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A message to our participants: unfounded claims in The Guardian

October 17th 2024

This is a message for our participants about a highly misleading and irresponsible article that has been published in *The Guardian*, and claims that a far-right network has had access to UK Biobank data.

Our utmost priority is the correct use of our participants' data, and we do not tolerate any misuse. We understand *The Guardian* article may be concerning for you to read and we strongly refute the article's claims based on our own full investigation, which found no evidence of misuse of UK Biobank data:

- None of the individuals named by *The Guardian* have ever been approved for access
- A specialist search of the internet and dark web has found no concerns
- Technical details in *The Guardian's* transcript, such as listing a file type that we do not use, cast major doubts on their claims
- Kirkegaard has previously claimed to have access to UK Biobank data, only to continue to make attempts to obtain it

Professor Sir Rory Collins, Principal Investigator and Chief Executive of UK Biobank, said:

“Our robust processes have ensured that none of the individuals named by The Guardian have ever been approved access to UK Biobank data. We launched an extensive investigation, including a third-party search of the internet and dark web, and found no evidence of these data being available to unapproved researchers.

“Our data analysts reviewed the section of the undercover transcript that The Guardian made available to us. They concluded that the individuals are most likely discussing publicly available summary data, not participant-level data to conduct their abhorrent research. This is based on comments in the transcript about key technical details, including the file type which we do not use.

“We are confident that our access procedures are working, but sadly we operate in a world where unethical people will seek to undermine this. However, the most likely conclusion of the evidence is that these individuals are using publicly available summary data.”

Our robust data governance

We have strict procedures in place to prevent deliberate or accidental misuse of the data, including in-depth vetting of each applicant to ensure that only bona fide researchers are approved to access UK Biobank data. These processes have oversight from our Board-level access and ethics committees.

Researchers sign a legally binding agreement before accessing the data, stipulating that they are not allowed to share the data and the data must be securely stored, processed and deleted after use. Researchers must also deliver an annual report of their project, which we check against their original application.

In addition, we have established a secure, cloud-based analysis platform for large-scale data access and analysis, which means researchers will no longer download de-identified data, and instead will access and analyse the data on this platform.

Flaws in the claims included in *The Guardian's* article

Kirkegaard and his team at the Human Diversity Foundation have been blocked by UK Biobank from accessing its data on the grounds they are not bona fide researchers. We have previous evidence of Kirkegaard claiming he has access to UK Biobank data while continuing to make attempts to obtain it. Statements made by this group – whether public or private – cannot be relied upon as fact.

Over the past few weeks, we have engaged with journalists at *The Guardian* to investigate this matter fully. Despite pointing out significant flaws in the conclusions they have drawn from the video transcript, *The Guardian* has portrayed an inaccurate picture and neglected to report key evidence we provided.

Our next steps

When our participants joined UK Biobank 15 years ago, they agreed that their health data could be used for health research in the public interest. This means the findings should benefit the health and wellbeing of society. The findings should not cause harm, such as perpetuate stereotypes about certain groups, and we do not allow researchers to use UK Biobank data for so-called ‘race science’.

If there was evidence that a researcher had misused our data, we would immediately revoke their access to our data and take legal action if appropriate.

We are asking *The Guardian* to share the full, unedited transcript and video, along with information directly from Kirkegaard in order to assist our investigations. We are fully prepared to use all legal measures available to us.

If you are a participant and have any questions about this misleading story, please email us at ukbiobank@ukbiobank.ac.uk and we will be back in touch.

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- [Call the Participant Resource Centre: 0800 0276 276](#)
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