



Keeping stuff private: why we collect information about you and how we keep it confidential

This information sheet explains about the data we collect about you and the promises we make about how we store it and use it. We keep records about your health, any treatment and care you receive and your family background. This helps us care for you when you come to Great Ormond Street Hospital (GOSH). It is vitally important that we have your up to date address, phone number and family doctor (GP) details - if these have changes, please tell us.

What sort of information do we collect?

We collect various types of data and information, all of which helps us to care for you better. It helps us if we know about your background and home life, your health up to now and what treatment you have had. This means we can plan your future treatment better. The sort of information we collect includes:

- Who you live with and other important people in your life
- Your religion if you have one, what language you speak at home and where you come from
- Details of any other healthcare professionals involved in caring for you
- Reports about your health, the care and treatment you have received
- Notes taken during appointments
- Photographs taken in hospital
- Results of tests and scans

Much of this information is stored on our computer system. Some information is kept on paper in your medical notes. Whether information about you is kept on a computer or on paper, only people who need to can access this information.

Who can see this information?

Generally, people directly involved in looking after you while you are at GOSH can access your computer record or medical notes. They might need to do this to:

- Plan your treatments
- Book appointments
- Check how well we are looking after you
- Look into any concerns or complaints

Remember, everyone working at GOSH has a duty to keep this information private.

Sometimes, we need to share your information to make sure that you are getting the best care possible. People we might share your information with include:

- Other teams at GOSH and other hospitals who may look after you after you
- Members of GOSH staff who check that the care we have given is as good as possible and look into concerns or complaints
- Members of GOSH staff who keep track of the money we spend

These people, even if they are not working at GOSH, also have a duty to keep this information private.

There are also occasions when we have to share information about you but we make it anonymous. This means that we remove your name, date of birth, address and anything else that could identify you. This anonymous data is used for various reasons including:

- Education and training
- Research projects
- Publications in medical journals or at conferences

Sometimes we may want to use your information for clinical education, training and research without making it anonymous. We will always ask permission before we use your information in this way. This includes using any pictures or scans from your medical records.

The law requires us to provide information in some serious circumstances, such as:

- Court cases
- Infectious disease reporting
- If a crime has been committed
- If you are at risk of serious harm or in danger

We will tell you if we are going to pass on information like this, except if doing so could put someone in danger.

Can I see this information?

In many cases, you will be able to look at this information just by asking the doctor in charge of your care. He or she will arrange for someone to explain what is written down if you find it hard to understand. The law also gives you the right to look at your information and when we think you are able to make decisions about your health, you will be allowed to say who can look at your information. There are some circumstances though, where the law can stop us letting you see your information. This is usually to protect information about other people. You can ask for a copy of your medical notes, but you will usually have to pay for this.

Can my parents see this information?

When you are old enough to make decisions about your health and treatment, you say whether your parents can look at your information. You could also stop them looking at certain parts of your medical notes if you want to keep some things private. If the doctor does not think you can make these decisions about your health, your parents will be able to look at your information without your permission. Usually, this is only if the doctor believes this is in your best interests.





What about letters from the hospital?

We routinely send your parents a copy of any letters we write to other healthcare professionals about your care. You can have your own copies sent to you as well if you like. All you have to do is tell us. As you grow older, we encourage you to have your own copies as part of your preparation to move to adult services. For more information about this, please see our *Transition: moving on to adult services* information sheet, available from ward staff or on our website.

Any questions?

If you have any questions, please visit the Pals Office, telephone them on 020 7829 7862 or email them at pals@gosh.nhs.uk.

If you would like to see the information we keep about you, please ring the Medical Records department on extension 5606

Will you give my parents information about me?

When you start to go to clinic appointments on your own, everything you tell us during the appointment remains private. We will only tell your parents if you give us permission, unless we are worried that you are at risk.

Final words

If you are unhappy about how we use your information or are concerned that something has not been kept private or is wrong, please talk to us. We will explain why we are using your information and correct anything that is wrong. We may also be able to limit who can see your information.

Notes

Compiled by the Clinical Nurse Specialist – Adolescent Medicine
in collaboration with the Child and Family Information Group

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