

Q&A – data protection (respondents)

This document answers some questions you may have on data processing and the NHS Patient Survey Programme. There are a number of hyperlinks which take you directly to pages containing more information.

Why have I been sent a questionnaire?

The questionnaire you have received is part of the NHS Patient Survey Programme. The programme includes a number of different surveys covering different areas of healthcare including adult inpatient services, urgent and emergency care, children and young people's inpatient and day-case services, community mental health services and maternity services.

They ask about your experiences of using services. If you decide to take part it will help to identify what was good about your care and what might need improving.

You can find out more about the NHS Patient Survey Programme on the [CQC website](#).

Who is running the survey?

The NHS Patient Survey Programme is managed by the Care Quality Commission (CQC). CQC regulate and inspect all health and social care providers across England to check the quality of care. You can find out more about CQC's work [on their website](#).

CQC work with the [Survey Coordination Centre](#) to develop and implement the surveys. However, neither CQC nor the Survey Coordination Centre receive your name, address or information from your medical records. This confidential information is held by the NHS trust(s) that provided your care.

Most trusts will use an '[approved contractor](#)' to administer the survey on their behalf. These are companies that have been through a competitive procurement process for which they had to demonstrate they have all the required skills to undertake a survey. This includes surveys skills as well as information governance and practices for ensuring data security. The approved contractors send out, receive, enter in data from the questionnaires and submit survey responses to the Survey Coordination Centre. They may also undertake other work as required such as reporting.

How did you get my name and address?

The NHS trust drew a sample of people who had recently used their services. This was used by the NHS trust, or their approved contractor, to send you the questionnaire and reminders.

This data is confidential and will only be used for the purposes of carrying out the survey. Your responses are not linked back to your name, address, or to other personal data that may identify you.

Each questionnaire has a unique reference number which is used by the trust, or the approved contractor to identify who has responded to the survey, and to send reminders to those who have not.

Once the mailing process for the surveys is complete, your name and address information will be securely deleted from records relating to the survey.

Are my responses confidential?

Yes. The survey includes a number of processes to ensure that responses are confidential. No one at the service you were seen at will know if you took part. Name and address information is never linked with survey responses.

All findings are reported by CQC at an aggregate level, either trust level, or England as a whole. To further help anonymity, answers are suppressed or redacted where fewer than 30 people responded (for the Children and Young People Survey, this is where fewer than 20 people responded).

Approved Contractors are only permitted to share an abridged version of the data set with trusts. Data must be anonymised to ensure that indirect identification by particular characteristics is not possible. This is achieved by:

- Deleting variables for ethnicity, sexual orientation and religion
- Deleting the variable for age and recoding this into age groups (16-35, 36-50, 51-65 and 66+)
- Any other additional information specific to a survey that can potentially be used to identify individual patients must be removed. For example, department type, CCG, and NHS site code.

Where a trust has carried out a survey themselves in-house (not used an approved contractor) only staff who have signed a data protection declaration are permitted access to the data. This means that staff have stated that they understand, and will comply with, the principles of the General Data Protection Regulation (GDPR). This document is also signed by the trust Caldicott Guardian. A [Caldicott Guardian](#) is usually a senior person within a trust who is responsible for protecting the confidentiality of people's health and care information and making sure it is used properly. When sharing survey results with staff, they must adhere to the same principles as described above.

What information do you receive about me?

Your name and address are only used to send you the questionnaire and are never linked to the survey responses. Only the trust, and if used, approved contractor, will hold your name and address information. This is not shared with CQC or the Survey Coordination Centre.

CQC, Survey Coordination Centre and the approved contractor also receive information on gender, age, ethnicity and [Clinical Commissioning Group](#) (CCG) of

people selected to take part in the survey. Other information we receive varies by survey:

- **Acute Inpatient:** Year of birth, date of admission, date of discharge, length of stay, [treatment function code](#), [ICD10 code](#), treatment centre admission, site code of admission, site code of discharge
- **Children and young people:** child/young person's month and year of birth; date of admission, date of discharge, length of stay, [main speciality](#) (of consultant), treatment function code, treatment centre admission, [route of admission](#), [site code](#) of admission, site code of discharge
- **Community mental health:** Year of birth, date of last contact, [Care Programme Approach](#) (CPA) status, [Care Cluster Code](#)
- **Maternity:** Mother's year of birth, date of delivery, place of delivery, NHS site code, [postcode sector](#)
- **Urgent and Emergency Care:** Year of birth, date and time of attendance, NHS Site code, [Department type \(Type 1 or Type 3\)](#)

This information helps us to ensure that the people who respond to the survey match the expected profile for each trust. We also use this information to undertake additional analysis to understand how peoples' experiences of care may differ.

In some cases, it may be possible to identify people from this data, but we would never attempt to do so. We recognise that this data is sensitive and private and we ensure that it is kept secure. We do this by having processes in place to ensure that responses are kept confidential (please see '*Are my responses confidential?*' above for more detail) and by ensuring that data is transferred and stored securely (please see '*How do you ensure that my data is held securely?*' below for more detail).

What is the legal basis for using my data?

Under the [General Data Protection Regulation](#) (GDPR), CQC and the individual trusts are responsible as a [data controllers](#) for the processing of [personal data](#) for the purposes of surveys in the NHS Patient Survey Programme.

