

Participant Information Sheet

A qualitative study exploring attitudes towards the use of the internet and social media in adults living with aniridia

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others, if you wish.

Thank you for reading this.

1. What is the purpose of this research project?

The purpose of this student research project is to gain a greater understanding of how adults living with aniridia use the internet and social media in relation to their condition. The aim is to explore experiences, opinions and attitudes towards internet and social media use to gain information and to connect with others who share similar experiences. In doing so this study will add to the research evidence, increase professional awareness of the value of online resources and identify whether members of Aniridia Network and the Aniridic Family Group feel online resources meet needs they have relating to their condition e.g. for information and connection.

Data generated from this study will provide a basis with which to improve online services for members of the Aniridia Network. The results will be used to identify what motivates members when using the internet and social media, and to evaluate whether online services currently provided by Aniridia Network meet member needs.

2. Why have I been invited to take part?

You have been invited because you are a member of Aniridia Network or Aniridic Family Group, identify as having aniridia, are able to communicate in spoken and written English and are aged 18+.

3. Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part, we will discuss the research project with you and ask you to provide your verbal consent which will be recorded in a consent form and audio recorded. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights. Your decision to take part or not to take part will not affect any current or future care you receive.

You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing or verbally consenting to the consent form.

4. What will taking part involve?

Participation will involve one online interview which will take approximately 60 minutes. The interview will be conducted virtually via a secure video-conferencing platform at a time arranged to suit you. During the interview you will be asked about your experiences, views and opinions of using the internet and social media relating to aniridia. The interview will be audio recorded to ensure that a transcript of the interview can be faithfully and accurately reproduced. Due to the virtual nature of the interview participants will require access to a device with online capabilities (e.g. smartphone or computer) and an internet connection. The researcher will provide access to the secure video-conferencing platform.

If you are unable to take part in an online interview, the interview can alternatively be conducted over telephone or, potentially, in person depending on distance and student researcher availability.

5. Will I be paid for taking part?

No. You should understand that any data you give will be as a gift and you will not benefit financially in the future should this research project lead to the development of a new method/test/assessment.

6. What are the possible benefits of taking part?

There will be no direct advantages or benefits to you from taking part, but your participation will contribute towards improving understanding of the motivations that drive internet and social media use in Aniridia Network and Aniridic Family Group members. Participation in the study can help identify unmet online needs of the community, providing a basis with which to inform future service developments and better meet the needs of adults living with aniridia.

7. What are the possible risks of taking part?

There is the possibility discussion of issues relating to living with a visual impairment and internet and social media use may risk triggering distress and affect your emotional wellbeing, particularly if you have had any negative online experiences. If you were to become distressed at any point you will be reminded of your right to discontinue your participation in this project with no consequence at any stage. In the event this happens you will be provided with a list of contact details for organisations that provide mental health support and cyber bullying support if appropriate. If the source of distress was specific to aniridia or visual impairment you would be offered referral back to Aniridia Network for further support if you wished.

8. Will my taking part in this research project be kept confidential?

All information collected from (or about) you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection

legislation. Please see 'What will happen to my Personal Data?' (below) for further information.

Confidentiality may be over-ridden in exceptional circumstances in which the research team feel they are legally and/or professionally required to over-ride confidentiality and to disclose information obtained from (or about) you to statutory bodies or relevant agencies. For example, this might arise where the research team has reason to believe that there is a risk to your safety, or the safety of others. Where appropriate, the research team will aim to notify you of the need to break confidentiality should it arise (but this may not be appropriate in all cases).

9. What will happen to my Personal Data?

Audio recordings of interviews will be securely stored by Cardiff University within the LearnPlus system for the required data retention period. This is a minimum of five years after completion of the research study or after publication of any findings based upon the data (whichever is later). Audio recordings will be transcribed and anonymised as soon as possible after the interview. Only the student researcher and her academic supervisor will have access to listen to audio recordings for the purpose of transcription. Once transcribed anonymised transcripts will be stored on a password-protected computer and on completion of data analysis will be sent to the academic supervisor for storage on the secure Cardiff University shared drive for the data retention period and deleted from all other devices. No identifiable participant information will be published, and pseudonyms will be used in transcripts. Anonymised information may be published in support of the research project and retained in accordance with the Cardiff University retention period mentioned above.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your

expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

If you are unable to access the above link printed copies of the documents mentioned can be made available on request.

Although participants will be recruited through Aniridia Network Cardiff University will not need to share your name, email address, or phone number with Aniridia Network for the purposes of this research project.

All personal data collected from or about you will be anonymised by the principal researcher as soon as possible after the interview, with the exception of your consent form. Your consent form will be sent to the academic supervisor overseeing the project immediately following completion of each interview to be stored on the secure Cardiff University shared drive and retained for the data retention period (see above) in accordance with the University Records Retention Schedules. Consent forms may be accessed by members of the research team and, where necessary, by members of the University's governance and audit teams or by regulatory authorities. Anonymised information will be kept for a minimum of five years but may be published in support of the research project and/or retained indefinitely, where it is likely to have continuing value for research purposes.

You can withdraw from this study at any point, but we may need to retain the information you provide for audit purposes. If you withdraw from the study any data collected may still be used in line with the relevant legal provisions. We will always try to respond to concerns or queries you may have and comply with your wishes as far as possible, but since the data collected will be anonymised as soon as possible to protect your privacy, it will not be possible to withdraw your data after this point.

10. What happens to the data at the end of the research project?

At the end of the research project, any data shall be disposed of in accordance with University guidelines and relevant GDPR legislation.

11. What will happen to the results of the research project?

The results of the research project will be written up and submitted as an MSc Dissertation to Cardiff University in the summer of 2023. A copy of the final dissertation may be obtained either through the Cardiff university library or by contacting the principal researcher or a member of the research team. It is the principal researcher's intention to publish the results of this research project in academic journals and present findings at conferences if the opportunity arises. The principal researcher will also produce a lay-friendly summary of the project's key findings for members of the Aniridia Network. Participants will not be identified in any report, publication or presentation but verbatim quotes from participants may be used in the finalised publication where appropriate.

12. What if there is a problem?

If you wish to complain, or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Emily Sterling (Principal Researcher) via SterlingER@cardiff.ac.uk or Professor Marion McAllister (Project Academic Supervisor) via McAllisterMF@cardiff.ac.uk. If your complaint is not managed to your

satisfaction, please contact the Chair of the School of Medicine Research Ethics Committee, Dr Ned Powell via PowellNG@cardiff.ac.uk.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

13. Who is organising and funding this research project?

This research is organised by Emily Sterling (MSc Student) and Professor Marion McAllister (Academic supervisor) as part of the MSc in Genetic and Genomic Counselling at Cardiff University Centre for Medical Education. The research is not funded.

14. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the School of Medicine Research Ethics Committee (SMREC) at Cardiff University.

15. Further information and contact details

Should you have any questions relating to this research project, you may contact me during normal working hours:

Emily Sterling (Principal Researcher)
Email: SterlingER@cardiff.ac.uk

Thank you for considering taking part in this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and a copy of your completed consent form to keep for your records.