

PIAG

Patient Information Advisory Group

A patient and public information leaflet

YOUR HEALTH RECORDS:

Safeguarding confidential information -
the role of the Patient Information Advisory Group



OVERVIEW

Whenever you go to your GP practice or hospital clinic, people ask you questions and write things down or put them on the computer. NHS professionals cannot do their jobs without making a record of what you say, what treatments you are given and what services you get.

Health professionals are careful to keep information about you confidential. There are certain times when information about you is shared, such as when a doctor asks other professionals to help with your treatment, but anyone who is not involved in your care, normally, cannot see this information unless you give them permission or the information is anonymised (see glossary).

There are, however, special situations when people who are not involved in your care want to see your information but where it may be difficult or inappropriate to seek your permission and fully anonymised information is unsuitable for the purpose. In these cases, they can only see information about you that might identify you if they get special permission from the Patient Information Advisory Group (PIAG).

This leaflet explains why PIAG is needed, what it does, and how its decisions could affect the use of information about you. PIAG is only concerned with the use of information about patients, not the provision of information about treatment and care for patients.

INFORMATION ABOUT PATIENTS IN THE NHS

Sharing information between health professionals

Information about patients is collected every day in the NHS in many different places including GP surgeries, hospitals, community clinics and in people's own homes. The main reason for collecting this information is obvious: doctors, nurses and other health professionals need it to ensure that individual patients get the best treatment and care possible. Whenever you talk to a health professional about your treatment and care, they will assume that you agree (consent) to information about you being recorded and shared between the different health professionals involved in your care.

Sometimes clerical staff will have a supporting role, which gives them access to your health information e.g. typing up referral or discharge letters. Supporting administrative staff are obliged to keep patient information confidential through the terms of their employment contract. If you have concerns about what access administrative staff have to your confidential health information, you should discuss this with a healthcare professional treating you, e.g. your GP or practice nurse.

Using information to improve quality - clinical audit

There are many other uses for the information collected from patients in the NHS. When information from many different patients is put together, it is possible to identify ways of improving the services, treatment and care that they get. This is called 'clinical audit' and it is common practice within the NHS. Clinical audit does not need the names of patients but sometimes needs identifying information to be able to link together different records about the same patients. Because clinical audit aims to improve the care that patients are receiving, patients, in the past, have not been asked if they agree to this use of their information. Consent to treatment was assumed to cover these wider actions to improve the quality of their treatment.

There are different levels of clinical audit: local audits, which should help improve your care and treatment directly, and national or regional audits, which compare services across the country.

Information for local registers

Information from many patients may also: be combined on local lists (registers) to make it easier for the NHS to keep track of people. Registers for people who have life-long diseases, such as diabetes, enable NHS staff to make sure that their patients come back to see them regularly. Information on registers is often also used for other purposes such as to compare the numbers of people with a particular disease in different areas, and to look at treatment outcomes. As well as health professionals who look after you, others may have access to information held on a register e.g. PCT staff or staff from a screening service. There are safeguards about when and who can access information held on a register.

Again, in the past, patients have been assumed to consent to being on these registers when they consent to treatment. You should be told if you have been included on a register and be given the opportunity to opt out. For new registers being set up now, your consent should be sought.

Information for public health and planning services

There are many other ways in which information about patients is used within the NHS, for example to help plan and run health services or to map the diseases and conditions that are present in any local population. For these wider purposes, information about individual patients first should be stripped of all the information that might identify individuals. These identifiers include: name, address, the full date of birth, postcode, occupation, NHS number and hospital ID number. When information about patients is 'anonymised' in this way it can be used by anyone as it is no longer personal information and the privacy of individual patients is protected.

If any health professional who is not involved in patient care wants to see information about patients that can identify them, they must either ask for permission first from the patients affected, or have a legal basis for doing so. In general, information about patients can only be used in one of the following ways:

- for personal treatment and care
- for work that directly supports personal treatment and care
- for other purposes, if the information is stripped of patient identifiers
- for other purposes, if a patient consents or there is a legal basis.

RESEARCH INTO HEALTH AND ILLNESS

Clinical trials

A great deal of research is carried out in the NHS to try to find better ways of treating illness and improving health. For example, health professionals sometimes ask patients to join clinical trials in which new treatments are compared with existing treatments. If you agree to join a clinical trial, you agree to information about your personal experience being shared with the researchers who are running the trial. If information about your experience is published at the end of the trial, it is always anonymised first.

Looking at past records

Some health researchers want to look back at the past experience of patients to try to find out what made a difference to their health and illness. To do this, they usually have to look at patients' health records. These records can be difficult to anonymise, especially if it is important to link different records such as hospital and GP notes, so the researchers have to ask patients for their consent to look at information about them. Unfortunately, however, there are some situations where it is very difficult or even inappropriate to ask for consent. For example, if researchers want to look at information obtained from patients a long time ago, it may be very difficult to find the patients to ask for their consent. It might be inappropriate to seek consent if to do so could cause distress, for example for research into terminal illness where patients are in the end stages of illness when diagnosed. Sometimes it will be inappropriate where patients lack the capacity to give consent.

There are some situations where there is a legal basis for using information without a patient's consent e.g. where a court has ordered information to be released or for notifiable diseases.

