



PARTICIPANT INFORMATION SHEET – Survey Participants **Identifying the dyslexia community's priorities for research**

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We would like to invite you to take part in a study looking at the research priorities for the dyslexia community. We are interested in the opinions of those who have a dyslexia diagnosis and their family members and caregivers. We are partnering with the Helen Arkell Dyslexia Charity for this study. Before you decide whether to take part, it is important that you understand why the research is being done and what it involves. Please take time to read the following information carefully and ask us if you have any questions. We also have an easy read information sheet if you prefer.

What is the purpose of the study?

While there has been lots of research into dyslexia, no studies have yet asked members of the dyslexia community about what research is most important to them, and what they would like to see researched in the future. Here we will find out from people with dyslexia and their family members or caregivers about what their research priorities are, so that future research efforts can be guided towards the areas that matter most to the dyslexia community. This will ensure that the results of research have the potential to benefit people with dyslexia.

Who can take part?

We are recruiting people living in the UK aged 18+ years who have a diagnosis of dyslexia (or who self-identify as having dyslexia) or who are caregivers or immediate family members of an individual diagnosed with dyslexia.

Do I have to take part?

No - it is up to you to decide whether or not to take part. If you decide to take part, you will be asked to sign a consent form. If you agree to participate, you are free to withdraw your consent without giving a reason, by closing the browser on the survey. We will not be able to withdraw your data after you have finished participating because data will be anonymised.

What will happen if I agree to take part?

You will complete an online survey lasting approximately 15 minutes. You will be asked to rate the importance of a range of research questions. You will also be asked about which research questions you would most like answered in the future. You will have the opportunity to enter a lottery for one of 10 £20 vouchers, if you provide your email address.

What will happen to the results of the research study and my data?

We will put the overall findings of the study on our website and disseminate them to members of dyslexia organisations (e.g., Helen Arkell Dyslexia Charity). You can also contact the researchers if you would like to be sent information about the overall findings. We also plan to publish the results in a scientific journal and disseminate the results at conferences.



Data will be stored securely on password protected computers and University servers or in locked filing cabinets within the University. Your data will be stored with an ID number, not with your name. If you give your email address to enter the lottery, this will be deleted as soon as the lottery has been drawn. No information that could lead to the identification of an individual will be disclosed to anyone outside of the research team. Anonymised data will be shared with other researchers so that it can be of greater scientific benefit.

Who has reviewed the study?

This project has been subject to ethical review, according to the procedures specified by the School level review at the University of Reading and has been given a favourable ethical opinion for conduct (ref: SREC 2021-190-CM).

Contact for further information

If you would like to take part, please fill out the online consent form. If you would like to discuss the research beforehand, or have any questions, please contact Dr Cathy Manning (c.a.manning@reading.ac.uk / 44(0)118 378 3454), Beverley Jennings (b.j.jennings@pgr.reading.ac.uk) or Professor Holly Joseph (h.joseph@reading.ac.uk) who will do their best to answer your query.

GDPR information

The organisation responsible for protection of your personal information is the University of Reading (the Data Controller). Queries regarding data protection and your rights should be directed to the University Data Protection Officer at imps@reading.ac.uk, or in writing to: University of Reading, Information Management & Policy Services, Whiteknights House, Pepper Lane, Whiteknights, Reading , RG6 6UR, UK.

The University of Reading collects, analyses, uses, shares, and retains personal data for the purposes of research in the public interest. Under data protection law, we are required to inform you that this use of the personal data we may hold about you is on the lawful basis of being a public task in the public interest and where it is necessary for scientific or historical research purposes. If you withdraw from a research study, which processes your personal data, dependant on the stage of withdrawal, we may still rely on this lawful basis to continue using your data if your withdrawal would be of significant detriment to the research study aims. We will always have in place appropriate safeguards to protect your personal data.

You have certain rights under data protection law which are:

- Withdraw your consent, for example if you opted in to be added to a participant register
- Access your personal data or ask for a copy
- Rectify inaccuracies in personal data that we hold about you
- Be forgotten, that is your details to be removed from systems that we use to process your personal data
- Restrict uses of your data
- Object to uses of your data, for example retention after you have withdrawn from a study

Some restrictions apply to the above rights where data is collected and used for research purposes. You can find out more about your rights on the website of the Information Commissioners Office (ICO) at <https://ico.org.uk>. You also have a right to complain the ICO if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer in the first instance.

Thank you for considering taking part in this study.