or a shield.

## **Creating a safe environment for your personal medical information**

Your medical record is a life-long history of your consultations, illnesses, tests, prescriptions, and other treatments. This information is extremely important for your care. Your record is also a description of your relationship with health care staff, doctors, nurses and others, over the years. This relationship is based on mutual trust and confidence and we will do everything we can to protect that trust.

## What information do we share and why?

Your health information and its confidentiality are very important. It is personal and sometimes very sensitive and you should feel confident that we keep this information safe. Patient confidentiality underpins the whole structure of the NHS and remains the highest priority, and improvements are continually being made to build upon this.

The NHS is made up of teams of dedicated professionals. In order for you to have access to the wide range of expertise in these teams, your information may be shared with others involved in the treatment or investigation of your medical problem.

The NHS uses new technology to help deliver better patient care, which means health records can now be securely stored and shared electronically. Some NHS departments have developed an Electronic Health Record, which is a way of storing your medical information electronically. This will allow doctors and other health professionals to access your up to date information, whether it is from your GP practice or from the hospital. This will enable doctors to make the decisions about your treatment and care more effectively (this is explained in more detail on page 6).

This booklet has been produced to help reassure you that we are doing everything we can to protect your confidentiality. However, it is also important that you should know that some of the information contained in your health record might also be used for reasons other than your own healthcare. These reasons are vital to the running of the NHS and may include working with other agencies to provide care, medical research, teaching, and planning. Wherever possible, the shared information will be anonymous but if you have concerns about this, you can choose not to allow the information to be used.

This booklet will help explain who we may share the information with and under what circumstances. It also explains the need to share the information, and help you understand the possible problems that may arise if you refuse consent.

## Who has access?

Doctors, nurses and other health professionals would need access to your records, but this is on a strict need to know basis and would only include those involved in your treatment and care. If you are referred to hospital, your health/medical information will need to be transferred from your GP to the hospital and back again. Secretaries, receptionists, and other clerical staff will need limited access in order to carry out administrative tasks such as typing letters, booking appointments and contacting the necessary people. All NHS staff have a duty of confidence to ensure that your information is not disclosed inappropriately. All staff employed by the NHS also work to a Code of Conduct for handling personal information.

The NHS has adopted a standard for processing information. We use the acronym **HORUS**, which means that your information should be:

- H**eld securely and confidentially.
- O**btained fairly and efficiently.
- R**ecorded accurately and reliably.
- U**sed effectively and ethically.
- S**hared appropriately and lawfully.

## What else happens to the information?

Some of this information may also be shared for purposes other than your own health care. This leaflet has been prepared to help explain who we may share the information with, and under what circumstances. This information is anonymous wherever possible and is always under strict control. If you have any concerns regarding the sharing of this information you have the right to refuse to allow some or all of your information being used.

## Teaching and training of healthcare professionals

Training is very important to ensure that healthcare professionals have the skills and knowledge to provide the healthcare services of the future. »

» Wherever possible data will be anonymised, (no personal information will be included) but this is not possible for training carried out as part of clinic activities. You have the right to refuse to allow identifiable information to be used for teaching and training purposes and this will not affect your immediate care in any way. However, this may limit the development of future staff whose services you may require.

## **To help plan future social care**

In order to offer a complete care package your information may sometimes be shared with Social Services or other non-NHS agencies. This will only be with your consent and you have the right to refuse, but such refusal will limit the ability to arrange any ongoing care you may need, once your NHS care is completed. These other organisations will have their own Data Protection procedures and will be bound by a confidentiality agreement. They will also have their own policies in place to ensure confidentiality.

## **Funding local health services**

Limited information must be transferred to obtain payment for your health services from the appropriate funding body (e.g. NHS, private insurance). This information will be restricted to the minimum necessary to secure those payments.

## **Health research projects**

Some medical research involves patients directly. For example: taking part in a clinical trial (where a new treatment is being tried). If you are asked to participate in a trial, it will be fully explained, and your express consent required. If you do not consent, you will not be included in the trial, and this will not affect the standard of treatment offered to you. Other research may not involve you directly, but may rely upon access to your clinical information. Some databases, e.g. the Cancer Registry, are set up for national research in the fight against diseases such as cancer. Research work is guided by the Medical Research Council document 'Personal Information in Medical Research'. This represents the working standard for the use of patient information for research purposes.

It sets out when and how researchers need to obtain your specific consent to access your information. You have right to refuse access to your information for research. Researchers who have access to clinical information must protect confidentiality, and ensure that information stored for any research project is made anonymous, wherever this is possible. They must also present their research proposals before an Ethics Committee to check that their research is appropriate and worthwhile, and that data protection issues have been considered.

