Appendix A

Literature Review

Table 1

Studies that did not add further contributions to knowledge about NBA people

Reason	Studies
Quantitative*	
• Did not include gender analyses	(Arnold *et al.*, 2020; Casagrande *et al.*, 2020; Pohl *et al.*, 2020; Riccio *et al.*, 2020; Kember and Williams, 2021; Qualls *et al.*, 2021; Rifai *et al.*, 2021; Strauss *et al.*, 2021; Weir, Allison and Baron-Cohen, 2021)
• Nonbinary groups combined with others for statistical analyses	(Cooper, Smith and Russell, 2018; Walsh *et al.*, 2018; Griffiths *et al.*, 2019; Sedgewick *et al.*, 2019; Sedgewick, Leppanen and Tchanturia, 2019; Botha and Frost, 2020; Graham Holmes *et al.*, 2020; Pecora *et al.*, 2020; Warrier *et al.*, 2020; McQuaid, Lee and Wallace, 2021)
• Excluded from statistical analyses	(Lorenz *et al.*, 2016; Cage and Troxell-Whitman, 2019; Bottema-Beutel *et al.*, 2020; Brosnan and Adams, 2020; Zheng *et al.*, 2021)
Qualitative*	
• Did not include gender labels with data	(Cage and Troxell-Whitman, 2019; Sosnowy

excerpts	*et al.*, 2019; Arnold *et al.*, 2020; Raymaker *et al.*, 2020; Riccio *et al.*, 2020; Ashworth *et al.*, 2021; Cook *et al.*, 2021; Cope and Remington, 2021; Gray, Kirby and Graham Holmes, 2021; Pellicano *et al.*, 2021; Romualdez *et al.*, 2021; Stark *et al.*, 2021; Zheng *et al.*, 2021)
• Did not include data excerpts from NBA participants	(Bottema-Beutel *et al.*, 2020; Pohl *et al.*, 2020)
• Referred to ‘gender diverse’ participants in labels accompanying data excerpts	(Strömberg *et al.*, 2021)

Note. *mixed methods studies may be represented multiple times in the table where appropriate

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Appendix B

Recruitment materials

Contents

Twitter message

Message sent to potential participants asking them to take part in the study:

> Hi, I am a postgraduate researcher at the University of Birmingham in the UK. I was wondering whether you would be interested in taking part in a research project looking at what research involving nonbinary autistic people should focus on. I am particularly interested in your unique perspective.
>
> I believe this research is important in highlighting the views of the community and directing future research.
>
> The study will consist of an online interview (either spoken or text-based) and a short pre-interview activity.
>
> If you're interested, please read the documents linked below for more information about the study. Alternatively, you can listen to the same information at https://www.youtube.com/watch?v=doU77M6JLa8 If you are interested, please complete the consent and demographic questionnaire linked below and send it to my university email address at [redacted] (if you don't receive a reply, you may need to check your Junk box). Please note, you will need access to a laptop/computer or a tablet for the interview. This study has been approved by the Ethics Committee at the University of Birmingham.
>
> Thank you,
>
> Charlotte Brooks
>
> Links for documents mentioned above (alternatively, you're welcome to email me for copies if you're concerned about spam):

Information sheet:
https://drive.google.com/uc?export=download&id=15gdywhaOTWIbE5vqJZFi05lLiuxvPnFg

Consent and demographic questionnaire:
https://drive.google.com/uc?export=download&id=13SfyIOjp4FL93VVwYoh2mkLINVcsPgPG

If you require screen-reading technology to access any of the above, NaturalReader is a free app available on android and iOS (https://www.naturalreaders.com/app/)

Information sheet

Study information:

I recognise there is a lot of text on this page. If you prefer, you can view a video of this information by following this link https://www.youtube.com/watch?v=doU77M6JLa8

Purpose of the study

This study is interested in providing an academic platform to talk about the research interests of the nonbinary autistic (NBA) community. I am hopeful that the findings of this study will be used to inform future research by being published in an academic journal, helping to ensure that future research is helpful and relevant to the community. I will also apply the findings of this study in my own research for my PhD.

