



Participant Information Sheet

Project Title: Reasonable Adjustments for Autistic Clinicians (RAAC)

Thank you for considering participating in this survey. The following information offers an overview of this research project and what participation will involve.

What is the purpose of this project?

The overarching aim of this project is to gather survey data about autistic clinical professionals (AuCP's) who are registered with either the GMC, NMC, or HCPC. Specifically, we wish to survey AuCPs' experiences of reasonable adjustments in their clinical workplaces.

The survey is designed to gather data about:

1. the reasonable adjustment needs of AuCPs,
2. reasonable adjustments that have been put in place for AuCPs, and
3. barriers to requesting/implementing reasonable adjustments experienced by AuCPs.

A word about the language we will use when reporting this work

In Great Britain, it is the Equality Act 2010 that provides legal protections for discrimination against disabled people due to their disability. Additionally, The Equality Act imposes a duty to make reasonable adjustments for disabled people when they are at substantial disadvantage to non-disabled people. For this reason, the reporting of this work will talk about 'disabilities', but we recognise and acknowledge here that not all people consider being autistic as a disability.

How long will the survey be open for?

The survey will be open for one month: 20th October 2022 through to 17th November 2022.

Why have I been invited to participate?

We are specifically looking for persons who are:

- Autistic
 - **You need not have a formal diagnosis of autism to enrol in this study.** We recognise that formal diagnosis of autism is a privilege and not something that is available to all who are autistic. *There are significant barriers to diagnosis, ranging from having a GP who is prepared to refer someone for assessment, to high cost if the only option is for private assessment, through to being a gender other than male when the assessor does not have experience of assessing autism in other genders.* We recognise

self-diagnosis as valid and anticipate one finding of this study to be that a lack of formal diagnosis may be a barrier to an AuCP accessing reasonable adjustments in their workplace.

Indeed, a diagnosis of autism is not required for the Equality Act to apply, only that there is evidence that the person's difficulties are chronic and substantial (Doyle and Medhurst, 2022).

- Current registrants with the General Medical Council (GMC), Nursing and Midwifery Council (NMC), or the Health & Care Professions Council (HCPC).
- Currently employed in clinical practice and working within the scope of their registration.
- Can read and type in English.
- Currently employed in Great Britain (England, Wales, or Scotland).
 - *The Equality Act 2010 covers only England, Scotland, and Wales, thus does not speak to other jurisdictions such as Northern Ireland, but output of this work may still be useful to AuCPs and their employers who wish to enable them worldwide, even in the absence of a legal duty.*

What will happen to me if I take part and what will I have to do?

The survey will consist of a mixture of closed multiple-choice questions and open questions which invite free-text responses. It may take around 30 minutes to complete.

You are welcome to give as much detail as you wish in your free-text responses. We do not collect your personal information (e.g., your name) so no one will be able to directly link your responses back to you, but please only give information that you are comfortable to share with us and that you are happy for us to use/quote (anonymously) when we report this survey's findings in publication(s) and presentation(s).

Please note that by submitting responses to this survey you are agreeing that you consent to participating in this research.

Do I have to take part?

You have an entirely free choice to take part in this study or not.

Can I withdraw from the study if I change my mind later?

No. Because we do not ask your identity, once you have submitted your responses at the end of the survey, your contribution will be irretrievable because data that is submitted is anonymous. It will not be possible to remove your responses from the dataset, and so you cannot change your mind and remove your data at a later date.

If you close the survey window before pressing 'submit' your responses will not be recorded and you will not have participated in the study.

What are the possible benefits and risks of taking part?

Risks:

We have not identified any substantial risk to you taking part.

All of your answers will be anonymous, and so even in the very unlikely event of a data leak your answers cannot be traced back to you.

There is a very small risk of your identity being determined through the use of the quotes you provide (please see the section below which discusses this).

It is possible that you may find thinking about some of the questions distressing: if participating in this survey is distressing you, please stop participating – your wellbeing is far more important to us. Please find a list of sources of support below.

