

NICOLA PRIVACY NOTICE

DATA PRIVACY IN NICOLA – INTRODUCTION

Queen's University Belfast is committed to protecting your personal data. This privacy notice is addressed to participants taking part in the research study entitled 'The Northern Ireland Cohort for the Longitudinal Study of Ageing (abbreviated to NICOLA).

This Privacy Notice tells you:

- i) why we need to collect personal information about you,
- ii) what we do with the information you share with us and
- iii) how we will look after it. It also tells you about your legal rights in relation to your "Personal Data".

It applies to information we collect by the following means:

- Phone, email or text
- Completed survey questionnaires
- Completed health assessments
- Requests to update your contact details
- Return completed questionnaires, consent forms, withdrawal forms, reply slips or other written information
- biological samples, for example blood and urine
- data from routine official records (for example NHS or other health records)

It also applies to the way we handle process and store your information in:

- Sending mail and emails
- Storing questionnaires, consent forms and withdrawal forms
- Updating new address details or making changes to your other personal data
- Providing research data for use in scientific research

If you have any questions about this Privacy Notice, please contact us. Our contact details are provided at the end of this document.

OUR COMMITMENT TO YOU

- Taking part in NICOLA is voluntary and you are free to withdraw at any time without giving a reason. If you choose to withdraw, you will be asked to complete a study withdrawal form so we have a written record of this.
- **You will not be identified** from the research.
- Every research project is checked to make sure it meets the highest scientific and ethical standard.
- We will maintain strict measures to protect your confidentiality. Identifiable personal data such as name, address, date of birth, health and care number is removed from all research data and is stored separately.
- Interview data collected on electronic devices during home interviews is encrypted, with data stored in a format which would be meaningless to any unauthorised person who looked at it. Laptops used during Health Assessments are encrypted and password protected.
- We do not conduct research for commercial gain – all our research aims to benefit Society and is not for profiting other companies /organisations.
- We will only grant access to anonymized data for ethically approved and scientifically approved research. All requests to use your data are reviewed by our NICOLA Data Access Committee.
- We have a comprehensive Data and Sample Access Policy and secure structures in place to prevent unauthorised access to all parts of NICOLA data and samples.
- Researchers are only permitted to use the data for statistical & research purposes. NICOLA will ensure that it will not be possible to identify any participants from published results.
- The University has considered and mitigated against the data protection risks associated with this research through a data protection impact assessment. Alongside internal audits by Queen's University Belfast we also undergo formal external audits by independent experts to ensure we continue to meet all the research and regulatory requirements.

WHO WE ARE

- We are a group of expert researchers from Queen's University Belfast, a University with a reputation for excellence in education and research. The core staff for NICOLA are located within the Centre for Public Health, which is part of The School of Medicine, Dentistry and Biological Sciences.
- All our research is underpinned by policies and procedures that ensure we comply with regulations and legislation that govern the conduct of research, including data protection laws. For health and social care research, such as NICOLA, we have to demonstrate that our research serves the interests of society as a whole.

HOW WE STORE YOUR DATA

The information you provide is stored in the following way:

Contact database: when you consent to take part in the NICOLA study, we ask for information about you such as your name, address, date of birth, phone number, and email address. This information is “directly Identifiable Personal Data” and is stored along with a unique Study ID. This file is always kept separate from other information you give us, for example your responses in the questionnaires about your health.

Raw dataset: this contains all the information provided by you during your interviews. These datasets are stored digitally on the secure NICOLA computer server and can only be accessed by a limited number of NICOLA staff.

Research datasets: These include answers that you (and other participants) have provided to questions during home interviews or self-completion questionnaires and/or data collected as part of the health assessment tests including

results from blood and urine analyses. The research datasets are pseudonymised; that means they do not contain any directly identifiable personal data (e.g. name, address, phone number or email address) and instead a unique Study ID is used alongside the data. These datasets are stored on a separate secure NICOLA computer server and are the versions accessed for research purposes. Researchers can only access information they have requested and which has been approved by the NICOLA Data Access Committee. Researchers do not have access to the entire raw dataset or your personal data.

Archived datasets: these include answers that you have provided to questions during home interviews and as part of the health assessment but they do not contain any directly identifiable personal data and in addition do not include your unique Study ID. This is referred to as anonymised data. These datasets have fewer variables than the main research dataset. These datasets are accessible through established and ethically approved research data repositories. The anonymised NICOLA data will sit with data from other population studies for the purpose of research that allows for comparisons across different populations. These repositories will have strict policies in place to control access to any of the data

Data from other sources: Where consent has been granted, we will also collect information about you from other sources. This involves combining the information you have already given us with information held about you by other health and/or government organisations.

This may include information from routine health and social care-related data such as NHS records, GP and dental records, hospital admission/discharge records, and disease registers. This is known as Record Linkage.

