

CONFIDENTIALITY POLICY

CQC collects information about patients' experiences of care through the National Patient Experience Survey Programme. This programme provides useful intelligence to CQC about the quality of care and helps providers improve services locally.

This statement provides details of how CQC ensures the confidentiality of the data that are collected as part of that programme. We do our best to ensure that the official statistics we publish do not reveal the identity of any individuals or organisations, or any private information about them. Private information that we collect as part of producing official statistics is confidential and we use it for statistical purposes only and it is managed, stored and deleted appropriately. By private information we mean information that could be used to identify a respondent to a survey that is not already in the public domain and would cause them damage, harm or distress if the information were made public.

Approval from the Confidentiality Advisory Group

Each survey is sent to a selected sample of patients that meet published eligibility criteria specific to each survey. To do this it is necessary to collect basic details about patients, including their names and addresses, in order to send a survey to the right people. These data are collected without prior consent to ensure that sample of people is not biased by the consent process.

Where patients do not want their details to be selected for a survey they are able to let us know and details of how to do this are advertised at each participating trust.

The [Confidentiality Advisory Group](#) (CAG) provides independent expert advice to the [Health Research Authority](#) (HRA) and the Secretary of State for Health on whether applications to access patient information without consent should or should not be approved.

For every survey we undertake, CQC applies to the CAG for approval. This approval allows CQC, on behalf of all participating trusts to set aside the common law duty of confidentiality in the undertaking of the surveys in line with section 60 of the Health and Social Care Act 2001 as re-enacted by Section 251 of the NHS Act 2006. This allows trusts, including those who use an approved contractor, to send a questionnaire to patients without their prior consent. Further details of Section 251 can be found on the [HRA's website](#).

In considering whether to approve any application, the CAG considers CQC's survey guidance, methods and tools. This ensures that we take all necessary precautions to protect patients' information.

CQC does not undertake a national survey without this approval and the approval is published alongside the results on the website:

www.nhssurveys.org

For further details see the following link for information about the CAG and Section 251 of the NHS Act 2006:

www.hra.nhs.uk/about-the-hra/our-committees/section-251/

How we protect confidentiality within the National Patient Experience Survey Programme

Collecting samples of people to survey

All samples are collected and checked in line with the process approved by the CAG.

This process ensures that only the trust where the patient was treated, or its approved contractor if they are using one, has access to the names and addresses of patients that are needed to post a questionnaire. This information is not shared with CQC or its Co-ordination Centre and the collection of the sample is undertaken using clear guidance published by the Co-ordination Centre on www.nhssurveys.org.

The file used for mailing questionnaires and the file that will be used to contain responses to the survey are encrypted and filed separately so that the data contained in each file are not combined at any time.

In order to make sure that samples are robust and represent all eligible patients, CQC's Co-ordination Centre does receive some information about the sampled patients. This includes details such as the age, gender and ethnic group of patients and date and time of attendances. As stated above, this does not include the names or addresses of any patients.

Before any details of the sample are sent, we require that each trust's Caldicott Guardian¹ and Survey Lead(s) sign a declaration stating that they are compliant with the Data Protection Act 1998 and that the Trust has followed the guidance published by CQC's Co-ordination Centre on data protection and confidentiality.

Once the survey is complete, and the results published, the names and addresses of sampled patients are deleted by the trust or its approved contractor. CQC holds the right to periodically review that this has been completed.

Informing people how we protect confidentiality

We inform patients who have been selected in the sample for each participating trust how we will protect confidentiality. Details of how we do this

¹ A Caldicott Guardian is a senior person responsible for protecting the confidentiality of patient and service-user information and enabling appropriate information-sharing.

are included in the letters patients receive alongside the questionnaires and in published FAQs that support each survey. These documents tell patients how we apply data protection and ensure that personal data are kept confidential.

Aggregating data and setting reporting thresholds

Once the field work stage is complete, the encrypted file that contains the responses to the survey is sent to CQC's Co-ordination Centre in order for the analysis to be undertaken. This file contains respondent level data but does not contain the names and addresses held separately by the trust or its approved contractor within the mailing file. The Co-ordination Centre is under contractual obligation to CQC to ensure that survey data and reports are held securely to ensure confidentiality. Both the Co-ordination Centre and the Approved Contractors are required to have satisfactory [Information Governance Toolkit](#) scores. The Toolkit is an online system which allows NHS organisations and partners to assess themselves against Department of Health Information Governance policies and standards.

The respondent level data are aggregated during analysis. This aggregation process means that individual responses to a survey are not reported in either the individual benchmark reports for each participating trust or the national tables and summaries.

CQC also sets a threshold on the number of responses required for each question. This threshold is consistent across all of CQC's surveys and is applied based on advice from CQC's Statistics Team on appropriate levels to ensure confidentiality and statistical robustness. Where the number of responses is below that threshold CQC does not benchmark that data or publicly report on the results for that question. This threshold is approved by the CAG to ensure that confidentiality is maintained where we have low numbers of responses.

Encrypted analysed data are shared with CQC to generate the national tables and reports. These files are stored securely and only accessible by members of CQC's Survey Team who are responsible for the production of the national results.

The final reports based on aggregated data are shared with NHS England. These extracts consist only of the data for those questions needed to generate the [Overall Patient Experience Scores](#). Encrypted data is shared on the basis that it is treated confidentially prior to its publication.

Post publication

CQC occasionally receives requests from researchers for information at the level of individual respondents in order to undertake specific analysis.

Such requests are dealt with on a case by case basis, with reference to the [Information Commissioner's Office code](#) on the anonymisation of data. In each case, we consider what information has been requested and whether:

- any new information would be released in the public domain, and
- whether any aggregation of variables would enable an individual to match new datasets with existing data to reconstitute the original datafile (as per the motivated intruder test outlined in the Information Commissioner's Office guidance).

If either outcome would result from the release of the data then further discussions would be held with the researcher to ensure that neither possibility occurs. We also consider CQC or its Co-ordination Centre is able to undertake this analysis without sharing the respondent level information. Where this is not feasible, we would also consider whether a cut down version of the dataset could be provided that would not enable an individual to later match the pattern of responses to those on the UK Data Archive to reconstruct the original dataset.

CQC would also advise whether approval should be sought by the researcher under section 251². All correspondence relating to such requests are logged with advice sought from the CQC's Information Governance team as appropriate.

Advice throughout this process, and final agreement on release, is sought from the Information Governance team unless a precedent has previously been set.

² See 'Approval from the Confidentiality Advisory Group' section above for further details on Section 251 including links to the HRA's website.