

Scottish Cancer Patient Experience Survey

Privacy Notice

The 2018 Scottish Cancer Patient Experience Survey asks about your experiences of your cancer care journey, from thinking that something might be wrong to the support you received after your diagnosis and treatment.

The survey is jointly funded by the Scottish Government (SG) and Macmillan Cancer Support¹. It is run in partnership by the SG and Information Services Division² (ISD, part of NHS National Services Scotland³). The SG, Macmillan 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 Health⁴, has been appointed to administer the survey fieldwork on their behalf.

This privacy notice explains how your personal data is used in relation to the Scottish Cancer Patient Experience Survey. In particular, it provides details on how we got your name and address and how your survey responses will be used.

More information about how NHS National Services uses patient data is available online in this leaflet: nhs.uk/leaflets/your-data-is-used-to-improve-your-care.

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¹ <https://www.macmillan.org.uk/>

² <http://www.isdscotland.org/>

³ <https://nhs.uk/>

⁴ <https://www.quality-health.co.uk/>

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

How we got your name and address

ISD selected names and addresses for all adults (16 and over) who had cancer related hospital activity between 1st January and 30th September 2017; and had an entry on the Scottish Cancer Registry⁵ between 1st July 2016 and 31st March 2017.

The SG submitted an application to the Public Benefit and Privacy Panel⁶ (PBPP) seeking approval to use NHS data to identify a survey sample and approach individuals. A copy of the approval letter from the PBPP is available at www.gov.scot/CancerSurvey.

Who has access to information that identifies you

Only specifically authorised personnel within ISD and Quality Health have access to the names and addresses 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 fieldwork 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 (NHSCR), 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, they **will not** be linked to your name and address. 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.

⁵ <http://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry/>

⁶ <http://www.informationgovernance.scot.nhs.uk/pbpphsc/>

No access to your identity, including name and address, will be given to individual hospitals, NHS Boards, the SG, Macmillan 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 Scotland⁷. 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 SG, Macmillan and Quality Health.

Before any analysis takes place, ISD analysts will use your postcode to identify whereabouts in Scotland you live (or lived when you were receiving cancer treatment). 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 then create the survey dataset by linking your unique survey ID number and your survey responses (but **not** name or address) to:

- your age group and sex so that we can make sure that responses are representative of the population;
- the hospital you were diagnosed in and hospital you were treated in so we can produce hospital level reports where possible; and
- your tumour type; the stage / grade of your cancer at diagnosis; when and how your cancer was diagnosed; when you had your first treatment; and what types of treatment you have received so we can analyse responses by these factors.

The survey dataset will be analysed by specifically authorised ISD and SG analysts who will **publish a national report and local level results in Spring 2019**. The survey results will be available at www.gov.scot/CancerSurvey. The SG will also share the survey dataset with specifically authorised Macmillan analysts so they can carry out further analysis to help identify areas for improvement. No individuals will be identifiable in the survey dataset or in any published results.

The arrangements for protecting the confidentiality and privacy of individual information within the analysis are made in accordance with the SG Statistician Group corporate policy statement on confidentiality⁸ and ISD protocols⁹.

⁷ www.informationgovernance.scot.nhs.uk/wp-content/uploads/2016/03/IS-Toolkit-v1April2016.pdf

⁸ www.gov.scot/Topics/Statistics/About/CPSconfidentiality

⁹ <http://www.isdscotland.org/About-ISD/confidentiality/>

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 SG and ISD.

Sometimes survey responses are linked to other data sources, such as other health information, in order to undertake additional 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 ⁷.

How your additional comments are used

Additional comments made by respondents on the survey form are shared with Macmillan and relevant 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 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 fieldwork 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 SG, ISD and Macmillan 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 cancer care experience. None of the health and care professionals involved in your care will know whether or not you have responded.

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. If you do not wish to be contacted about this survey again, please call the survey helpline for free (the helpline number is provided on your survey letter) and request that you are not sent a reminder letter.

NHS Scotland produced 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-and-data-protection/confidentiality-when-using-the-nhs.

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/>.

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

- to be informed;
- of access;
- to rectification;
- to erasure;
- to restrict processing; and
- to object.

The Information Commissioners Office provides more information on your rights under Data Protection legislation at ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/.

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/CancerSurvey.