

A large, decorative arc made of the same multi-colored lines as the logo, spanning across the middle of the page and framing the title text.

Information on adding administrative health records

Introduction

The National Health Service (NHS) maintains routine medical and other health-related records on all patients accessing the health services so they can provide health services to us when we need them. While we can learn about people's lives, well-being, experiences, and behaviour by asking direct questions, it can sometimes be easier to obtain some of this information from administrative records. Administrative health records may also help us to keep in touch with you and keep our records up to date.

We would like to ask for your permission to add information from administrative health records to the answers you have provided in the interview. This leaflet explains more about this.

Please take a moment to read it.

What information would be added?

The information to be added is collected for administrative purposes by the NHS and held within statistical health databases by the NHS Information Centre, the Departments of Health, the General Register Offices and the Office for National Statistics. Some of this information is linked across central UK NHS and registration bodies.

The information may include, for instance:

- Admissions or attendances at hospital (including dates of admission, discharge or attendance, diagnoses received, treatments and surgical procedures, waiting times).
- Records of specific conditions such as cancer or diabetes (including type of condition)
- Health registration details (including name of the Health Authority registered with, NHS numbers, and if a person who took part in the study were to have passed away, the date and cause of death).

Who will use it?

Like your survey responses, the additional information may be used by academic and social policy researchers for non-commercial statistical analysis. Any sensitive information about specific health conditions or treatments would only be made available to them under restricted access arrangements such as legally binding licences, which make sure that the information is used responsibly and safely. Names, addresses and NHS numbers are strictly confidential and are not available to those using the data for statistical analysis. No individual can be identified from research findings.

Your permission – what does it cover?

Any information can only be released with your permission. In order to access the information, we will provide some necessary personal details such as your name, date of birth and address to the NHS and government departments holding the information. These personal details will only be used to identify your information. Before any information you have authorised is sent back to us, your name and other details will be deleted by the NHS. None of your survey responses will be disclosed to the NHS or government departments for any other purpose.

Like the answers you have given us in the survey, the additional health information will be completely confidential in accordance with the Data Protection Act. Your current or future dealings with the NHS or any government department or agency will not be affected.

How long does your consent last?

We would like to add information relating to your present, past and future circumstances. We are not putting an expiry date to this consent as we do not know exactly when we will obtain and add the information. We will remind you every three years of the permissions you have given, and you are free to withdraw your consent at any time.

What about your children's information?

We would like to add information on your child(ren) from birth up to age 16. We need to seek parental consent to add information on your children aged under 16. We understand that some children would be able to make this decision on their own behalf. You should make the decision that represents your child's wishes and best interests. Please discuss this with your child as appropriate. You can withdraw your consent at any time. Once your child reaches the age of 16 we will ask your child directly for their permission.



What about data security?

Your name, address and other personally identifying information such as your NHS number will always be strictly confidential. Your health records and your survey answers will only be used for research and statistics. We are very security conscious and all of our systems are password protected and your personal details can only be accessed by a small number of authorised staff. Your information will be encrypted and sent via secure transfer systems. We are compliant with the standards of the ISO 27001 data security protocols and procedures. Your personal details will be secure at all times.

What if you change your mind?

If you wish to withdraw your permission at any point in the future, please write to **Freepost RRXX-KEKJ-JGKS, Understanding Society, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ** stating: "I < your name>, currently living at < your address and postcode> am a participant on *Understanding Society* and I wish to withdraw my permission for administrative health data and health registration details to be added to my survey data." Please sign and date your letter. You may choose to withdraw only part of the permissions you have given. To withdraw permissions you have given on behalf of your child(ren), you need to include their full name in your letter.



Thank-you

If you have any questions or concerns,
just call our **Freephone number 0800 252 853**
or write to **Freepost RRXX-KEKJ-JGKS,**
Understanding Society, University of Essex,
Wivenhoe Park, Colchester, CO4 3SQ

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