CQC considers that the lawful basis for the processing data for the NHS Patient Survey Programme is Article 6(1) (e) of the GDPR:

'processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.'

The NHS Patient Survey Programme also includes some [special categories of personal data](#). This is data that under the GDPR is considered more sensitive and needs more protection, examples include, ethnicity and health information.

CQC considers that the lawful basis for the processing special categories of data is Article 9(2)(h):

'processing is necessary for the purposes of [...] the management of health or social care systems and services'

CQC and the Survey Coordination Centre obtain [section 251 approval](#) for each survey (of the NHS Act 2006 and Health Service (Control of Patient Information)

Regulations 2002) from the [Confidentiality Advisory Group](#) (CAG) at the [Health Research Agency](#) (HRA). This provides a legal basis for patient information to be used to carry out the survey, where this would otherwise be prohibited by the common law duty of confidentiality.

We also obtain [ethical approval](#) for each survey.

I do not want to take part, what should I do?

This survey is voluntary. If you do not want to take part, this will not affect your care and you do not need to give us a reason.

Please either return the blank questionnaire using the Freepost envelope or call the helpline number. This will ensure you don't receive any further reminders for the survey.

Doing this will remove you from the current survey only. If you would like to opt out of other types of research or surveys you will need to contact the NHS Trust who sent you the survey directly. Usually the Patient Advice and Liaison Service (PALS) will be able to advise you.

Does the National Data Guardian Opt Out apply to the survey?

No. The [national data opt-out](#) does not currently apply to the surveys running under the NHS Patient Survey Programme.

Should you wish to opt out please see the above question.

Who do you share data with?

We share survey data with other organisations to help them with their work. This does not include names and addresses so it is not possible to directly identify you.

[NHS England](#) will use the results to understand patients' experiences of NHS services and to drive improvements to them. You can find out more about this [here](#).

[The Department of Health and Social Care](#) and NHS England may use the results to generate aggregate indicators at local, regional and national level. These indicators form part of the range of the [Outcome Frameworks](#) and other publications. The NHS Outcomes Framework is a set of indicators developed by the Department of Health and Social Care to monitor the health outcomes of adults and children in England. This includes indicators on peoples' experience of care. The data will also be shared with [NHS Digital](#) or other organisations, working on behalf of Department of Health and Social Care or NHS England for the purpose of generating these indicators.

We also send a heavily abridged version of the survey dataset to the [UK Data Archive](#) so data can be used by other researchers. This dataset is heavily anonymised to ensure that no respondents are identifiable through the data. This involves a number of variables being deleted and others being recoded (for example, age is grouped into age bands, ethnicity is deleted).

What happens to my answers?

Your answers are put together with everyone else's who takes part. .

This information is then analysed to help understand peoples' experience at trust level, and for England as a whole. The results are published on the [CQC website](#).

Results are used by a number of different organisations for the purposes of helping to improve NHS healthcare in England.

- CQC will use survey results in the regulation, monitoring and inspection of NHS trusts in England. Survey data will be used in CQC's Insight system, which provides inspectors with an assessment of risk in areas of care within an NHS trust that need to be followed up. The survey data will also form a key source of evidence to support the judgements and ratings published for trusts.
- Trusts, and service commissioners, are expected to take action to improve services based on the results
- We also share data with NHS England and the Department of Health and Social Care as described in the question above.

How do you ensure that my data is held securely?

CQC take data security very seriously and have a number of policies, procedures and processes in place to help ensure information is protected.

All data is collected and handled securely in line with relevant legislation including the General Data Protection Act 2018 and the [NHS Code of Practice on Confidentiality](#) (2003) .

These precautions include appropriate physical security of our offices, controlled access to computer systems, use of secure, encrypted internet connections and use of restricted files accessible to authorised staff only.

CQC have implemented the following roles with responsibilities for Information Governance:

- The Caldicott Guardian ensures that CQC handles information about people who use services in an ethical and lawful way.
- The Senior Information Risk Owner (SIRO) ensures that risks relating to information are identified and properly managed
- The Data Protection Officer (DPO) monitors and advises on compliance with data protection law

All staff are required to undertake annual information governance training.

Data security is embedded in the contracts of organisations with which we work to implement the NHS Patient Survey Programme.

The Survey Coordination Centre and Approved Contractors have been through a competitive procurement process as part of which they provided information about their processes for ensuring the confidentiality and security of personal information.

They are compliant with the [Information Governance Toolkit](#) which enables organisations to demonstrate that the way they hold and process information meets Information Governance policies and standards.

Detailed instructions are provided both for trusts and contractors on how to undertake the surveys. This includes guidelines on the use and security of the data which are available on the [NHS surveys website](#).

When information is no longer required it is destroyed. Once the mailing process for the survey is complete, name and address information is destroyed. Paper copies of the questionnaire are destroyed once data checks and analysis are complete.

How do I contact CQC?

If you have any further questions regarding the survey programme, or would like any further information, please contact the Survey Team at CQC directly by emailing: patient.survey@cqc.org.uk

If you have any concerns about your care, or the care of others, or any other feedback, please contact [CQC enquiries](#).