

Health & Care Experience Survey 2017

Privacy Notice

The 2017 Health & Care Experience Survey asks about your experiences of your GP practice; Out of Hours healthcare; care, support and help with everyday living; and caring responsibilities.

The survey is run in partnership by the Scottish Government and Information Services Division¹ (ISD, part of NHS National Services Scotland²). Both the Scottish Government and ISD are involved in the planning and organisation of the survey, as well as analysing and reporting on the survey responses. An approved patient survey contractor, Quality Health, has been appointed to administer the survey fieldwork on their behalf.

This privacy notice explains how your personal data collected through the survey is used.

More information about how NHS National Services uses patient data is available online in this leaflet: <https://nhsnss.org/media/1054/how-we-use-personal-information-apr-16.pdf>.

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¹ http://genss.nss.scot.nhs.uk/portal/page?_pageid=515,1&_dad=portal&_schema=PORTAL

² <https://nhsnss.org/>

Why this survey is needed

This survey is a means for Scottish Ministers to monitor how well they are fulfilling their duty, under Section 1 of the NHS (S) Act 1978, to continue to promote a comprehensive and integrated health service that is designed to secure:

1. improvement in the physical and mental health of the people of Scotland, and
2. the prevention, diagnosis and treatment of illness, and for that purpose to provide or secure the effective provision of services in accordance with the 1978 Act.

The information gathered through this survey contributes to:

- a national and local picture of the quality of these health and care services from the perspective of those using them;
- the ability to benchmark the quality of these health and care services over time and against others;
- our understanding of areas of best practice and areas for improvement.

How we got your details

ISD picked names and addresses at random from all those who are registered with a GP Practice in Scotland and are aged 17 and over.

The Scottish Government submitted an application to the Public Benefit and Privacy Panel³ (PBPP) seeking approval to use the NHS database of patients registered with a GP practice to identify a survey sample and approach individuals. A copy of the approval letter from the PBPP is available at www.gov.scot/GPSurvey.

Who has access to information that identifies you

Only specifically authorised personnel within ISD and Quality Health have access to the name and address of the individuals who are sent the survey.

Quality Health has only been given your name and address for the purpose of mailing you the survey and they are required to destroy this information once the survey mail out has been completed. They have signed a confidentiality agreement which stipulates this. They do not have access to any other information about you.

ISD also securely shares some identifiable data with staff at the NHS Central Register (NHS CR), who run checks to reduce the risk of sending a survey pack to someone who has died.

Individual survey responses are tracked and stored using a unique survey ID number. Only specifically authorised NHS analysts at ISD will retain a record of the identity of those who took part in the survey and this will be stored separately from the survey responses.

³ <http://www.informationgovernance.scot.nhs.uk/pbpphsc/>

No access to your identity, including name and address, will be given to GP Practices, NHS Boards, the Scottish Government or any other organisation or individual. The health and care professionals involved in your treatment or care will not know whether or not you took part in the survey.

All of the organisations involved in handling your name and address for the purpose of this survey adhere to the Information Sharing Toolkit Scotland⁴. This brings together all of the statutory requirements, standards and best practice that apply to the handling of personal information, including requirements set out in Data Protection legislation. All transfers of personal or identifiable data are carried out securely.

How your survey responses are used

Access to your individual responses, held against the unique survey ID number, is very tightly controlled and is restricted to named individuals within ISD, the Scottish Government and Quality Health.

Before any analysis takes place, ISD analysts will use your postcode to identify whereabouts in Scotland you live. They will then link your survey responses to the area of Scotland you live in (so that we can compare responses from people living in different areas). ISD analysts will also link your survey responses to the GP practice you are registered with (so that we can produce reports about each GP practice) and to your age group and sex (so that we can make sure that responses are representative of the population). The survey responses will then be analysed by specifically authorised ISD and Scottish Government analysts who will produce national and local reports on the results. No individuals will be identifiable in the responses dataset or in the reported results. The reports will be published in April 2018 and will be made available at www.gov.scot/GPSurvey.

The arrangements for protecting the confidentiality and privacy of individual information within the analysis are made in accordance with the Scottish Government Statistician Group corporate policy statement on confidentiality⁵ and ISD protocols⁶.