## **To help plan future health services**

We need to be able to plan ahead so that the care provided is of the highest standard. It is important that health services should regularly review the quality of care they provide. We need to investigate how we provide treatment and care and this means getting information from patient records or sending out questionnaires. Where treatment is provided across a number of hospitals, it is necessary to share data using centralised disease registers in order to assess the overall treatment delivered. Some clinical information is therefore routinely transferred into approved disease registers, but access to this information is strictly controlled. When analysing the results of audits, anonymised and summary information is used – not individual patient information.

## **Managing the data**

We need to process electronic information or move it between systems, extracting the data and modifying it for the next system. Data may also need to be transferred to a secure data archive on a different site. Occasionally, tests will need to be made on the data to check that it has been transferred correctly. This will only be done under carefully controlled conditions and all employees and contractors will be under strict contractual obligations to protect confidentiality.

## What else do we do with the information?

- The NHS must by law, notify the government of certain infectious diseases for the public health purposes, e.g. measles, mumps, meningitis, tuberculosis, *but not HIV/AIDS*.
- Births and deaths must also be notified.
- Limited information is shared with Primary Care Trusts to assist with the organisation of national public health programmes, e.g. breast screening, cervical smear tests, and childhood immunisation.
- A Court of Law can insist that medical information be disclosed to them. On very rare occasions, organisations may divulge information to the police, if it is felt to be in the patient's or public interest.
- Solicitors sometimes request medical reports but these requests must be accompanied by your signed consent. Third party information, e.g. about or provided by your wife, husband or partner in the record will be withheld unless the third party has given written consent.
- Life assurance companies frequently ask for medical reports on prospective clients. You have the right to request to see these reports before they are sent. All relevant information must be disclosed unless you have requested otherwise. In these circumstances, the insurance company must be informed that you have made this request.

## More about the Electronic Health Record (EHR)

The EHR is being developed as a way of storing your medical information electronically, which will enable doctors and other health professionals directly involved in your care to access up-to-date information about you.

## Why do we need an Electronic Health Record?

Under the historic system, GPs, hospitals and other health care professionals can only access information kept in their own records. If you have an accident and have to go to hospital, the healthcare

staff at the hospital cannot see any information contained in your GP records. You may not be in a position to remember information that may make a difference between prompt care and delayed care.

### **What information will the EHR contain?**

The EHR stores different types of information such as:

- Your name, your date of birth and where you live.
- Your GP's name and address.
- A list of what operations you may have had and any Out Patients appointments that are due.
- Details of any conditions you may have, along with any medications you may have been prescribed.
- You may be allergic to certain drugs, this too will be recorded.

### **Who will be using my Electronic Health Record?**

At the moment doctors, nurses and other healthcare staff involved in your care have access to your medical records, these same people will have access to your Electronic Health Record. This will make it easier to co-ordinate your care to ensure it exactly meets your needs.

### **How will this benefit me as a patient?**

- Your care will be improved by accessing information at various stages of your treatment.
- In an emergency doctors can access vital information about you.
- It will be easier and faster for the doctor to decide on the best treatment because they will have more information to hand.
- Long term care will be improved, especially in the area of cancer.
- Other special clinical data will improve care in diabetes, coronary heart care and may other diseases.

## The Future

As part of the government's modernisation of the NHS service, different communities throughout the country are trying out new ways of providing better healthcare. It will involve a continual development of a record of all visits to your GP and hospital; and other health services. If this scheme works it will be made available throughout the UK.

If you would like further information about the national EHR you can visit The National Care Records Service website at:

[www.nhscarerecords.nhs.uk](http://www.nhscarerecords.nhs.uk)

## Access to medical records

Requests for access to your personal information should be in writing to your GP, or the Health Records Office if applying to a hospital. The organisation must respond to your request within 40 days and a charge may be made for this. The NHS has a duty to keep medical records up to date and accurate. If you feel anything has been added to the record that is factually incorrect, you have the right to apply to have it amended or deleted in accordance with the guidance in the Act.

## Can any of my records be withheld?

Yes, any information contained in your records, which is likely to cause harm to your mental or physical state or that of other people may be withheld. However, a senior clinician will always make this decision. Also, any third party information (not about you) contained in your record would not be revealed without the consent of those involved.

For further information about accessing your personal information, see the leaflet '**Using the law to protect your information**' published by the Information Commissioner, telephone **08456 30 60 60** or visit their website at: [www.ico.gov.uk](http://www.ico.gov.uk)

This booklet has been produced by Liverpool NHS Primary Care Trust. This organisation has a Caldicott Guardian, who is responsible for agreeing and reviewing protocols for governing the disclosure of personal information across organisational boundaries.