

NHS England Publications Gateway Reference 00969

Frequently asked questions for patients

1. Why do I need to read the leaflet ‘Better information means better care’?

The leaflet contains important information about your health records. It explains that NHS organisations share information about the care that you receive with those who plan health and social care services, as well as with approved researchers and organisations outside the NHS, if this may benefit patient care.

It is important you know how information about your health is used, shared and protected and what choices you have.

2. Why is information collected?

By using information about the care you have received, those involved in providing health and care services can see how well different services are performing and where improvements need to be made.

Sharing information about the care you have received helps us understand the health needs of everyone and the quality of the treatment and care being provided. It also helps researchers by supporting studies that identify patterns in diseases, responses to treatments, and the effectiveness of different services.

3. What is the “secure environment” mentioned in the leaflet?

The secure environment is called the Health and Social Care Information Centre, which is a public body based in Leeds. The Health and Social Care Information Centre was set up in April 2013 as the central source of health and social care information in England.

The role of the Health and Social Care Information Centre is to ensure that high quality information is used appropriately to improve patient care. The organisation has legal powers to collect and analyse information from all providers of NHS care. It is committed and legally bound to the very highest standards of privacy, security and confidentiality to ensure that your confidential information is protected at all times. Access to information is strictly controlled. Further information about the Health and Social Care Information Centre is available at www.hscic.gov.uk/patientconf

4. What is changing?

For decades, the NHS has been using information from health records for purposes other than providing your direct care, for example to support research and to help plan new health services. However, we need to upgrade our information systems and collect information from more places where you may receive care. Doing so will make sure that we have joined-up information about all parts of the NHS, as well as public health and social care services.

5. Why are these changes needed?

The NHS has some of the best information systems in the world. Since the 1980s, we have been collecting information about every hospital admission, nationwide. This information is brought together at the Health and Social Care Information Centre, where it is anonymised (see question 7 below). The information has been invaluable for monitoring the quality of hospital care, for planning NHS services, and for conducting research into new treatments. However, the information collected is incomplete with areas such as prescribing and test results not currently included. Additionally, while we have this type of information already for some of the care provided outside hospitals, there are significant gaps. As a result, it is not currently possible for us to see a complete picture of the care that patients receive.

NHS England has therefore commissioned a programme of work on behalf of the NHS, public health and social care services to address these gaps. Known as the care.data programme, this initiative has been designed to ensure that there is more rounded information available to citizens, patients, clinicians, researchers and the people that plan health and care services. Our aim is to ensure that the best possible evidence is available to improve the quality of care for all.

6. When will these changes occur?

The first change is that information from GP practices will be brought in to the Health and Social Care Information Centre in spring 2014. This information will be joined to the hospital information that is already held by the Health and Social Care Information Centre. In the future, we will also collect information from different parts of the health and social care system to create a joined up picture of all the care delivered.

7. Will confidential information be shared?

The Health and Social Care Information Centre collects information from a range of places such as your GP practice, hospitals and community services. This information includes postcodes and dates of birth so that the information about an individual can be joined together accurately. However, there are very strict rules about what information the Health and Social Care Information Centre can release to the NHS and outside organisations. Information can be released in three ways:

- Anonymised information: this information does not identify any individuals, nor small numbers of patients with rare characteristics or diseases. Anonymous information may be published in public reports produced by the Health and Social Care Information Centre.
- Potentially identifiable information: this is information about individual patients but it does not include any identifiers (i.e. there are no personal details such as your date of birth and postcode included). We would never publish this type of information because there is a risk that you might be identified. For example, if you were the only person in an area who had a rare disease then someone may work out that it was you even though your identifiers were not included. As a result, there are strict controls about how we release potentially identifiable information. For example, we would only ever release this type of information to approved organisations for approved purposes, and there must be a legal contract in place with penalties for any misuse of the information.
- Identifiable information: information that identifies you can only be disclosed where you have given your explicit consent (such as where you have agreed to participate in a research study) or there is a legal basis for doing so (please see question 22).

