Q&A – data protection (trusts and contractors)

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.

Most of the information you require is found in the <u>relevant survey handbook</u>, and in the <u>generic instruction manuals</u>, see particularly the survey instructions for data protection and confidentiality.

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 <u>Survey Coordination Centre</u> to develop and implement the surveys.

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.

What are the benefits of using an approved contractor?

It is very strongly recommended that you employ the services of an approved contractor to undertake the survey on your behalf as they have the specialist skills, knowledge and resources to undertake a survey.

Planning, undertaking and reporting surveys is an administratively complex task requiring dedicated resources for several months, and it is easy to underestimate the skills, money, resources and staff time required. Previous surveys within the programme have shown that more mistakes are made by trusts undertaking the survey in-house.

A list of contractors approved to undertake surveys for the patient survey programme may be found on the NHS Surveys Website. Trusts may commission one of these contractors without further tendering the work. You must use one of these and may not use any other company.

The services provided by an approved contractor will vary depending on what you commission them for, but at a minimum they will include sample checking, mailing and data entry, and may also include report writing, advice on areas to target for quality improvement and different types of analyses etc. Before committing to a contractor, you are strongly advised to check exactly what is covered within the cost quoted, and to consider exactly what you might need.

What are the governance requirements between approved contractors and trusts?

The General Data Protection Regulation (GDPR) places further obligations on data controllers (trusts) to ensure contracts with processors (approved contractors) comply with the GDPR. Processors must be able to provide controllers with 'sufficient guarantees' that the requirements of the GDPR will be met and the rights of data subjects protected.

The Survey Coordination Centre, and the Approved Contractors have all 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 complaint with the <u>Information Governance Toolkit</u> which enables organisations to demonstrate that the way they hold and process information meets Information Governance policies and standards.

A 'model contract' is provided for use between trusts and approved contractors which have been updated to be GDPR complaint which can be found in the <u>relevant survey folder</u>. You are advised to share these with your own legal departments and seek legal advice as required to ensure that they meet all legal requirements.

If you do not use these, you are advised to ensure your own contracts are GDPR compliant.

How can data security be ensured?

The General Data Protection Regulation requires personal data to be processed in a manner that ensures its security and must not be processed or accessed unlawfully.

You must take steps to ensure that personal data shared with an approved contractor is done in a secure way. To ensure this trusts should comply with the guidelines on the use and security of the data which are available in the 'Data protection and confidentiality' instruction manual on the NHS surveys website.

Once information is no longer required it should be destroyed. This is described in the survey instructions as found in the <u>relevant survey folder</u>. Sample information used for the survey, which includes people's names and address, must be destroyed once the mailing process is complete. This must be done by both the trust and the approved contractor. The paper questionnaires should be destroyed once the data analysis and reporting is complete.

What is the legal basis for the surveys?

Under the <u>General Data Protection Regulation</u> (GDPR), CQC is responsible as a <u>data controller</u> for the processing of <u>personal data</u> by the Survey Coordination Centre for the purposes of surveys in the NHS Patient Survey Programme.

Each trust has its own responsibility as data controller for the patient/service user data that they process, or is processed on their behalf by an approved contractor, for the purpose of conducting surveys.

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 <u>special categories of personal data</u>. This is data that under the GDPR is considered more sensitive and needs more protection, examples include, ethnicity and sexual orientation.

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'.

Personal data processed by the trust and approved contractor (acting under the trust's responsibility) takes place under the professional duty of confidentiality. Personal data processed by (or on behalf of) CQC is subject to the protection from disclosure provided by section 76 of the Health and Social Care Act 2008.

CQC and the Survey Coordination Centre obtain <u>section 251 approval</u> for each survey (of the NHS Act 2006 and Health Service (Control of Patient Information) Regulations 2002) from the <u>Confidentiality Advisory Group</u> (CAG) at the <u>Health Research Agency</u> (HRA). This sets aside the common law duty of confidentiality, to allow patient/service user information to be used to carry out the survey as detailed in the survey instruction manual. If you collect any information outside of this, such as increasing sample size, or additional sample variables, this is not covered by the approval and you are advised to consult your trust's Caldicott Guardian for advice on whether you should seek additional approval.

We also obtain ethical approval for each survey.

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

No. The <u>national data opt-out</u> does not currently apply to the surveys running under the NHS Patient Survey Programme in 2018/19 and you must not exclude people on this basis.

The programme will continue to use the separate opt-out mechanisms as described in the relevant <u>survey instructions</u>. For further information please see the <u>National</u> <u>Data opt-out operational guidance policy</u>.

Why is patient/service user consent not required?

As detailed above, we have identified a lawful basis for the survey under the General Data Protection Regulation, and receive Section 251 approval for each survey.

We therefore do not consider that consent is required to include patients/service users in the survey. However, as has always been the case, patients/service users must be given the opportunity to opt-out.

How should we inform people about the survey?

The General Data Protection Regulation strengthens peoples' rights, and this includes the right to be informed. It is important that trusts meet their legal obligations to notify people of how their personal data will be used. You must take steps to inform people using your services that their contact information may be used for the purpose of carrying out surveys in the NHS Patient Survey Programme, that, where relevant, this will include passing those data to an approved contractor, and that they have the right to opt-out of this.

One way to do this is to ensure that the privacy notice for your trust includes the NHS Patient Survey Programme.

This can also be achieved by following the relevant <u>survey instructions</u>. You should display posters ahead of the fieldwork for each survey which are provided by the Survey Coordination Centre and may be found in the <u>relevant survey folder</u>. This will enable people to opt out of the survey before it starts. Any objection to taking part must be respected. The <u>generic instruction manual</u> on publicising the survey also includes information and ideas for promoting the survey such as through local and social media.

Who do you share data with?

We share data with other organisations to help them with their work. This does not include name and address information. It does include information submitted on the sample file, and demographic information completed by the respondent in the 'about you' section of the questionnaire. Information on gender, date of birth, ethnicity and Clinical Commissioning Group (CCG) is obtained in the sample file for each survey. Other information varies by survey, please see the <u>sampling instructions for the relevant survey</u> for details.

NHS England will use the results to understand patients'/service users' 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 <u>UK Data Archive</u> 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).

How do I know when there will be a survey?

Please see the forward planner available on the <u>CQC website</u>.

CQC write to all trust CEO's and survey leads to notify them ahead of each survey.

Where can I find more information?

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

The websites below are some further sources of further information. However, you should also consult your Caldicott Guardian and / or Information Governance Department for advice if required.

- The individual survey instructions providing detailed descriptions of the processes for undertaking surveys are available at: www.nhssurveys.org
- Further information on the General Data Protection Regulation can be found on the Information Commissioners Office website: https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr
- Further information on the Section 251 and the Confidentiality Advisory Group can be found at: www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/