The survey dataset, containing individual level survey responses **but not including anything that identifies individuals**, will sometimes be shared with a third party, such as a charity or academic researcher, for the purpose of undertaking additional analysis. **Before any data are shared**, the third party must seek the necessary approvals from the relevant NHS research, ethics and governance groups and sign a Data Processing Agreement or Data Sharing Agreement with the Scottish Government and ISD.

⁴ www.informationgovernance.scot.nhs.uk/wp-content/uploads/2016/03/IS-Toolkit-v1April2016.pdf

⁵ www.gov.scot/Topics/Statistics/About/CPSconfidentiality

⁶ <http://www.isdscotland.org/About-ISD/confidentiality/>

Sometimes survey responses are linked to other data sources in order to undertake other analyses. **Linkage of survey responses can only be done by specifically authorised NHS analysts working at ISD and is only done once the necessary approvals have been granted** by the relevant NHS research, ethics and governance groups. All personnel involved with this additional analysis are governed by the Information Sharing Toolkit ⁴.

How your additional comments are used

Additional comments made by respondents on the survey form are shared with Health and Care services for service improvement. **All comments are anonymised before they are shared or analysed** to ensure your identity is protected.

This means that all personal details; all references to staff / patient / ward / unit names; and any other information which might allow an individual to be identified, such as specific diagnoses / tests / procedures **will be removed**.

For example, if an individual had written “Doctor Smith was very nice”, this would be anonymised to “Doctor [name removed] was very nice”. Similarly, if an individual had written “I work as a male midwife on Trinity Ward”, this would be anonymised to “I work as a [job title removed] on Ward [name removed]”.

Anonymised additional comments from the survey will sometimes be shared with a third party, such as a charity or academic researcher, for the purpose of undertaking additional analysis. **They will only be shared once appropriate approvals and governance are in place**.

How long your information is stored for

All survey responses are stored securely and confidentially under the terms of Data Protection legislation.

Quality Health are required to destroy names and addresses once the survey mail out is complete. They will destroy hard copies of returned surveys once scanned copies are available and stored securely.

The survey dataset, containing individual level survey responses **but not including anything that identifies individuals**, will be stored by Quality Health for a period of 5 years and by the Scottish Government and ISD indefinitely. This is to allow additional analysis to be carried out as required, for example time trends or more detailed analysis of particular aspects of the survey responses. This retention will be reviewed regularly to ensure that it is still appropriate to hold the data.

A file containing personal identifiers and the respondents’ unique survey ID numbers will be stored by ISD indefinitely. This file will be stored separately from the individual level survey responses. This file is retained to allow future data linkage with other data. This linkage would only be done where the necessary approvals have been granted by the relevant NHS research, ethics and governance groups.

Your rights

Taking part in the survey is voluntary. Completing the survey gives you an opportunity to provide feedback on your experience of health and care services in your local area. You don't have to answer every question if you don't want to and you will be asked to skip questions that don't apply.

None of the health or social care professionals involved in your care will know whether or not you have responded.

Data Protection legislation gives rights to individuals in respect of the personal data that organisations hold about them. These include the right to:

- access a copy of the information an organisation holds about them;
- object to processing that is likely to cause or is causing damage or distress;
- prevent processing for direct marketing;
- object to decisions being taken by automated means;
- have inaccurate personal data rectified, blocked, erased or destroyed in certain circumstances; and
- claim compensation for damages caused by a breach of the Act.

NHS Scotland produces a leaflet 'Confidentiality – It's your right' which provides information on how to 'opt out' of your data being available for use in improving public health and NHS services. A copy of this leaflet is available online at www.nhsinform.scot/care-support-and-rights/health-rights/confidentiality/confidentiality-when-using-the-nhs.

The Information Commissioners Office provides more information on your rights under Data Protection legislation at <https://ico.org.uk/for-organisations/guide-to-data-protection/principle-6-rights/>.

If you are concerned about our information rights practices you should contact us directly. However, if you have engaged with us and are still dissatisfied, you have the right to lodge a complaint with the Information Commissioners Office. For more information see <https://ico.org.uk/concerns/>.

How to contact us

Please contact us if you have any concerns about our privacy policy or information we hold about you. You can contact us:

- by emailing us at: patientexperience@gov.scot;
- or by writing to us at: Care Experience Team, Basement Rear, St Andrew's House, Regent Road, Edinburgh, EH1 3DG.

More information about the survey is available at www.gov.scot/GPSurvey.