8. What kinds of information sharing can I object to?

There are two types of information sharing you can object to:

- You can object to information containing data that identifies you from leaving your GP practice. This type of objection will prevent the identifiable information held in your GP record from being sent to the Health and Social Care Information Centre's secure environment. It will also prevent researchers who have gained legal approval (see question 22) from receiving your health information.
- Information from other places where you receive care, such as hospitals and community services, is collected nationally by the Health and Social Care Information Centre. The Health and Social Care Information Centre only releases this information in identifiable form where there is legal approval for doing so such as for medical research (please see question 22).

This legal approval is only granted where:

- It is in the interests of patients or the wider public to do so; and
- It is impractical to obtain each individual patient's consent; and
- It is not possible to use anonymised data.

If you object, this type of information will not leave the Health and Social Care Information Centre to researchers with approval. The only exceptions are very rare circumstances such as a civil emergency or a public health emergency.

9. Will my whole GP record be used?

No. Only the agreed amount of information required will be used. GP representatives and an independent advisory group have been involved in deciding which health, care and treatment information should be extracted. Your date of birth, postcode, NHS number, and gender (but not your name or full address) will be used to link your records in a secure environment at the Health and Social Care Information Centre but will then be removed (see question 3). Once this information has been linked, a new record will be created with a reference number that does not identify you. This new record will not contain any information that identifies you.

10. I can't get in to my GP practice to object. What should I do?

Please contact your GP practice by telephone or email to discuss with them what arrangement would work best. If you have a query or a question about the leaflet you received through your letterbox, you can call our patient information line on 0300 4563531.

11. How long have I got to decide if I want to object?

You can decide to object at any time. If you would like to object before any information is extracted from your GP practice then we recommend you do so within four weeks of receiving the leaflet through your letterbox. The first extraction of information is planned for spring 2014. You can change your mind at any time (please see question 12).

12. Can I change my mind?

Yes. You can change your mind at any time and as many times as you wish. If you object but then change your mind then you will need to inform a member of staff at your GP practice to ensure your preferences are kept up-to-date. Likewise, if you do not object now but you later decide you wish to object, then just inform a member of staff at your GP practice and ask them to record your wishes in your health record.

13. What should I do if I have concerns?

We have produced a leaflet called "Better information means better care", which provides information about how your information is stored and used. There is also information on the Health and Social Care Information Centre website about how we look after confidential information www.hscic.gov.uk/patientconf

If you still have questions or concerns, you can call the patient information line on 0300 456 3531 or talk to staff at your GP practice. If you want to object you should inform a member of staff at your GP practice (please see question 8).

14. I have opted out of the Summary Care Record. Do I still need to inform my GP practice if I have any concerns?

Yes, you should still inform a member of staff at your GP practice. There are important differences between allowing the NHS to use your information for planning and research and the Summary Care Record (SCR).

The SCR may be used by authorised health professionals to support your care. It would be wrong for us to assume that just because you have chosen not to have an SCR that this automatically means you also wish to stop the use of your information being used to improve health and care services. So you still need to inform a member of staff at your GP practice if you have concerns about sharing your information for improvements to services, planning and research.

15. Will information about me be safe and secure?

Yes. The Health and Social Care Information Centre maintains the highest levels of confidentiality both within the organisation itself and in the systems and services that we provide for the wider health and care system, in order to protect all information. We are continually testing, reviewing, and improving our security systems.

16. Can I stop information that does not identify me being used?

No. Information that does not identify you is neither personal nor private and the law says that it can therefore be used much more freely. Because this information does not identify you and because it can be so helpful to the NHS, public health and social care, it is important that we make the best possible use of it for the benefit of all.

17. Do I need to do anything if I am happy for my information to be used?

No. If you are happy for your information to be shared to help improve health services, then you do not need to do anything. Your information will continue to be used for that purpose and to benefit all patients.

18. I am a carer for someone who lacks capacity to decide whether to allow their information to be shared. Can I decide on their behalf?

