

Older Autistic's Kit questionnaire

Information and Consent

The Study: This survey is part of a project to develop an application (app) or website to support older Autistic people in overcoming some of the barriers they experience and improving their quality of life.

We are carrying out this research with funding from UK Research and Innovation and support from Zinc as part of their [Healthy Ageing Catalyst Awards 2021](#).

This study is for people assessed as Autistic, identifying as Autistic or seeking an autism diagnosis. We are particularly interested in responses from 60-year and older Autistic folks.

Investigators: We are all Autistic.

Marion Hersh is a senior lecturer at the University of Glasgow.

Michael Dawson and Panda Mery are involved in projects with Autistic people in Glasgow and London. They are both employed as project researchers by the University of Glasgow.

Procedures, confidentiality and anonymity: The questionnaire has five parts. You can complete it in 20-30 minutes and do so anonymously.

The section 'Personal Information' asks for personal data, such as age and gender. All questions, other than the initial consent question, are optional. We hope you will provide this information as it helps us identify any groups of members of the Autistic community that are missing and try to recruit them. It also allows us to investigate any differences in the experiences and perspectives of different groups of Autistic people.

We will store all data securely. If you give your agreement, your anonymous responses will be stored in the Glasgow store of research data. Otherwise only the three researchers will see the responses, they will not be shared with anyone else and we will delete or destroy all copies by two years from the end of this one-year project, by 31 August 2024. This will give us time to write up paper(s) for academic journals.

We will be producing a publicly available report. We hope to make presentations to stakeholders and submit our results to an academic journal. We will only publish statistical data and anonymised comments.

Benefits and risks: The main benefit is helping us develop solutions which are useful to older Autistic people. We are looking to make the preliminary version of the app or website available quickly and to obtain funding for features we are not able to include in the preliminary version. We consider there is no risk of physical harm and minimal risk of emotional harm in completing this questionnaire.

Voluntary participation: Completing the questionnaire is entirely voluntary. You can decide not to reply to one or more questions and to submit a partially completed questionnaire, though we hope you will answer all of them.

Ethical approval: We have received ethical approval from the Ethics Committee of the College of Science and Engineering of the University of Glasgow.

Further information: Please contact us if you have questions or would like further information about our research. You can also provide an email address or other contact details at the end of the questionnaire to participate in follow-up research or receive a copy of our report. We will store the contact details securely and separately from the responses. We will delete them by three months after the end of this one-year project, by 30 November 2022.

Contact details:

Dr Marion Hersh

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- Address: Dr Marion Hersh, Biomedical Engineering, Rankine Building, University of Glasgow, Glasgow G12 8LT.

Michael Dawson

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Panda Mery

- Email: panda.mery.2@glasgow.ac.uk

1. Consent: I have read the information about the study, understand I can withdraw at any time, how my data will be used and that it will be deleted or destroyed by 31 August 2024 if I do not give permission for it to be stored in a data stores. I agree to participate in the study. (*Required*)

Yes.....

No.....

Please proceed with the rest of the questionnaire only if you accepted this consent form by ticking Yes.

Experience of Technology

We are asking about your level of experience of technology to help us design an app or website that is appropriate for most.

A website can be accessed from a web browser on any computer even on the smaller size of smartphones and tablets screens. An app needs to be downloaded and installed before it can be used. Apps can offer more features than websites and, on a smartphone or tablet, have an icon present on the screen that you can touch to open them.

If you need more space, fill free to continue writing on additional blank pages.

2. Please rate your level of experience and skill with the following technologies.

	Expert user	Use it often	Use it occasionally	Rarely use it	Don't use it
Smartphone					
Tablet					
Laptop computer					
Desktop computer					
Connecting to the Internet (e.g., wifi, mobile data, broadband)					
Apps					
Websites					
Email					
Messaging					
Social networks					

3. Please comment on your willingness to learn new technologies and how easy you find this.

4. Which of the following formats would you prefer?

	Like	Dislike	Unsure
Apps on smartphones			
Websites on smartphones			
Apps on tablets			
Websites on tablets			
Apps on laptops or desktop computers			
Websites on laptops or desktop computers			

4a. Please describe all aspects of these different formats you like.

4b. Please describe all aspect of these different formats that you dislike or could cause you difficulties.

5. Which of the following tools and support are of interest to you?

	Very interested	Somewhat interested	Not interested
Strategies to overcome barriers to participation or access			
Signposting to several sources of advice for dealing with new or difficult situations			
Tools for structuring problems and prioritising actions			
Confidence and assertiveness tools			
Peer mentoring			
Support network of Autistic people			
Guide to Autistic-friendly spaces			

6. What types of information would you like signposting to?

	Very interested	Somewhat interested	Not interested
Autistics and organisations of Autistic people			
Counselling services suitable for Autistic people			
Counselling and support for family, friends and relationship issues			
Local advocates for guidance and support			
Local sport and leisure activities			
Online leisure activities			
Health information			
Support and training for independent living			
Support and training for improving your qualifications and getting a more interesting job			
Help in using technology			
Help with online security			
Help with personal finance			
Sources of informal help with daily activities			

7. Please provide any additional comments on the tools, support and types of information you would find useful and how you would use them.

