

## PRIVACY NOTICE

### Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA)

#### 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, health and care number 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 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 when you:

- Phone, email or text us
- Complete our questionnaires
- Complete health assessments
- Update your contact details
- Return completed questionnaires, consent forms, reply slips or other written information
- Provide biological samples, for example blood, urine
- Collect 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 and consent forms
- Finding participants who we lose contact with
- 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 Privacy Notice.

## WHO WE ARE

1. We are a group of expert researchers from 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.
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 current data protection legislation. 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 WE COLLECT YOUR DATA

- 3: **Information you provide:** 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, email address. This information is known as your "Personal Data" and is stored 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 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 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. Some of this information includes 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. The research datasets 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 that has been approved by our Data Access Committee. Researchers 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.

4. **Data from other sources:** Where consent has been granted, we will also collect information about you from other sources and this also forms part of “Personal Data” and “Sensitive Personal Data”. This involves combining the information you have already given us with information held about you by other health or government organisations. This includes information from:
- routine health and social care-related data (unless you opted out to this) such as NHS records, including your Health and Care number (H&C Number), GP and dental records, hospital admission/discharge records, death registration and disease registers. To obtain your routine data from these systems, we share some personally-identifiable details such as your name, date of birth, address and your H&C number with each of these NHS organisations and they will send us your data back. This will all be done using secure encrypted 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.
  - The NHS Business Service Organisation which provides us with address updates in case we lose touch with you.

## 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 is 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 NICOLA research team will be able to link your study number to your name, contact details and H&C number.
  - In order for us to link your NICOLA data to your health and social care-related data we need to hold your H&C number within NICOLA as it ensures that your NICOLA data is correctly matched to information held within these other health or social care datasets. By matching this number we can perform the required data linkage and data extraction processes to carry out our research. 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. Within NICOLA, the H&C number is only used as a tool to facilitate the linkage with other health or government data and is always kept separate from your other NICOLA information.
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. 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".
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". This is because our research aims to help those, for example, in government, charities, and university researchers, when they are planning services which affect people aged 50 years and over. For example, things like work, pensions and healthcare which could affect you and your family.
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 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**

11. 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.
12. In line with our Data Access Policy and Procedures we may share your information including Personal Data and Sensitive Personal Data with the following parties for the following research purposes:

- Designated research personnel for the purposes of achieving the research outcomes and only where the research has received ethical approval and has been deemed acceptable by the NICOLA Data Access Committee.
- IPSOS MORI: security checked organisation who administered the survey for Waves 1 and 2 of NICOLA and have been vetted by us, with signed agreements to ensure that strict data security arrangements are followed.
- UK Longitudinal Linkage Collaboration (unless you previously opted out)
- Organisations in-charge of the collection and administration of routine data for the purposes of achieving the 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 Archive. Your anonymised information is combined with thousands of survey answers from other NICOLA participants and is securely deposited in the UK Data Archive, which is based at the University of Essex and operates under a strict licence agreement. Researchers can register with the UK Data Archive to access anonymised NICOLA data, which can only be used for genuine research for public interest and never 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.
- The data shared with data portals such as the UK Data Archive, government and public bodies, and bona fide researchers is always anonymised. It does not contain names, addresses, phone numbers, email addresses or other information which can identify you. The purpose of sharing this anonymised data is to allow research to be undertaken that aims to improve the public good.

13. We do not share your data with commercial companies.

14. 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.



15. 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.
16. If the NICOLA team receive a data request from a researcher who resides outside of Northern Ireland or is external to Queen's University Belfast 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 or remote access to specific anonymised data that have been agreed by the NICOLA Data Access Committee.
17. 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.
18. 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.

#### **DATA PROCESSING OUTSIDE EUROPE**

19. We will not transfer your "Personal data" and Sensitive Personal Data outside of the United Kingdom and European Economic Area without informing you via a letter or Information Sheet.

#### **HOW LONG YOUR INFORMATION WILL BE KEPT?**

20. Information where you can be identified will be kept for a minimum amount of time and in accordance with our research objectives.
21. Data retention periods of personal and research data will vary according to specific contractual requirements and the nature and sensitivity of the research. Because NICOLA is a longitudinal study, your personal data will be



retained for the life of the study for communication and participation reasons. This also allows 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 NICOLA or to inform you about future studies related to health and lifestyle that we may be conducting. Unless you opted out of data linkage, we will retain your NHS H&C 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.

22. 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.
23. We place great importance on the security of the Data that we hold, including the use of physical, technological 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.

## **YOUR RIGHTS?**

24. You have the following rights over the way we use your Personal data 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.
25. Please note that the rights set out above 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.

26. If you wish to exercise any of the rights set out above, or require further information about any of the rights, please contact us.
27. 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

28. 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: Mrs 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)

## COMPLAINTS

29. 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

30. 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.