**PARTICIPANT INFORMATION SHEET**

# Public perceptions of health data sharing for AI research (PHAIR)

Central University Research Ethics Committee Approval Reference: [R79725/RE001]

## Introduction

We’d like to invite you to take part in our research study. The information in this leaflet explains why we are doing this research and what it involves for you. Please take time to read it before you decide whether you want to take part. Some people find it helpful to talk it over with friends or family.

If there is anything that is not clear, or if you would like more information, please ask us. We are happy to speak on e-mail, the phone or over a video call to answer any questions you might have.

## What is the purpose of this study?

Artificial intelligence (AI) is a type of technology that allows computers to learn from data in a similar way to humans. AI is developing quickly and is behind many parts of modern life, from virtual assistants to chatbots.

Using AI in healthcare could help us to diagnose illnesses, make predictions about people’s health and understand more about diseases. For example, AI could help to diagnose lung cancer by spotting changes on an x-ray or scan. This could improve patient health and relieve pressures on the National Health Service (NHS).

AI programmes need large amounts of information (‘data’) to work properly. This could be many millions of patient scans, hospital and GP records, test results and other documents. AI may also need information about the person, such as age, sex and ethnicity. Sometimes this information might be very sensitive. Because so much data is used, sometimes it is not possible to ask everyone for their consent.

Some healthcare AI programmes are developed by healthcare professionals and researchers, and some are developed by commercial companies. This means that patient health data might be shared with a wide range of people.

This study aims to understand what people (the public) think and feel about sharing their health data for AI research and testing. We want to find out public views about how ‘AI’ and ‘healthcare data’ are perceived and how, to whom and what healthcare data is shared for AI research. We aim to do this by running focus groups with members of the public.

 This will help us to make sure that future healthcare data sharing is performed appropriately.

## Why have I been invited to take part?

You have been invited to take part as you are aged 18 years and over, and live in the UK.

We are aiming to include a wide range of different people. For example, we would like to make sure that people of all ages and ethnicities are involved in this research. If you decide to take part, we will ask you to provide us with some more information about yourself.

## Do I have to take part?

No. It is up to you to decide whether to take part. If you decide to take part, you can withdraw yourself at any time, without giving a reason.

If you withdraw during the focus group itself, any contributions you have made up until that point will be included for analysis. This is because when people are in a focus group, what they say influences how the discussion goes.

## What will happen to me if I take part in the research?

You will be asked to sign a consent form, fill in a questionnaire and attend a 90-minute online focus group.

Consent

To consent to take part in this research, we would like you to read this document carefully, and sign the **consent form** which is attached to this e-mail. If you would like more information or to talk things over with us, please let us know.

Online questionnaire

We will ask you to fill in an online questionnaire about yourself, which will help us to confirm your eligibility.

We will ask you for more information about your age, sex, ethnicity, the county that you live in, your approximate household income, your highest level of education, whether or not you have a health condition (yes or no) and roughly how often you use NHS healthcare.

This information will help us make sure that the focus groups represent the diversity of the UK population. We are aiming to include a wide range of people, and so you might not be invited to take part in a focus group if there are many people like you. If this happens, we will let you know, and your details will be deleted.

Online focus group

You will be asked to take part in a focus group on Microsoft Teams. The focus group will take 90-minutes, with a short comfort break halfway through. There will be between five to seven other participants, and two researchers.

We will ask you to keep your camera on during the focus group and to introduce yourself. Some people might share their personal experiences with healthcare during the focus group, so please take part from somewhere that is private (for example, in your own home, rather than in a busy coffee shop).

The focus groups will be video-recorded, and later transcribed into written notes, so we can analyse the conversation.

Follow-up

If you would like to be informed of the outcomes of the research, please let us know on the **consent form**. We will send a copy of our findings to you within a year of you taking part, and you are invited to add any thoughts, or ask any questions that come to mind.

## What are the possible disadvantages and risks in taking part?

We will be discussing sharing health data for AI. You may find this upsetting if you have been a victim of data leakage in the past. We will let you know the broad topics for discussion before the focus group so you are able to withdraw or let us know if you feel that this would cause you distress.