Benefits:

Participation is unlikely to benefit you directly, although you may find the opportunity to reflect on your experiences beneficial. The publication of this work aims to help all autistic clinical professionals who feel that they are alone and do not know what reasonable adjustments to ask for, and so your participation will hopefully benefit others.

We hope that autistic clinical professionals can use this work to start conversations with their employers about the nature of their differences and the variety of reasonable adjustments which can be adopted to help them to continue to contribute and shine in health services.

Will my participation be kept confidential and what will happen to my survey responses?

We will not be asking for or recording your personal details.

Your responses will be kept securely on secure, password protected, University of Bristol systems. During analysis, they will only be accessed by researchers who are directly involved in this project.

However, we will be using survey responses, e.g., quotes, when we report this survey. Whilst no-one will know who has contributed any of the quotes, we strongly recommend that you consider how specific your responses are and that your words might be published or repeated by the researchers in a presentation when we disseminate the study's results.

We aim to report the survey's findings in a general sense to avoid the identity of participants being triangulated. To aid that aim, we request that participants not provide information that is too specific. For example: instead of telling us that you work in a one-of-a-kind position which would make you immediately identifiable, please instead tell us the general area that you work in.

What will happen to the results of the research project?

Survey responses will be analysed, written up into a report, and submitted to academic journals for publication as well as hopefully being presented at conferences for audiences such as academic and/or clinical professionals.

We additionally aim to use the survey's responses to inform the design of a co-construction project to produce guidance about reasonable adjustments for clinical employers and employees who are autistic. The aim of this co-construction project would be to improve equality, diversity, and inclusion of autistic clinical professionals in their workplaces.

Journal articles and presentations resulting from this work will be announced via the Centre for Ethics in Medicine's Twitter account (@BristolEthics).

Who is organising and funding the research?

The Principal Investigator and main researcher of this study is Helen Smith (she is autistic and a registered nurse). Jonathan Ives is Co-Investigating and supervising this work.

This work is funded by the University of Bristol's Elizabeth Blackwell Institute Research for Equality, Diversity & Inclusion in Health and Biomedicine. The funds awarded include contributions from the Wellcome Trust Institutional Strategic Support Fund; specifically, from the Open and Transparent Research initiative.

Who has reviewed this study?

Clinician-academic members of Autistic Doctors International (Dr Sebastian Shaw and Dr Mary Doherty) are providing support as a steering committee to help support and guide this work.

The University of Bristol's Faculty of Health Sciences Research Ethics Committee has reviewed and approved this research prior to commencement. (Ref: 12134)

What will happen to my data?

Your involvement in the study will remain confidential as we will not be collecting personal identifiable information, e.g., your name, date of birth, or email address.

At the end of the study, your responses will be combined into a dataset and be stored in the University of Bristol's Research Data Storage Facility (RDSF) for a minimum of 5 years.

Access to this study's data will be closed: the stories that people will give in their answers will be specific and personal, this could make them potentially identifiable. For this reason, the dataset will not be made available to other researchers or for other studies or projects.

The data provided may be seen and used by researchers directly working on this study, and they may use it for future related projects.

Further information and contact details

The contact details for the Principal Investigator of this study are:

- Helen Smith: helen.smith@bristol.ac.uk

If you have any concerns related to your participation in this study, please direct them to the Faculty of Health's Research Ethics Committee, via the Research Governance Team (research-governance@bristol.ac.uk).

Participating in this survey has distressed me, what help is available for me?

If participating in this survey is distressing you, please stop participating – your wellbeing is far more important to us.

If your distress is ongoing, here are some options for support:

- You could talk through how you are feeling with a trusted friend, colleague, or Samaritans on 116123
- You could contact an organisation that specifically helps clinical professionals, for example:
 - Nurse Lifeline 0808 8010455
 - Practitioner Health 0300 0303 300
- You could contact your GP to discuss further support

OK, I am happy to participate. What should I do?

Many thanks! Please continue to the survey.

I do not wish to participate

That's absolutely fine.

We thank you very much for reading this far and considering participating in our study.

You are welcome to now close this page.