Who is organising and funding my research?

I am a PhD student at the University of Birmingham looking into the experiences of NBA people, specifically in relation to autistic masking, and the inclusion of NBA people in schools. I am being supervised by Dr Prithvi Perepa and Professor Karen Guldberg (contact information below). There has been no additional funding for the current project other than Economic and Social Research Council (ESRC) scholarship funding for my own PhD.

Do I have to take part?

Participation in the study is entirely voluntary. Refusal or withdrawal from the study will involve no penalty or loss, at this time or in the future. Please note that you will be able to withdraw at any time until a month after our interview has taken place.

What will happen to me if I take part?

The study will consist of an interview and an activity that takes place a week before the interview. In the message I sent you on Twitter, I also provided you with a copy of a questionnaire to complete - this includes your consent to take part in this study and some questions about who you are (e.g. your age, the country where you live). This information will be used when I write up the research into a report, to give readers some idea of who you are (though your actual identity will stay anonymous). This questionnaire will also ask for your consent to take part in the study.

Interviews

- Interviews will take place online using Zoom, voice call or instant messaging (depending on your communication preferences). Zoom and voice calls will be recorded to collect data for the study.
- If you decide to take part, we will select a time for the interview that is convenient for both of us.
- One week before the interview, I will contact you with information about a short activity for you to complete and return before the interview. This activity will involve going about your everyday life and coming up with questions about your identity and the needs of the community that you think research should address. I will provide you with some support documents on how to do this.
- In the interview we will talk about what you think research involving autistic nonbinary people should focus on. We will do this by discussing what you produced in the pre-interview activity. We will also talk about another exercise that will involve clicking and dragging statements into order.
- After the interview has been transcribed, I will analyse your responses and organise them into themes. I will then send you a copy of what I have done to ask for your comments – if you don't agree with what I've said, both interpretations will be reported alongside each other when I write up the research.

Are there possible disadvantages and/or risks in taking part?

Some aspects of the interview may ask you to reflect on aspects of your identity that make you feel happy. It may also bring up things you find difficult or experiences of being treated unfairly and/or when you have faced prejudice.

If this does happen, I will respond sensitively and also remind you that you don't need to talk about anything that makes you uncomfortable. If needed, I will also be able to signpost you to resources if you wish to seek support from a group or service.

What are the possible benefits of taking part?

I am hopeful that the findings of this study will be used to inform future research by being published in an academic journal and presented at conferences. This means that by participating in the study you may be able to influence the kinds of research that takes place involving nonbinary autistic people. You will also have the opportunity to learn more about what research has been done so far including nonbinary autistic people. I also believe that the activities I have chosen for the interview should be fun and enjoyable.

What will happen to my information and the results of the research project?

All information you give me will be stored securely on University servers with access given only to me and my supervisors. After the interview has taken place, I will use the recording to transcribe what both of us said during the interview into a written format using Otter transcription software (which is GDPR compliant). After the interview has been transcribed, I will delete all information from Otter, however it is possible that they may retain a trace of the recording.

I will then analyse the transcript using a technique called interpretive phenomenological analysis (IPA). This technique is particularly good at preserving the ‘voice’ of participants. IPA involves finding patterns and themes in what you have said.

After I have analysed your transcript, I will contact you for comments on what you think of any interpretations I have made. After I have analysed the transcript, the original recording of our interview will be deleted.

Writing up the research – the findings of the study will be written into a report, which will include excerpts of what you have said in the interview and some of the demographic information from the questionnaire to help readers to put your responses in context of who you are. I will use a pseudonym instead of your real name, to keep your identity anonymous. The report will then be submitted to the University of Birmingham as a Master’s in Social Research Methods dissertation. A revised version of this report may also be published in an academic journal and/or an open research portal at a later date and in an alternative format for presentation during conferences.