All identifiable information discussed in the focus group will be confidential. When the research is published, your information will be anonymised. We ask that all members of the focus group keep any personal health information shared confidential.

## Are there any benefits in taking part?

While there are no immediate benefits for participating, we hope that this research will be able to guide researchers, clinicians and policymakers in best practice for health data sharing.

## Expenses and payments

You will receive £25 reimbursement for taking part in this study.

## What information will be collected and why is the collection of this information relevant for achieving the research objectives?

We will keep your information confidential, including your taking part in the research.

The research team will collect information about you as part of the study and will be able to identify you. However, they will only use your information for the purposes of this research: to explore public perceptions of health data sharing for AI, and to help us include a wide range of people.

All information collected about you will be stored securely in a study database on password protected University of Oxford computers and Microsoft Office OneDrive for Business. The information we will collect includes: a signed copy of your consent form, the information from the questionnaire and the transcript of the focus group you take part in. If you do not take part in a focus group, we will remove your information immediately.

All information about you will be coded with a study identification number (study ID) so that you cannot be identified by anyone other than the research team. The study team will keep a document containing your study ID and e-mail address, if you would like to be informed of the results of the study.

To receive reimbursement for the focus group, you will need to share your electronic banking details with the research and finance team.

## What will happen to my data?

We will be using the information we collect about you to complete this study. We will keep identifiable information about you for no more than 3 months after the study has finished. This does not include your signed consent forms, which will be held securely at the University of Oxford for 3 years after the end of the study. Video-recordings of focus groups will be transcribed by University Transcriptions (<https://www.universitytranscriptions.co.uk/university-of-oxford/>), a GDPR Accredited transcription company.

If you have agreed to be contacted with the outcomes of the research, we will keep your name and e-mail address for one year after the research has been completed.

Research documents without identifiable information, such as anonymised transcripts of focus groups, will be held securely at the University of Oxford for 3 years after the end of the study.

## Will the research be published? Could I be identified from any publications or other research outputs?

The findings from the research will be written up and shared. This will be part of a PhD thesis and shared in academic publications, conference presentations, and may be publicised on websites such as the NDORMS website ([NDORMS Home — Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (ox.ac.uk)](https://www.ndorms.ox.ac.uk/) or on social media. This will help our research have the widest reach and impact. You will not be identifiable from the findings.

Any direct quotations taken from your focus group will be anonymised. For example:

*‘I have not taken part in research before.’ Participant AB, 49-year-old woman.*

In any publication, we would like to include an anonymised summary of the information you provide in the questionnaire (age, sex, ethnicity, county, household income and level of education, and presence/absence of an existing health condition) for each focus group. This will help anyone reading about the research to see what sort of people the focus groups represented.

## Data Protection

The University of Oxford is the data controller for this study and will process your personal data for the purpose of this research. Research is a task that is performed in the public interest. Further information about your rights with respect to your personal data is available from the University’s Information Compliance web site at <https://compliance.admin.ox.ac.uk/individual-rights>.

## Who is organising and funding the research?

This research is organised by a research team based at the Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS), at the University of Oxford. The study is funded by the National Institute for Health and Care Research (NIHR302562).

Our research group includes two Patient and Public Involvement (PPI) representatives, who have provided input into the study design, the information provided in this leaflet and on the website.

## Who has reviewed this research?

This research has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee. (Ethics reference: **TBC)**.

## Who do I contact if I have a concern about the research or I wish to complain?

If you have a concern about any aspect of this research, please contact us on phair@ndorms.ox.ac.uk and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the University of Oxford Research Governance, Ethics & Assurance (RGEA) team at rgea.complaints@admin.ox.ac.uk or on 01865 616480.

Further Information and Contact Details

Further information is available on the study website: <https://www.ndorms.ox.ac.uk/research/phair-public-perceptions-of-healthcare-ai-research>

Please contact Rachel Kuo on phair@ndorms.ox.ac.uk.

If you would like more general information about taking part in research, please follow the following link: [I want to take part in a research study | NIHR](https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-take-part-in-a-study.htm)