Frequently Asked Questions

Contents

GameChanger: The research project

- **What is GameChanger?**

- **Why is Alzheimer's Society supporting GameChanger?**

- **Who is funding the GameChanger project?**

- **Who can take part?**

- **Why are only people without dementia asked to take part at this stage?**

- **How do I sign up?**

- **If I miss a day or some days of playing the games, can I still take part?**

- **Is this project ethically approved?**

- **How can I keep up to date with news from the GameChanger project?**

GameChanger: Round 2

- **What's new in GameChanger round 2?**

- **Who can take part in GameChanger round 2?**

- **When can I take part in GameChanger round 2?**

- **Why are we asking people to take part in GameChanger for a second year?**

- **I took part in GameChanger round 1, how do I sign up for GameChanger round 2?**

- **I didn't take part in GameChanger round 1, can I take part this year?**

- **I didn't receive an email about GameChanger round 2 from the research team, how can I get involved again?**

- **I received an email about GameChanger round 2 from the research team but my invite code has expired – is it too late to join?**

GameChanger: Round 3

Data and technology

Dementia risk and GameChanger

Withdrawing from the project

Technical problems

Other information

GameChanger: The research project

• What is GameChanger?

GameChanger is a research project from Oxford University's Big Data Institute supported by Alzheimer's Society to help researchers learn more about how the brain changes over time.

This project uses a smartphone application containing a collection of brain games designed to provide researchers with information about how our brains work and change over time. This information is vital as it will help researchers understand more about the effects of dementia on the brain.

• Why is Alzheimer's Society supporting GameChanger?

Dementia today affects 850,000 people across the UK. Research will beat dementia – but we need your help to take research to the next level.

The diagnosis of dementia has improved in recent years but we know that it can still take some time for people with the condition to receive a diagnosis and the support and treatment they need. This can also mean there is a delay in people entering into clinical trials at the very early stages of the condition when new treatments could be effective.

The very early signs of Alzheimer's can appear more than 10 years before diagnosis, but detecting these tiny changes is very difficult. Using the app, researchers are able to learn more about memory, thinking and learning skills of people without dementia.

In the future this vital information will help us to identify the early changes in people who will go on to develop the condition. Researchers and doctors will then be able to make sure people showing early signs of the condition can take part in the latest and most promising research studies and clinical trials.

GameChanger will, ultimately, support research that could prevent, slow down, or even stop the progression of dementia.

• Who is funding the GameChanger project?

The app development was funded through grants from Roche pharmaceuticals, Eli-Lilly pharmaceuticals, the Robertson Foundation, and Oxford Health NHS FT Biomedical Research Centre.

- **Who can take part?**

People without dementia over the age of 18.

- **Why are only people without dementia asked to take part at this stage?**

Before we can use this technology to identify changes in memory and thinking which may help identify dementia, we first need to understand how a brain without dementia works and changes over time.

We need thousands of people without dementia to build a picture of our brains so that we can then use this information to compare against people at the very early stages of the condition.

- **How do I sign up?**

Signing up is easy. Visit www.alzheimers.org.uk/gamechanger and follow the link to the GameChanger site.

1) Read the information available on the GameChanger website
2) Complete the form and input your email address
3) You will receive an email with your unique participant code.
4) Download the 'Mezurio' smartphone app from either the Apple App Store or the Google Play Store, and sign in using the unique code in the email.

Then start playing!

- **If I miss a day or some days of playing the games, can I still take part?**

Yes, ideally the researchers are looking for people to take part every day for a month but if you miss a couple of days (or more) it's not too late to go back to the app and continue playing.

- **Is this project ethically approved?**

Yes this project has been thoroughly reviewed and received ethical clearance through the University of Oxford Research Ethics Committee to ensure it is safe and properly managed. (Reference number: R58202/RE001).

- **How can I keep up to date with news from the GameChanger project?**

The research team will be sharing all the latest news and development from the GameChanger project through their blog at www.joingamechanger.org. Volunteers signing up to take part in GameChanger have the option of receiving a regular newsletter via email.

GameChanger: Round 3

- ### Will there be a GameChanger round 3?

One of the most important things about GameChanger is that it will help us to understand how our memory and thinking skills change with time. GameChanger is inviting everyone who took part in round 1 and 2 to complete a third month of brain games in 2022.

