

Evaluating the RNIB's Bookshare scheme

Information Sheet for Parents/Carers

We are asking if you and your child would like to take part in a project. This sheet will tell you all about it.

You are being invited to take part in a research project. Please take time to read this information sheet. This sheet will tell you why the study is being done and what taking part will involve. Then you can decide if you would like to take part. Discuss it with others if you wish. Ask us if you have any questions. Thank you for taking the time to read this.

Who is doing this study?

The study is being led by Dr Emma Ashworth from Liverpool John Moores University. The team includes Professor Lucy Bray from Edge Hill University and Dr Joanna Kirkby, also from Liverpool John Moores University.

What is the purpose of the study?

- This study is trying to find out about how children and young people (aged 7 to 16) with vision impairment or a print disability (e.g. dyslexia) use books.
- We are also looking to find out whether the Bookshare service is/would be beneficial for your child. Bookshare is a scheme provided by RNIB to make books accessible for children with vision/print disabilities.
- You can take part whether your child has used the Bookshare service or not.

Why have we been invited to take part?

- We would like to understand more about how your child (aged 7 to 16) with vision impairment or a print disability (e.g. dyslexia) uses books.
- We are specifically interested in how the Bookshare service helps with using books.
- Your child does not have to be using Bookshare right now in order for you to join in.

Do I or my child have to take part?

- No. It is up to you to decide.
- You can take part without your child having to take part. But your child can only take part if you do.
- If you do not wish to take part there is nothing more that you need to do.

What will happen if I take part?

- You will be asked to complete a short online survey.
- It will take about 10 minutes to fill out.
- The survey asks questions about your child's use of books.
- If your child has used the Bookshare scheme, you will be asked how the Bookshare scheme has helped your child, and how it could be improved.
- If your child has not used the Bookshare scheme, you will be asked if you think the Bookshare scheme could help your child.
- You will not have to answer any questions you do not want to.
- You can end the survey at any time.
- We will not know that your answers belong to you.
- There will be a separate link at the end of the survey where you can leave your contact details if you would like to volunteer to take part in an interview.

What will happen if my child takes part?

- Only children who have used the Bookshare scheme can take part.
- If you and your child decide they would also like to take part then please read the children's information sheet about the study with them.
- The children's survey is at the end of the parent's one. There is a box at the beginning of their survey which we will ask you to tick to say you are happy for them to take part.
- Your child can fill in their part of the survey on their own, or you can help them by typing in what they say.
- The survey for children will take about 10 minutes for them to fill out.
- They can share their views by writing, using emojis, or uploading a picture.
- We will not know the answers belong to your child.
- Your child will not be able to go back and see your answers.

Will I or my child be photographed or video/audio recorded and how will the recorded media be used?

No. We will not take any photographs. No video recording will take place.

Are there any possible disadvantages or risks from taking part?

- We hope that taking part will not involve any risks for you or your child.
- You do not have to answer any questions that you do not want to.
- At the end of the survey and this sheet there are some links and numbers to support services.
- As we will not know who has filled out a survey, we will not be able to offer individual help or support.

What are the possible benefits of taking part?

We hope that what we find out from this study will help the Bookshare service to run well for other children and young people.

Payments for taking part

There will be no payment for taking part in this study.

What will happen to the results of the study?

- We will share the results in articles and presentations.
- We will also work with parents and children to write a summary of the key findings which will be posted on our webpage.
- The report from the project will be shared with the RNIB and put on their website.

What will happen to information/data provided?

- We will not ask you to give us any of your personal data.
- We are using Survey Monkey which is a third party site. Here is a link to their privacy information: <https://www.surveymonkey.co.uk/mp/privacy/>
- You may choose to provide your name and contact details in order to take part in a follow up interview. You will be able to click on a separate link to give your contact details. Your contact details will not be linked to your answers. Your contact details will be deleted straight away after the study is finished.
- We will write our reports in a way that no-one can work out that you took part.
- Your answers will be kept for five years after the study has finished.

Who is organising and doing the study?

This study is funded by the Royal National Institute of Blind People (RNIB). The study is being done by Liverpool John Moores University and Edge Hill University.

Who has reviewed this study?

This study has been reviewed and given ethics clearance through the Liverpool John Moores University Research Ethics Committee. UREC Reference: 22/PSY/024

What if something goes wrong or I have a concern?

- If you have a concern about any part of this study, please contact the lead researcher, Dr Emma Ashworth (E.L.Ashworth@ljmu.ac.uk). Emma will do her best to answer your concern within 10 working days.
- If you wish to make a complaint, please contact the chair of the Liverpool John Moores University Research Ethics Committee (researchethics@ljmu.ac.uk). Your complaint will be sent to an independent person.

Data Protection Notice

Liverpool John Moores University is the data controller with respect to your personal data. Information about your rights with respect to your personal data is available from:

<https://www.ljmu.ac.uk/legal/privacy-and-cookies/external-stakeholders-privacy-policy/research-participants-privacy-notice>

Contact for further information

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Thank you for reading this sheet