

Maternity Care Survey 2018

Privacy Notice

The 2018 Maternity Care Survey asks about your recent NHS maternity care experience. It covers the maternity care journey from antenatal care through to care at home after the birth.

If you've received a letter asking you to participate in this survey, you'll find the online questionnaire [here](#).

The survey is run by the Scottish Government (SG) with support from National Records of Scotland (NRS)¹. The SG are involved in the planning and organisation of the survey, as well as analysing and reporting on the survey responses. NRS will select the maternity cohort using the Statutory Register of Births and provide names and addresses for these women. An approved patient survey contractor, Quality Health has been appointed to administer the survey fieldwork on our behalf.

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

A copy of the NRS Data Protection Policy is available at www.nrscotland.gov.uk/files//record-keeping/legislation/nrs-data-protection-policy.pdf

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¹ <https://www.nrscotland.gov.uk/about-us>

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 maternity care services from the perspective of those using them;
- the ability to benchmark the quality of maternity 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

NRS picked names and addresses at random from all the births registered on the Statutory Register of Births in February and March 2018 in Scotland where the mother is aged 17 or over.

NRS carries out the functions of the office of the Registrar General for Births, Deaths and Marriages for Scotland. Section 56 of the Local Electoral Administration and Registration Services (Scotland) Act 2006 allows the Registrar General to provide information in the Register of Births to public bodies. Section 33 of the Data Protection Act 1998 also allows records containing the personal data of identifiable living individuals to be used for statistical research purposes provided that:

- the data are not processed to support measures or decisions with respect to particular individuals; and
- the data are not processed in such a way that substantial damage or distress is, or is likely to be, caused to any data subject.

The SG submitted an application to the Public Benefit and Privacy Panel² (PBPP) seeking their approval that the use of the Statutory Register of Births to identify a survey sample and approach individuals was appropriate and proportionate. A copy of the approval letter from the PBPP is available at www.gov.scot/MaternitySurvey.

Who has access to information that identifies you

Only specifically authorised personnel within NRS 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 do not have access to any other

² <http://www.informationgovernance.scot.nhs.uk/pbpphsc/>

information about you. NRS will also run checks on each morning survey packs are mailed to reduce the risk of sending a survey pack to someone who has died or where a baby 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 NRS analysts 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.

No access to your identity, including name and address, will be given to individual hospitals, NHS Boards, the SG or any other organisation or individual, other than the contractor. 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 Scotland³. 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 responses, held against the unique survey ID number, is very tightly controlled and is restricted to named individuals within the SG and Quality Health.

NRS analysts will link your unique survey ID to:

- the area of Scotland you live in, based on your postcode, so that we can compare responses from people living in different areas;
- your occupation code so we can compare results from different socio-economic groups;
- an estimate (in weeks) of time since birth when you respond with a completed questionnaire; and
- the hospital you gave birth in so we can produce hospital level reports.

This information will be shared with the SG who will link them to your survey responses for analysis of the survey results.

The survey responses will be analysed by specifically authorised SG 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 December 2018 and will be made available at www.gov.scot/MaternitySurvey.

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 confidentiality⁴.

³ www.informationgovernance.scot.nhs.uk/wp-content/uploads/2016/03/IS-Toolkit-v1April2016.pdf

⁴ www.gov.scot/Topics/Statistics/About/CPSconfidentiality

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 research, ethics and governance groups and sign a Data Processing Agreement or Data Sharing Agreement with the SG.

Sometimes survey responses are linked to other data sources, such as other health information, in order to undertake other analyses. **Linkage of survey responses can only be done by specifically authorised NRS analysts in a secure area and is only done once the necessary approvals have been granted** by the relevant research, ethics and governance groups. All personnel involved with additional analysis are governed by the Information Sharing Toolkit ³.

How your additional comments are used

Additional comments made by respondents on the survey form are shared with 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 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 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. This is all specified in their contract with the SG.

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 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 NRS 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 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.

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/.

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/MaternitySurvey.