Data and technology

- ### Which operating systems does the app work on?

The app will work with both iOS (i.e. iPhone) and Android devices.

- ### Will taking part in GameChanger affect my mobile phone bill?

The app will need to access the internet, both to download the GameChanger games and to send your results back to the research team. If you are using your mobile data network, this will count in your existing mobile data plan. To make sure you don't incur any costs as a result of being in the GameChanger project, we suggest you use the app when you are connected to Wi-Fi.

- ### Does the app work on iPads and tablets?

The app is only available on smart phones at this stage.

- ### What types of data will the project collect and why?

The unique participant code you receive when you register with GameChanger will be used to identify your performance by members of the research team. The app will measure aspects of your memory, thinking and learning, plus ask you to rate your mood, sleep, and how you perceive your mental abilities in everyday life.

We ask you to provide the following *personal information* as part of GameChanger including:

- Email address
- Date of birth
- Ethnicity
- Postcode

This will be used to explore how your background affects your GameChanger performance. In addition, we ask if you would be willing to provide your *email address* so we can contact you to ask if you might be interested in taking part in GameChanger again in a years' time. This will provide the research team with valuable information about how the brain changes over time.

Voice recording

Some of the tasks in this app will ask you to provide short spoken responses. We ask to use your smartphone's microphone to record your voice as natural speech, both what we say and how we say it, can provide important clues into how the brain works. It will be clear which tasks involve voice recording and we will delete your voice recordings once our analyses are complete.

• How will my data be stored?

Data collected by GameChanger will be encrypted and sent to a secure University of Oxford server. This data will be stored separately from your email address, with access restricted to members of the research team. Voice data collected by the app will be deleted following automatic transcription. Direct quotes of your speech will not be used in research outputs.

• How will my data be used?

Your data will be analysed as part of the wider study population. The results of the study will be shared with the wider scientific community. In addition, if you belong to an existing UK-based research study, we ask your permission to feedback your GameChanger performance to this research group. We will hold onto your individual data for at least three years in accordance with the University of Oxford guidelines.

• Will my data be shared? And if so, with whom and why?

Only members of the GameChanger study team will have access to your data. GameChanger will not share your personal information or individual GameChanger performance data without your permission.

If you belong to an existing UK-based research study, we ask permission to share your GameChanger performance with this research group. By combining the information that you have provided across approved research studies, we can create a more valuable resource for dementia research. To join information, we may need to use your personal information (email address, date of birth, postcode) to help make the link.

Dementia risk and GameChanger

- **Can this app tell me if I'm at risk of dementia, going to get dementia or have it already?**

No, at this stage the app cannot predict or detect whether someone has dementia now or will go on to develop it later in life. We hope in the future the app might be used as a tool to spot the very early signs of dementia but at the moment that isn't possible. The app will need to be tested thoroughly and validated through further research before this is possible.

- **Will playing these games or joining the GameChanger project reduce my risk of dementia?**

We know that keeping your brain active is a good idea and is likely to help reduce your risk of dementia. The games involved in the GameChanger are a good use of various thinking and memory skills but we can't be sure whether they reduce our risk of developing dementia. Fortunately we do know that they won't cause you or your mind any harm.

Withdrawing from the project

- **Once I have given consent, do I have to take part?**

No, you are free to withdraw from the study at any time and you don't need to give a reason.

- **How do I withdraw from the project?**

Simply delete the app from your device to stop participating.

- **Is it possible to delete the data I've provided, if I decide to withdraw?**

You can withdraw your information and data from the GameChanger project via the withdrawal page of GameChanger website. We will then be able to delete your data up until the point when it is no longer traceable back to you.

Technical problems

- **I'm having trouble accessing the GameChanger website, what do I do?**

    Firstly check your internet connections. In addition, make sure you are accessing www.joingamechanger.org. If you are still having problems, the website may be having technical problems. Please try again later.

- **I've submitted my email address via the GameChanger website but did not receive an authentication email, what do I do?**

    The email could take up to 10 minutes to arrive in your inbox. Please ensure that you have a good internet connection. If you cannot find the email in your inbox, it may have been automatically filtered by your email provider into your 'Junk' or 'Spam' folder. If you still do not receive an email, you can use the same email to re-register on the GameChanger website at www.joingamechanger.org

- **I've lost the authentication email with my participant code, what do I do?**

    You can revisit the www.joingamechanger.org and resubmit your email to receive another copy of your authentication email with the participant code.

