



PRIVACY NOTICE

The Supporting MumS (SMS) study

Queen's University Belfast, Bradford Teaching Hospitals NHS Foundation Trust, Cardiff University, the University of Stirling, and the London School of Hygiene & Tropical Medicine ("we", "us" and "our") are committed to protecting your personal data.

The notice is addressed to individuals who are taking part in the research study entitled 'The Supporting MumS (SMS) study' ("you" and "your").

This Privacy Notice tells you why we need to collect personal information about you, what we will do with it, and how we will look after it. It also tells you about your legal rights in relation to your Personal Data.

If you have any questions about this privacy notice, please contact us. Contact details are provided below.

WHO WE ARE

1. We are a group of expert researchers from the organisations listed above. The study is led by Queen's University Belfast and is funded by National Institute of Health Research and the Public Health Agency Northern Ireland.
2. All our research is underpinned by policies and procedures that ensure we comply with regulations and legislation that govern the conduct of research. This includes data protection legislation: the UK General Data Protection Regulation (GDPR) and the Data Protection Act 2018 (DPA). In the case of health and social care research, which should serve the public interest, where we have to demonstrate that our research serves the interests of society as a whole.

HOW YOUR PERSONAL DATA IS COLLECTED

3. **Information you provide:** When you consent to take part in the SMS study we will ask for information about you, such as your name, address, NHS number, date of birth, telephone number, email address and date of birth of your youngest child. This is known as your "Personal Data". We may also ask you for some special categories of information (for example information about your physical and mental health). This is known as your "Sensitive Personal Data" and has additional protections.
4. **Data from other sources:** We will also collect information about you from other sources and this also forms part of "Personal Data" and "Sensitive Personal Data". This includes information from:

- the system we are using to send and receive text messages for the study, for example we will automatically collect the replies you send to the text messages. This system is owned and operated by the London School of Hygiene & Tropical Medicine.
- routine health-related data (if you have consented to this option) such as NHS records, GP and dental records, maternity and health visiting records and disease registers. To obtain your routine data from these systems, we will share some personally-identifiable details such as name, date of birth, address and NHS number to each of these organisations and they will send us your data back. This will all be done using secure data transfer systems that have been set up carefully to keep your information safe and complies with regulations and legislation governing the conduct of research.

HOW WE USE YOUR PERSONAL DATA

5. We use your Personal Data and Sensitive Personal Data in the following ways:
 - to contact you to invite you to take part in the study and to discuss research-related queries. If you do not consent to take part in the study, your personal data, such as contact details (e.g. name, address, phone number), will be confidentially destroyed and will not be retained by us.
 - after consent to take part is provided, personal data is used to contact you to arrange and conduct study visits, to request information or to send you relevant study documents or equipment and to inform you about any relevant study developments.
 - access to, and sharing of, special category and sensitive personal data is controlled very carefully. Sensitive personal data is collected and pseudonymised – this means each person who takes part in this study will be given a unique study number and this unique study number is used on all the study paperwork and in study databases. Only authorised members of the SMS research team will be able to link your study number to your name, contact details and NHS number.
6. In order to protect your rights and freedoms when using your personal information for research and to process special category information we have special safeguards in place to protect your information, and all information is kept in line with our policies and regulatory requirements.
7. In addition to the above safeguards, data protection legislation requires us to meet the following standards when we conduct research with your personal information:
 - the research will not cause damage or distress to someone (e.g., physical harm, financial loss or psychological pain).
 - the research is not carried out in order to do or decide something in relation to an individual person, unless the processing is for medical research approved by a research ethics committee.
 - the Data Controller has technical and organisational safeguards in place (e.g. appropriate staff training and security measures).
 - if processing a special category of data, this must be subject to a further public interest test to make sure this particularly sensitive information is required to meet the research objectives.

LEGAL BASIS FOR COLLECTING AND USING YOUR PERSONAL DATA

8. We will only use your Personal Data if we have valid reasons for doing so. These reasons are known as our “legal basis for processing”.
9. In the context of research, the lawful basis upon which we will process your personal information is usually where “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” (Article 6 of GDPR).
10. We also collect and use more sensitive personal information (Special Category data) where “the processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes... which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject”. (Article 9 of GDPR).

