University of Reading

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PARTICIPANT INFORMATION SHEET - Focus groups

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 have included an easy read information sheet and we can go through the information sheet on the phone with you 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 aged 18 years and over in the UK who have a diagnosis of dyslexia or who are parents/caregivers/other immediate family members of an individual with a dyslexia diagnosis.

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 at any time and without giving a reason. This can be done by informing the researchers.

What will happen if I agree to take part?
You will be invited to take part in a group discussion with 5-7 other people with you online on MS Teams or face-to-face at the University, or at another convenient location (e.g., a school or parent group setting). The session will take approximately 1 hour and will be recorded (using MS Teams for online sessions or audio-recorded using a Dictaphone for face-to-face sessions) so that we can transcribe the information later. Before the focus group session, you will be asked to complete a short demographic questionnaire.

Are there any possible disadvantages or benefits of taking part?

The proposed study will not pose any risk of harm to participants directly. The researchers will ensure that you are happy to continue throughout the session, and you can take a break if you need to or leave the focus group. While there are no direct benefits of taking part, you will be able to voice your opinion, and it is hoped that the results of the study will guide future research efforts to in turn benefit individuals with dyslexia in the future. You will be given a £20 voucher to thank you for your time.

What will happen to the results of the research study and my data?
You will receive a report of the overall results of the study. 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. The personal information we collect about you is kept strictly confidential. Your contact details will only be used for the purposes of this study (e.g., organising focus groups and providing updates about the results) and deleted after the study is complete, unless you tell us you are interested in hearing about similar studies in the future. Audio/video recordings obtained from the discussion groups will be kept on secure University networks and deleted after being transcribed and checked for accuracy. Any identifying information (e.g., your name) will be removed from the transcript and replaced with ID numbers. Anonymised transcribed information will be used in research reports. All other data (e.g., questionnaires) will be stored only with an ID number, and not with participant names. 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: 2021-190-CM).

Contact for further information
If you would like to take part, please fill out the consent form. For online focus groups, you can complete the consent form online or by emailing a scanned copy to the researcher. For in-person focus groups, you can return the consent form to the researcher at the session. 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), Raveen Rayat (r.rayat@student.reading.ac.uk) or Dr 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.

If we have included any additional requests for use of your data, for example adding you to a registration list for the purposes of inviting you to take part in future studies, this will be done only with your consent where you have provided it to us and should you wish to be removed from the register at a later date, you should contact Dr Cathy Manning by email (c.a.manning@reading.ac.uk) or by phone (+44(0)118 378 3454).

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.