- **I can't find the app in the App Store or Play Store.**

Remember that the app is called **Mezurio**. **It is not called GameChanger.** Check you are searching the correct name and that you have a good internet connection. Below are examples of what the **Mezurio app** appears as on the Play Store (left) and Apple App Store (right).
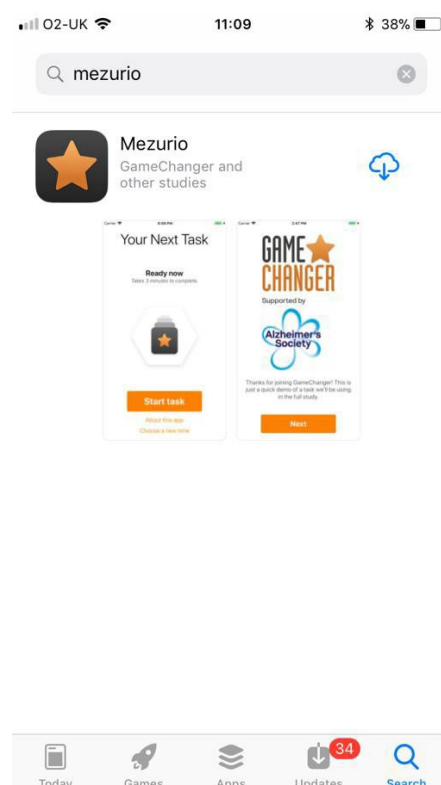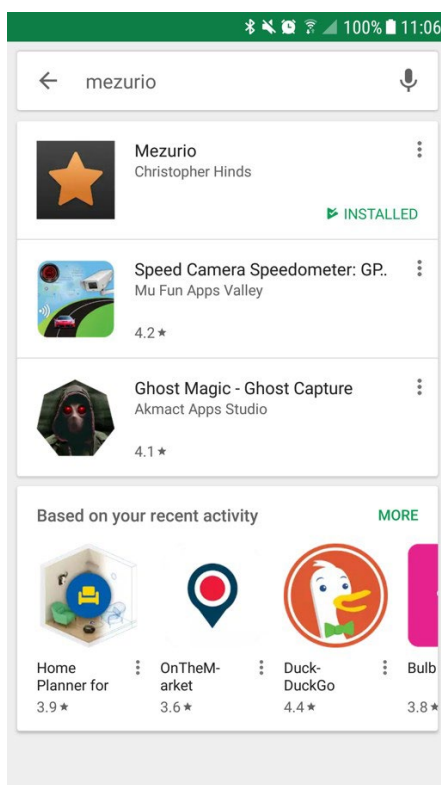
- **I'm having trouble accessing and downloading the app, what should I do?**

If you have found the app but are having trouble downloading it, check your internet connection or try back another time.

- **I'm having problems using the app or games, what do I do?**

Unfortunately, due to the size of the GameChanger project it is not possible for a member of the research team to provide one-to-one help on how to use the app or games. Most common queries are address in this document otherwise you can contact the research team at the University of Oxford via the email address below.

Other information

- **I have another question about GameChanger.**

If you have a concern about any aspect of GameChanger, please contact the research team at University of Oxford by emailing gamechanger-complaints@bdi.ox.ac.uk

- **I'd like to raise a concern about the GameChanger project.**

If you are unhappy or wish to make a formal complaint about the GameChanger project, please contact the Research Ethics Committee at the University of Oxford who will seek to resolve the matter at ethics@medsci.ox.ac.uk

- **I would like further information about dementia.**

Alzheimer's Society is the UK's leading dementia support and research charity. Visit www.alzheimers.org.uk to find out more about dementia or call our free national helpline on 0300 222 11 22.

- **I would like further information about taking part in research.**

If you are interested in getting involved in research or taking part in other research studies, please visit www.alzheimers.org.uk/research or call our free national helpline on 0300 222 11 22.

- **I'm concerned I or someone I know might have dementia, what should I do?**

If you are worried about yourself or a loved one, visit your GP or encourage your loved one to visit their GP, to discuss your concerns as soon as possible.