8. Please provide any additional comments on your experiences of technology and any suggestions for technologies you might find useful.

App or Website Features

This section is to help us identify what features the app or website should provide to be most useful.

9. Please identify any tasks or activities you do or want to do that might benefit from some form of support or help.

10. What would you like an app or website to do to help provide the support you identified in the previous question?

11. If a website or app helped you to do the tasks or activities you identified in question 9, how do you think this would improve your quality of life?

12. What customisations would help make the app or website more accessible to you?

	Yes	No	Unsure
Choice of screen layout			
Choice of text size and colour			
Audible feedback			
Visual feedback			
Option to turn any feedback on and off			
Choice of text menus or icons to initiate actions			
Speech input option			
Speech output option			
Changing the order of menus			

13. What makes particular technologies easy or difficult to use by you?

14. Please provide any additional comments and suggestions that would help us make an app or website most useful to you.

Payment Models

Some funding or revenue will be required to cover running costs and maintenance of an app or website. Indications of what you find good models of funding will help us to find ways to make the app or website sustainable.

15. Which of the following payment models would enable you to use the system?

- Annual subscription, based on what you can afford.....
- Monthly subscription, based on what you can afford.....
- One-off payment, based on what you can afford.....
- Advertising.....
- Sponsorship.....
- Other.....

15a. If you selected Other, please specify:

16. Which advertising and sponsorship technologies are acceptable to you?

	Acceptable	Difficult	No opinion
Text ads			
Still image ads			
Pop ups			
Moving images			
Background music			
Colourful screens			

16a. Are there any other advertising and sponsorship technologies which you find particularly good?

16b. Are there any other advertising and sponsorship technologies which you find particularly difficult?

16c. Would the use of any of these technologies stop you from being able to use the app or website?

17. What types of organisations or individuals would you find advertising or sponsorship from acceptable?

18. What types of organisations or individuals would you find advertising or sponsorship from unacceptable?

19. Please add any comments about what makes sponsorship or advertising acceptable or unacceptable to you and how much you would be willing to pay, if at all, for an app or website with some of the features and functions you identified in the previous sections.

Personal Information

Answers in this section will help us identify any groups of members of the Autistic community that are missing and try to recruit them. It will also allow us to investigate any differences in the experiences and perspectives of different groups of Autistic people.

20. Are you Autistic?

Yes, I have a formal medical diagnosis of autism (including Asperger's syndrome or any other autism spectrum diagnosis).....

Yes, I self-identified and do not want a diagnosis.....

I am in the process of seeking a diagnosis.....

No.....

Don't know.....

21. How old are you (in years)?

22. What is your gender identity?

Male.....

Female.....

Non-binary.....

Other.....

22a. If you selected Other, please specify:

23. How would you describe your ethnicity?

24. What are your living arrangements? Indicate all that apply.

- Alone.....
- With partner(s).....
- With your children.....
- With close friend(s).....
- With parent(s).....
- With other family.....
- House-share.....
- Live-in care.....
- Sheltered or retirement housing.....
- Housing-with-care (e.g., retirement village, close care housing).....
- Residential care home.....
- Nursing home.....
- Homeless.....
- Other.....

24a. If you selected Other, please specify:

25. Please provide more details about your living situation and any changes you would like to make in it.

26. Where do you live?

- Large city.....
- Medium sized town or city.....
- Small town or city.....
- Rural area or village.....
- Other.....

26a. If you selected Other, please specify:

27. What country do you live in?

- Scotland.....
- England.....
- Wales.....
- Northern Ireland.....
- Ireland.....
- Other.....

27a. If you selected Other, please specify:

28. What is your employment status?

- Retired.....
- Unemployed.....
- Full time employment.....
- Part time employment.....
- Self-employed.....
- Other.....

28a. If you selected Other, please specify:

29. Please comment on your employment situation and any changes you would like to make to it.

Follow-ups

30. Would you like to participate in a follow-up interview or other follow-up research for this project?

Yes.....

No.....

31. Do you consent to having your anonymised responses stored in the Glasgow store of research data?

As explained in the Information and Consent page, if you answer *Yes*, your anonymous responses will be stored in the Glasgow store of research data and accessible to other researchers even after we finish all publishing activities related to this project. This may help other projects.

Otherwise, if you answer *No*, only the three researchers will see the responses, they will not be shared with anyone else and we will delete or destroy all copies by two years from the end of this one-year project, by 31 August 2024. This will give us time to write up paper(s) for academic journals.

Yes.....

No.....

32. Would you like to be informed of the outcome of this research?

Yes.....

No.....

33. If you answered *Yes* to either of the two previous questions, please provide your contact details, including an email address if possible. This information will only be used by the three researchers on this project and stored securely and separately from your responses. It will be deleted by three months after the end of the project, by 30 November 2022.

Returning this filled in questionnaire

Thank you for having participating in this research project. If you are able to scan the pages, then please email them to:

panda.mery.2@glasgow.ac.uk

Otherwise, please post them to:

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