WHO WE SHARE YOUR DATA WITH

11. In line with our Data Protection Policy and Procedures we can share your information, including Personal Data and Sensitive Personal Data, with the following parties for the following research purposes:
 - London School of Hygiene and Tropical Medicine (LSHTM) text message system – to allow you to receive and reply to the text messages (the LSHTM is a study collaborator)
 - Designated research personnel for the purposes of achieving the research outcomes
 - The Northern Ireland Clinical Trials Unit (NICTU) for the purposes of entering your completed questionnaires onto a study database (NICTU is a study collaborator)
 - Qualtrics research software supplier for the purposes of the online completion of the study questionnaires (privacy notice can be viewed here - <https://www.qualtrics.com/support/survey-platform/getting-started/data-protection-privacy/>).
 - Transcription services for the purpose of transcribing recorded interviews (if consent provided for this optional element)
 - Organisations in-charge of the collection and administration of routine data for the purposes of achieving the research outcomes (if consent provided for this optional element)
12. In all cases, information shared will be on a need to know basis, not excessive and with all appropriate safeguards in place to ensure the security of your information.
13. When we use third parties (known as data processors) to carry out a task on our behalf, such as a transcription service as indicated above, we have contractual terms, policies and procedures to ensure confidentiality is respected.

DATA PROCESSING OUTSIDE EUROPE

14. We will not transfer your Personal Data and Sensitive Personal Data outside of the United Kingdom and European Economic Area.

HOW LONG YOUR INFORMATION WILL BE KEPT?

15. Information where you can be identified will be kept for a minimum amount of time and in accordance with research objectives. Researchers will de-identify information, i.e. anonymise or pseudonymise, as soon as possible as described in point 5.
16. We will keep your Personal Data and Sensitive Personal Data for up to 10 years from when the research has been completed to allow for full and final publication of the research results. If you have provided consent (this is optional), we will retain your record of consent and personal data (name, telephone number, email address, address) for the purpose of conducting longer-term follow-up for the SMS study or to inform you about future studies related to health and lifestyle that we may be conducting. If you have consented, we will retain your NHS number for data linkage purposes. You can decline to receive communications at any stage. We will only keep your information if we need it for one of the reasons described above.
17. We place great importance on the security of the Personal Data that we hold, including the use of physical, technological and organisational measures to ensure your information is protected from unauthorised access and against unlawful processing, accidental loss, alteration, disclosure, destruction and damage.

YOUR RIGHTS

18. The DPA provides you with a number of legal rights in relation to your Personal Data, including the right:
 - to request access to your Personal Data;
 - to request correction of your Personal Data that is wrong or incomplete;
 - to request erasure or the restriction of processing of your Personal Data;
 - to request the transfer of your Personal Data in a structured; commonly used machine-readable format;
 - not to be subject to automated decision making; and
 - to withdraw your consent.
19. If you wish to exercise any of the rights set out above, or require further information about any of the rights, please contact us.
20. There may also be times where we cannot stop using your Personal Data when you ask us to, but we will tell you about this if you make a request.

CONTACTING US

21. If you have any questions or comments about this privacy notice, please contact the SMS team:

Dr Dunla Gallagher
SMS Trial Manager
Centre for Public Health
Institute Clinical Science A
School of Medicine, Dentistry & Biomedical Sciences
Queen's University Belfast
d.gallagher@qub.ac.uk

Professor Michelle McKinley
SMS Chief Investigator
Centre for Public Health
Institute Clinical Science A
School of Medicine, Dentistry & Biomedical Sciences
Queen's University Belfast
m.mckinley@qub.ac.uk

Alternatively, you can contact:
Data Protection Officer
Information Compliance Unit
Lanyon South
Queen's University Belfast
University Road
BT7 1NN
Info.compliance@qub.ac.uk

COMPLAINTS

22. You have the right to complain about how we treat your Personal Data and Sensitive Personal Data to the Information Commissioner's Office (ICO). The ICO can be contacted at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

CHANGES TO THIS NOTICE

23. We may update this Privacy Notice from time to time. We will notify you of the changes where we are required by law to do so.