It depends. If you have *Lasting Power of Attorney for health and welfare* then you can object on behalf of the patient who lacks capacity. If you are a carer or relative who does not hold a Lasting Power of Attorney then you can raise your specific concerns with the patient's GP. The GP will make a decision based on an assessment of the patient's best interests, taking your views into account.

19. I am a parent/guardian of a child. Can I make the decision on their behalf?

It depends. If you have parental responsibility and your child is not able to make an informed decision for themselves, then you can make a decision about information sharing on behalf of your child. If your child is able to understand and make an informed decision, then the decision must be theirs.

20. Will you sell data?

No. While the Health and Social Care Information Centre charges a fee to cover our costs, we do not make profits from providing data to other organisations, nor do we subsidise any applicants to receive it.

21. What research will be carried out on information that identifies me?

Examples of approved projects are:

- A national study of people who have had a heart attack, and
- A study of the time that people had to wait for treatment for cancer and the effect of these waiting times on survival.

Details of approved studies can be found at www.hra.nhs.uk/about-the-hra/our-committees/section-251/cag-advice-and-approval-decisions/

22. When does the Health and Social Care Information Centre allow researchers to access confidential information about me?

In most cases, researchers can carry out their studies using information that does not identify you. Occasionally, however, medical researchers need to use information that does identify you.

Only researchers who have obtained your permission or who have been granted legal approval are allowed to access confidential information that identifies individuals. Only the Secretary of State for Health or the Health Research Authority (HRA) can grant this legal approval and they do so following independent advice from the *Confidentiality Advisory Group (CAG)*.

CAG considers each application in great detail against the legal framework, and recommends whether approval should be provided together with any conditions. Applicants must demonstrate:

- 1) That the research is in the public interest and for the benefit of the health service;
- 2) That it is not possible to use information that does not identify you; and
- 3) It is not possible to ask your permission. There are a variety of reasons why it might not be possible to ask people; for example, where there are extremely large numbers of patients.

Access to the information is restricted to the specific information necessary for the research. All approvals must demonstrate compliance with the Data Protection Act 1998.

23. Will information that identifies me be used by commercial organisations?

Please see question 7 about the different ways in which the Health and Social Care Information Centre shares information.

Any organisation can make an application to the Health and Social Care Information Centre for identifiable or potentially-identifiable information and each application is considered individually.

An organisation making an application would only be allowed confidential information that identifies individuals if they have:

- Already obtained your permission (i.e. patient consent); or
- Have been granted legal approval by the Secretary of State for Health or the Health Research Authority (HRA) following independent advice from the Confidentiality Advisory Group (CAG) (please see question 22); or
- Where we are legally required to provide it for a public health emergency such as an epidemic.

So that we can ensure that confidential information about you remains protected, the organisation making an application must sign a data sharing contract and a data sharing agreement with the Health and Social Care Information Centre. This contract sets out the terms of how the information is shared, what it can and cannot be used for (its purpose), security requirements on how it is stored, and restrictions on onward sharing or publication.

For case studies and examples of how customers have used information from the Health and Social Care information Centre, please see www.hscic.gov.uk/dlescst

For clinical trials, pharmaceutical companies may work with your GP practice who will contact you first to ask if you are willing for a researcher to contact you about a particular trial for which you may be eligible. You will not be contacted by a pharmaceutical company or any other third party unless you have specifically agreed.

The Health and Social Care Information Centre will not share information about you with insurance companies or solicitors. If an insurance company or solicitor wanted information about you, they would need to approach your GP practice directly and you would need to give your explicit consent before any of your information could be shared with them. If you do not agree to their specific request for your information then it will not be shared with them.

Data will not be shared or used for marketing purposes.

24. Can I have a greater number of choices and allow information to be used for some but not other research projects?

No. Currently, you have the right to say yes or no to your information leaving your GP practice or being shared by the Health and Social Care Information Centre. Our systems do not let you say yes or no to your information being used for specific projects. However, if a researcher is working directly with your GP practice for their study then, unless they have approval (please see question 22), your GP will check with you first to see if you are happy for your information to be shared as part of the study.