Applying to PIAG for Section 60 support

Where there is no other legal basis for the use of the information that can identify patients then organisations can apply to PIAG for legal support under Section 60 of the Health and Social Care Act 2001. This support provides a lawful basis for information that may identify patients to be released to medical researchers, NHS bodies or other health bodies without first seeking patient consent. Applying organisations have to make a strong argument that their work is in the public interest, needs identifiers and that it would not be feasible or appropriate to get patient consent. PIAG has to decide whether these arguments are good enough.

THE PATIENT INFORMATION ADVISORY GROUP

PIAG is an independent public body. Its members include patients, members of the public, medical researchers, doctors and other healthcare professionals. All members have been appointed through the NHS Appointments Commission.

The overall role of PIAG is to give advice to the Government (the Secretary of State for Health) about the use of information about patients. Its main task is to decide whether researchers and NHS professionals should be given permission to see information about identified patients without first getting the consent of these patients.

To apply for this permission, researchers or others have to:

- **provide a lot of information about what they are trying to achieve**
- **explain why they cannot use anonymised information and why they cannot seek consent from patients**
- **show how they will keep the information secure and confidential during the research**
- **explain how they will either get consent in future or will move to using anonymised information**
- **demonstrate that they have had their plans approved by a Research Ethics Committee and whether they have consulted patient groups.**

The members of PIAG consider every application in detail. They have to consider how sensitive the information is and how patients might feel about their information being used in this way. They have to balance this against the possible benefits of the research to patients and the public in general.

The support given by PIAG is only temporary; applicants are expected to work towards either finding technical solutions to using anonymised information or seeking consent. Where research needs identifiable patient information for more than a year, the Advisory Group reviews their activities and considers whether Section 60 support is still necessary.

PIAG's decisions about applications are documented in the minutes of the meetings and approved applications are included on a register. Both of these are published on the PIAG website www.advisorybodies.doh.gov.uk/piag.

Some of PIAG's decisions

When PIAG rejects an application, it gives advice about how the research or activity could be done differently.

PIAG has agreed that local clinical audit, which helps to improve the quality of care directly, is to be regarded as part of care and treatment and consent for this use of information can continue to be implied as part of consent to treatment. For national and regional clinical audits, which do not have such a direct bearing on the quality of care patients receive, PIAG expects anonymised information to be used where possible and either consent or Section 60 support to be sought if identifiers are needed.

Disease registers are similar because they also support care and treatment, however, the information they contain are used for other purposes as well. PIAG has therefore agreed that, as a minimum, people need to be informed that their details will be included on a disease register and given the opportunity to opt out if they have concerns about how their information may be used.

WHAT THIS MEANS FOR YOU

The confidentiality of the information you give to a doctor, nurse or other health professional is protected by law. Sometimes information about you may be used more widely in the health service but all the details that identify you will be removed first.

You may also be asked if you are willing to let information that identifies you to be used for special purposes such as medical research. You can always refuse these requests - doing so will not affect your own personal treatment and care.

It is possible for information that identifies you to be used without your consent. This should only happen exceptionally. Researchers or other professionals can only do this with approval from PIAG or another legal basis.

PIAG decisions are about uses of information relating to groups of patients that fall into a particular category researchers want information about. If you, as an individual patient, object to your information being used for medical research and you make this clear to the health professionals treating you, this will be respected and your information will not be shared with the researchers even if they have Section 60 support.

The Data Protection Act requires the NHS to make reasonable efforts to inform you about how information about you may be used. Sometimes posters are put up in GP surgeries or leaflets left in waiting rooms in hospitals. Posters are not, by themselves, sufficient to meet the requirements of the Data Protection Act. The NHS is expected to do more to try to inform individual patients about how their information is used. Currently, this does

not appear to happen and many people may be unaware of how their information is used. If you want to know what information the NHS holds about you, you can ask. If you want to see the full record, you need to apply in writing and may have to pay a fee.

Glossary

Anonymised - this is the process of turning information that identifies you into anonymous information through the removal of identifiers.

Identifiers - information that either on its own, or in combination with other identifiers, can be used to identify individuals. Identifiers include: name, address, postcode, date of birth, ethnicity and occupation.

Consent - when you give your permission. This can be either explicit, when you are asked and you agree either verbally or in writing, or it can be implied by your actions such as you being given information about how your information is used and you not choosing to opt out.

Where to get more information

If you have concerns about how information about you is used, you should discuss this, in the first instance, with a health professional.

For information about the Patient Information Advisory Group, and the applications it has accepted, see the website www.advisorybodies.doh.gov.uk/piag

For further queries contact the PIAG secretariat at:
2nd Floor, Princes Exchange, Princes Square, Leeds LS1 4HY
or telephone: **0113 397 3095/3378**.

The Information Commissioner is an independent official appointed by the Crown to oversee the Data Protection Act 1998 and the Freedom of Information Act 2000. The Commissioner's role is to promote public access to official information and to protect your personal information. You can contact the Commissioner's office at: www.ico.gov.uk or telephone 01625 545 745.

To obtain further copies of this leaflet please visit
www.connectingforhealth.nhs.uk/publications
or call 08453 700760 quoting reference number 2236