
GameChanger Data Privacy Notice

This Privacy Notice describes how personal data collected about you as part of the GameChanger study is handled and processed in accordance with the UK General Data Protection Regulation (UK GDPR).

It is important that you read this policy, as well as any other privacy notice we may provide on specific occasions when we are collecting or processing information about you, so that you are aware of how and why we are using your information. We may update this policy at any time.

What is personal data?

Where we refer to ‘personal data’, we mean any information we collect about you from which you can be identified. It does not include data where your identity has been removed (anonymous data).

Who is responsible for your data?

The University of Oxford is the “data controller” for the information we collect from you as part of the GameChanger study. This means that we decide how to use this data and are responsible for looking after your information in accordance with the UK GDPR.

Why are we collecting data?

Over 850,000 people are living with dementia across the UK today. The very early signs of Alzheimer’s disease (the leading cause of dementia) can appear more than 10 years before an individual is diagnosed, but detecting these small changes is difficult. Understanding the very earliest stages of the disease is crucial for advancing research that will prevent, slow, or even treat the condition. The data we collect as part of the GameChanger study will help us understand what healthy cognition (i.e., thinking) looks like in people from a range of backgrounds using the [Mezurio](#) smartphone app. Future research can use this data as a baseline for detecting individuals at risk of developing Alzheimer’s disease.

Personal data we collect about you

Information for the GameChanger study will be collected directly from you through the Mezurio smartphone app. Mezurio will measure aspects of your memory, thinking and learning, as well as asking you to rate your mood and sleep. Personal information collected includes your email address, date of birth, ethnicity, postcode, and IP address. We will also collect voice data as part of a story narration task, as natural speech, both what we say and how we say it, provides important clues about how we think. The app will ask permission to access your microphone before you start the task, and it will be clear when the app is using voice recording.

Members of the research team will be able to link the information collected by Mezurio back to you using the unique participant code we provide when you register with GameChanger.

Linking with other research

GameChanger is developing links with UK-based research projects, for example Children of the 90’s, Generation Scotland, and the Exeter 10,000. If you have already provided information for research, such as performance on traditional tests of thinking abilities, genetic information, information regarding your general state of health (e.g., blood pressure, cholesterol, and medical history), and your background and lifestyle, we may be able to connect this information with your performance in the

GameChanger study. Linking research in this way creates a more valuable resource for understanding how to detect, slow down, or even treat Alzheimer's disease.

If you think you have previously been involved with a UK research project and are happy for us to check, please let us know when you complete the GameChanger registration form. Before attempting to link your GameChanger performance with data held by another UK research project, each research collaboration will be reviewed by the University of Oxford Central Research Ethics Committee. With your consent, we will share information that can be used to identify you (email address, date of birth or postcode) with approved research projects so they can check whether you are a participant in their study. If you are already a participant in a research project we are working with, we will be able to connect your GameChanger performance with information you provided previously. When we share information, it will be pseudonymised, meaning only approved members of the study team will be able to link data back to you based on your unique participant ID code.

Data protection

We collect and process your data (including your special category data, such as ethnicity or genetic data) for the purpose of performing scientific research that is being carried out in the public interest. This is known under data protection law as our "legal basis" for processing personal data (Article 6(1)(e) and Article 9(2)(j) UK GDPR).

Further information about the University of Oxford's Policy on Data Protection can be accessed via the following link

<https://www.admin.ox.ac.uk/councilsec/compliance/gdpr/universitypolicyondataprotection/>.

Data access and sharing

Data collected by GameChanger will be encrypted and sent to a secure University of Oxford server. We will store your performance on the tasks within Mezurio separately from your email address. Access to your data will be restricted to members of the GameChanger study team who need to view it as part of their work, in order to carry out the research purposes described above. Additionally, we will need to use third-party services such as Google and Amazon to transfer, process and back up your data. These third-party service providers are required to take appropriate security measures to protect your data in line with our policies, and cannot use your data for their own purposes. If you have agreed to link GameChanger data to other research projects, we will also share information with collaborating research organisations working with us.

With your consent, we will use your email address to invite you to take part in GameChanger annually for the next three years. You can also opt in to receive updates about new GameChanger activities and research findings. When we share the findings of GameChanger with the wider scientific community, any information that could be used to identify you will be removed.

Retention period

Your GameChanger performance will be held for at least three years after the study ends, in accordance with the University of Oxford guidelines. We will also ask to retain your personal details so we can invite you to take part in future research studies, and to help us identify information you have provided as part of a collaborating research project. We will delete any personal data you provide three years after the study is complete, unless you indicate you are happy for us to hold onto them for longer.

We may need to retain your personal data for longer if it is necessary to fulfil our purposes, including any relating to research, legal, accounting, or reporting requirements. This will always be done in accordance with data protection laws.

Your rights

Under the UK GDPR, you have certain rights with respect to your personal data. A summary of these rights is available here: <https://compliance.admin.ox.ac.uk/individual-rights>

If you want to exercise any of the rights described or are dissatisfied with the way we have used your information, you can contact the University's Data Protection Officer by email (data.protection@admin.ox.ac.uk). If you remain dissatisfied, you have the right to lodge a complaint with the Information Commissioner's Office at <https://ico.org.uk/concerns> or by calling their helpline on 0303 123 1113.

How to withdraw from the study

Participation in GameChanger is entirely voluntary and you can delete the app at any time to stop contributing data to the project. If you wish to withdraw the information you have already provided, you can do so by following this [link](#). You are free to do this at any time and do not have to give us a reason. However, we will only be able to delete your data up until it is no longer traceable back to you (i.e., after the end of the GameChanger study).

Contact us

If you wish to provide feedback on the study or have a question about any aspect of GameChanger, please contact us at gamechanger@bdi.ox.ac.uk. The research team value your feedback and will do their best to get back to you when a response is needed.

If you are unhappy about any aspect of the study, please email gamechanger-complaints@bdi.ox.ac.uk. To make a formal complaint about the running of GameChanger, please contact the Chair of the University of Oxford Central University Research Ethics Committee who will seek to resolve the matter: curec@admin.ox.ac.uk.