In order for NICOLA to link your study data to your health and social care related data we need to hold your H&C (subject to ethical approval from an NHS/HSC Research Ethics Committee). This unique identifier ensures that your NICOLA data is correctly matched to information held within other health or social care datasets. The H&C number is used only as a tool to facilitate the record linkage and is always kept separate from your other NICOLA information on a secure server. Record Linkage will only take place once we have both your consent and the ethical approval from an NHS/HSC Research Ethics Committee

Obtaining your routine health and social care data through record linkage requires sharing some personally identifiable details such as your name, date of birth, address and your H&C number with these health organisations. Access to data will be in line with specific data access policies and comply with regulations and legislation governing the conduct of research and data protection.

Existing research data can be substantially enhanced with additional health related information from other sources. It helps build a more comprehensive picture and allows researchers to study trends or patterns in large population studies such as NICOLA.

The NHS Health and Social Care Business Service Organisation (BSO) facilitates the maintenance of our NICOLA cohort and provides us with address updates and notification of death registration.

HOW WE USE YOUR PERSONAL DATA

We use your Personal Data in the following ways:

- To contact you to invite you to take part in the next wave of the study or NICOLA related research and to discuss research-related queries.
- After consent to take part is provided, directly identifiable 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, personal data is controlled very carefully. All personal data collected for research purposes is pseudonymised. Only authorised members of the NICOLA core team will be able to link your

study ID to directly identifiable personal data, e.g. your name and contact details.

- The research data that you provide (i.e. answers to survey questions, questionnaires, health assessment measures and blood or urine samples) is used for research purposes with the intention to understand the health of people aged 50 years and over, the biological and/or environmental factors that assist in successful ageing, needs for economic or support services, the contributions that people aged 50 years and over are making to society, all with the aim of understanding how their lives could be improved. For further details on research, please refer to the NICOLA Participant Information Sheet and the NICOLA website. The NICOLA newsletter will also highlight recent key research publications.

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

NICOLA's purpose is to conduct scientific research that aims to improve the public good. We will only use your "Personal Data" if we have valid scientific reasons for doing so. These reasons are known as our "legal basis for processing".

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". This is because our research aims to help those, for example, in government, public services, and third sector when they are planning policies and services that affect people aged 50 years and over. For example, things like work, pensions and healthcare, which could affect you and your family.

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 research 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 interest of the data subject".

WHO WE SHARE YOUR DATA WITH

NICOLA helps to build a picture of ageing in Northern Ireland, and the data we collect is used for statistical and research purposes only. Information shared will be on a need to know basis, not excessive and with all appropriate safeguards in place to ensure the security of the information.

In line with our Data Access Policy and Procedures, we may share your anonymised Personal Data with the following parties for the following research purposes:

- Designated research personnel for the purposes of achieving the research outcomes as approved by the Ethics Committee and deemed acceptable by the NICOLA Data Access Committee.

- UK Longitudinal Linkage Collaboration (unless you previously opted out) for the purpose of UK wide research
- Organisations in-charge of the collection and administration of routine data for the purposes of achieving research outcomes
- Organisations that act as data portals or hubs for large population based research studies such as NICOLA. An example of this is the UK Data Service. Your anonymised information is combined with thousands of survey answers from other NICOLA participants and is securely deposited in the UK Data Service, which is based at the University of Essex and operates under a strict license agreement. Researchers can register with the UK Data Service to access anonymised NICOLA data, which can only be used for genuine research for public interest and not for commercial gain.
- Governmental and public bodies, for example the Department of Health, Public Health Agency, local Councils to inform policies and strategies.
- Bona fide researchers in other organisations across the world including Universities in the UK, EU, US and Australia for the purpose of extensive global research.
- We do not share your data for commercial purposes.
- NICOLA operate a secure 'Trusted Research Environment (TRE) facility whereby researchers from within and outside of QUB can access anonymised NICOLA data subject to approval by the NICOLA Data Access Committee. All researchers have to review and acknowledge the NICOLA data access policy to use the 'TRE' and sign a confidentiality agreement.
- In cases where third parties (known as data processors) carry out a task on our behalf, we have contractual terms, policies and procedures to ensure confidentiality is respected.
- We will not transfer your personal data outside of the United Kingdom and European Economic Area without informing you via a letter or Information Sheet. Please note, as stated above, anonymised data may be shared internationally.

KEEPING YOUR INFORMATION

- Information where you can be directly identified will be kept for a minimum amount of time and in accordance with our research objectives.
- As NICOLA is a longitudinal study, your personal data will be retained for the life of the study in order for research to continue
- If you have provided consent for follow up we will retain your record of consent and directly identifiable personal data (name, telephone number, email address, address) for the purpose of conducting longer-term follow-up for NICOLA or to inform you about future studies related to health and lifestyle that we may be conducting.
- Unless you opted out of record linkage, we will retain your NHS H&C number for record linkage purposes. This can only happen when ethical approval from an NHS/HSC Research Ethics Committee has been provided).
- If you want to opt out of record linkage subsequently in the study please contact the NICOLA office who will discuss this with you and follow the procedures to action accordingly.
- Personal data will also be kept for the purpose of record and audit requirements.
- You can decline to receive communications at any stage.

