



## NICOLA Privacy Notice for Research Participants

### OUR COMMITMENT TO YOU

- ✓ Taking part in NICOLA is voluntary and you are free to withdraw at any time without giving a reason
- ✓ **You will not be identified** from the research – researchers do not see your name with your information – they just see a unique ID number
- ✓ Every research project is checked to make sure it meets the highest scientific and ethical standard
- ✓ In the same way as a doctor who treats you is bound to keep your information confidential, NICOLA and all the researchers we work with are bound to keep your information confidential. We will maintain strict measures to protect your confidentiality. Any information you tell us is anonymous. This means any information which can identify you, such as name, address, date of birth is taken off the data and samples and is stored separately. Any interview data collected on laptops during home interviews is also secure. All data is stored in a format which would be meaningless to any unauthorised person who looked at it. Laptops used during Health Assessments are also password protected. We will treat your information in the strictest confidence under current data protection legislation.
- ✓ 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 anonymised, non-identifiable data for ethically approved and scientifically approved research and statistical use. All requests to use your data are reviewed by our NICOLA Data Access Committee. Researchers are only permitted to use the data for statistical purposes. NICOLA will ensure that all data being used for research purposes is anonymised, which means that it will not be possible to identify any participants from published results.
- ✓ NICOLA has been approved by the Faculty of Medicine, Health and Life Sciences in Queen's University Belfast, which checks that proper safeguards are in place in accordance with Data Protection regulations.

- ✓ 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
- ✓ 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.

## DATA PRIVACY IN NICOLA

Queen's University Belfast is committed to protecting your personal data. This privacy notice is addressed to participants taking part in NICOLA.

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

## WHO WE ARE?

We are Queen's University Belfast, a University with a reputation for excellence in education and research and a member of the Russell Group. Founded in 1845 as Queen's College Belfast, we became an independent university in 1908.

## HOW WE COLLECT YOUR DATA?

The data we collect from you is stored in the following way:

**Contact database:** this contains your "Personal Data" i.e. name, address, phone number, email address, along with a unique NICOLA identifier. This file is always kept separate from other information you tell 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 on the secure NICOLA server and can only be accessed by a limited number of NICOLA staff

**Research datasets:** These include answers that you have provided to questions during home interviews or self-completion questionnaires or data collected as part of the health assessment tests including results from blood and urine analyses. They contain your unique NICOLA identifier but they do not contain your contact details (name, address, phone number or email address). These datasets are stored on the secure NICOLA computer server and are the versions accessed for research purposes. These datasets do not contain all the data that

you have provided. Researchers only get access to the information that they have requested and do not have access to the entire raw dataset.

**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 your contact details or your unique NICOLA identifier. These datasets have fewer variables than the main research dataset. These datasets are accessible through established and approved data repositories.

## HOW WE USE YOUR PERSONAL DATA

We use your “Personal Data” in the following ways:

1. To process communications with you throughout the study and to keep you informed
2. To analyse data against medical or demographic information

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” (Article 6 of UK GDPR).

Where we also collect and use more sensitive personal information (Special Category data) we only do so 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 UK GDPR)

In addition the UK GDPR and the DPA also require 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.

## WHO DO 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. All the information we collect is held in accordance with current data protection legislation.
- We do not share your data with commercial companies.
- We only share your data with relevant researchers and only where their research has received ethical approval and has been deemed acceptable by the NICOLA Data Access Committee.
- If we need to share your “Personal data” with other researchers or collaborators for the purpose of achieving the research outcomes, we will write to you to inform you of this.
- We will never transfer your “Personal data” outside of Northern Ireland without informing you via a letter or Information Sheet.
- 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.
- NICOLA operate a secure ‘safe setting’ facility in the NICOLA office whereby researchers from within and outside of QUB can access the anonymised NICOLA dataset subject to approval by the NICOLA Data Access Committee. All researchers undergo training to use the ‘safe setting’ and sign a confidentiality agreement. All computers in the facility are set up so that data cannot be copied or removed from the premises. This is to facilitate access to data for researchers outside the NICOLA team. No personal data (names, contact details etc) is available.
- If the NICOLA team receive a data request from a researcher outside of Northern Ireland then we set up a “Data Transfer Agreement”. This is a legal document drawn up between Queen’s University Belfast and the external University/Research body. This agreement ensures your confidentiality and only approves transfer of specific anonymised data that have been agreed by the NICOLA Data Access Committee.
- Mortality information is an important outcome in a longitudinal study of ageing. When a participant passes away, NICOLA receives information from the death registration records. This information is transferred securely and is only used for this purpose.

## WHAT ARE YOUR RIGHTS?

You have the following rights over the way we use “Personal data” such as your name, address, phone number and email address (contact details).

The Data Protection Act 2018 provides you with a number of legal rights in relation to your “Personal Data”, including the right:

- to request access to any of your data,
- to request correction of your data that is wrong or incomplete,
- to request erasure or the restriction of the processing of your data (if still in raw form and we no longer have justification for retaining them)
- 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

Please note that these rights will not apply to any coded data being used for research purposes, as the study is a longitudinal study which relies on large amounts of data to be effective and therefore any removal of data obtained for this research, is necessary for the achievement of this study, which is in the public interest.

## HOW LONG WILL YOUR INFORMATION BE KEPT?

Information where you can be identified will be kept for a minimum amount of time and in accordance with our research objectives. Some information such as signed records of consent, will be kept for the minimum amount of time as required by funders or our policies and procedures. We place great importance on the security of the 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.

## 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: 028 9097 8920 or 028 9097 8921**

**Email: [nicola-research@qub.ac.uk](mailto:nicola-research@qub.ac.uk)**

Alternatively, you can contact Queen's University Belfast Data Compliance Manager: Sandra McDonald, Queen's University Belfast, University Road, Belfast, BT7 1NN. Telephone: 028 9097 2576 or email [info.compliance@qub.ac.uk](mailto:info.compliance@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](mailto:f.kee@qub.ac.uk)