- Research data, working papers and published reports produced through the life of the project will never contain any identifiable personal data about you. NICOLA Newsletters that are sent to participants may contain identifiable information to promote the work of the study but only if written permission has been obtained from the participant.
- We place great importance on the security of the data that we hold, including the use of physical, technical and organisational measures and comprehensive policies and procedures to ensure your information is protected from unauthorised access and against unlawful processing, accidental loss, alteration, disclosure, destruction and damage.

WITHDRAWING YOUR CONSENT

NICOLA will be most valuable to science and society if few people withdraw from the study however taking part is voluntary, and you are free to withdraw at any time without giving a reason.

You (or someone acting on your behalf (spouse, partner, relative, carer or friend) will be sent a participant withdrawal form to complete. You will also be able to discuss your withdrawal with the NICOLA study team before making your decision.

If you withdraw from the NICOLA study, your previously collected data will not be deleted. As a longitudinal study (i.e. a study that takes place over a period of time) the withdrawal of your data would impact on the integrity and outcomes of the research. If you would like to find out more about why your data cannot be deleted please contact NICOLA or the University's Information Compliance Unit via the contact details noted below.

If you provided samples (for example blood, urine, saliva) you can continue to permit researchers to analyse your samples as part of approved research or you can request disposal of your samples. Some research may have already taken place using your samples, prior to your withdrawal of consent, and this cannot be undone.

There will be no further contact from the NICOLA Study after you withdraw.

YOUR RIGHTS

You have 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 (please note as stated above we cannot delete your research 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
- to withdraw your consent (where we are relying on consent to process your data).

If you wish to exercise any of the rights set out above, or require further information about any of the rights, please contact us.

CONTACTING US

If you have any queries or comments about this privacy notice regarding the use of your data, then please contact the NICOLA Team:

Telephone: 07788320299

Email: nicola-research@qub.ac.uk

Alternatively, you can contact Queen's University Belfast Data Protection Officer: Mrs Sandra McDonald, Queen's University Belfast, University Road, Belfast, BT7 1NN. Telephone: 028 9097 2576 or email dpo@qub.ac.uk.

If you have a complaint or have any concerns about your data please contact: NICOLA's Scientific Director Professor Frank Kee 028 9097 8943, f.kee@qub.ac.uk

You have the right to complain 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

REVISIONS TO THIS NOTICE

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.

GLOSSARY

Please find below an explanation of some of the words and terms used in this document

Terminology	Explanation
Anonymised	To remove identifying particulars or details from data The individual is no longer identifiable
Data Controller	The Data Controller determines the purposes for which, and the manner in which, any Personal Data that it holds, are processed. The Data Controller is responsible for ensuring that all Personal Data processing complies with the Data Protection Regulations. Queens University Belfast is the Data Controller
Data Access Committee (DAC)	The committee guides policy and decision-making on access to data hosted by the NICOLA trusted Research Environment. Access to anonymised datasets are managed according to Data Access Guidelines that include the data access criteria and principles governing the DAC review.
Data Processor	Data Processors act on behalf of, and only on the instructions of, the relevant controller.
Data Repository	Also referred to as a data library or data archive. It is a large database infrastructure or several databases that collect, manage, and store data sets for data analysis, sharing and reporting.
Directly Identifiable Personal data	Information that directly identifies an individual, i.e. name, address, email address
Encrypted	Convert (information or data) into a code, especially to prevent unauthorised access.
Health & Care (H&C) number	The H&C number is a unique, 10-digit patient identifier assigned to every individual in the UK and is used to consistently and correctly identify you across health and social care systems
Longitudinal (study)	Researchers repeatedly examine the same individuals to detect any changes that might occur over a period of time.
Personal data	Personal data only includes information relating to natural persons who can be indirectly identified from that information in combination with other information. In the case of NICOLA we refer to your survey and questionnaire answers as personal data. Biological samples and other health data would also be considered personal data. The data however has been anonymised before any research access and therefore no individual can be identified
Pseudonymised or Pseudonymisation	Replacing any information, which could be used to identify an individual with a pseudonym, or, in other words, a value, which does not allow the individual to be directly identified. For NICOLA we replace directly identifiable Personal data with a unique Study number
Record Linkage	Record linkage is a method of bringing information from different sources together

	about the same person or entity to create a new, richer dataset.
Sensitive/special category personal data	For example personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs. In NICOLA the data regarding 'The Troubles', health (physical and mental) could be viewed as sensitive data
TRE	Trusted Research Environment - Provides approved researchers with a secure environment to access the anonymised data