Ethical review of the study

The study has been approved by the ethics committee at the University of Birmingham. The Research Committee monitors the application and delivery of the university’s code of practice for research across the university. Ethical guidelines published by the ESRC have also been followed.

Contact for further information

If you have any questions or concerns, please contact me, Charlotte Brooks.

If you have any serious concerns about me or my research, please contact my supervisors Dr Prithvi Perepa or Professor Karen Guldberg.

Researcher: Charlotte Brooks, School of Education, University of Birmingham, email
[redacted]

Research supervisors:

Dr. Prithvi Perepa, School of Education, University of Birmingham, email
[redacted]

Prof. Karen Guldberg, School of Education, University of Birmingham, email
[redacted]

Consent and demographic questionnaire

This is a consent form and demographic questionnaire for my project looking at what research involving nonbinary autistic people should focus on.

This document will ask you about your preferences about being quoted directly from your interview data. Please make sure you have read or listened to the information about the study before completing this form.

If you wish to participate, please complete and send this document to my email address at [redacted]

The following questions relate to your consent to take part in the study. Please edit the **bold text** in the statements below so they reflect your choices

1. **I do/not** agree to participate in the research study. I understand the purpose and nature of this study and I am participating voluntarily. I understand that I can withdraw from the study at any time, up until a month after the interview takes place, without any penalty or consequences

2. **I do/not** grant permission for the data generated from the interview and this document to be used in the researcher's academic work and publications on this topic

3. **I do/not** grant permission for the interview session to be recorded and saved for purpose of review by the researcher and their supervisors

4. **I do/not** grant permission to use information from my Twitter bio to help describe who I am (please note this information will only be used if doing so will keep your identity anonymous)

5. **I do/ not** grant permission for the researcher to use direct, anonymised quotations from my interview

Thank you for filling in the information about your consent. This next part of the questionnaire will ask for some details about you as a person, which will be used to describe who you are in any reports of the study (though your actual identity will be kept anonymous).

Please answer as many questions as you feel comfortable answering and in as much detail as you would like. There will be space left underneath each of the questions for you to respond – please provide short answers in a few words.

1. Please write as many labels you like to describe your gender e.g. genderfluid transmasculine:

2. What are your pronouns?

3. What sex were you assigned at birth?

4. Do you have a diagnosis of autism (or related e.g. Asperger's)?

5. If you do have a diagnosis, what age were you diagnosed as autistic (or related e.g. Asperger's)?

6. Are you multiply neurodivergent? E.g. autistic AND dyslexic or autistic AND have attention differences (or ADHD)

7. If you are multiply neurodivergent, in what ways?

8. Are you physically disabled?

9. What is your year of birth?

10. Use as many labels as you would like to describe your ethnicity

11. What country were you born?

12. Do you still live in the same country you were born? If not, please say where you live now

13. Are there any other countries you've lived that you feel have contributed to your sense of identity? If so, please list them below

14. Is there any other information about your race, culture or ethnicity you would like to provide?

15. Are there any other aspects of your background you believe are important to your identity? E.g. your sexuality, being a parent, being a non-speaker or AAC user or your job

16. What format would you prefer the interview to take? Delete options that do not apply.
Online video interview / Online audio interview / Written interview

17. What time zone are you in?

18. Please provide details of any accommodations you will need for the interview e.g. a copy of the interview guide beforehand

Email to make interview arrangements

Thank you for sending through the questionnaire. When would be a good time to arrange for our interview? It will need to take place somewhere you feel comfortable talking freely with minimal distractions. You will also need access to a tablet or laptop/computer for one of the activities during the interview.

The interview should take about an hour. I will also contact you one week before about a short activity to complete in the week leading up to the interview (it should take no more than a couple of minutes each day).
Will you have access to a tablet or laptop/computer at this time?

Please make sure that you’re somewhere you feel comfortable to speak freely and with limited distractions

Many thanks

Charlotte Brooks

If you require screen-reading software to access any of the emails or documents, NaturalReader is a free app available on android and iOS (https://www.naturalreaders.com/app/)

Appendix C

Pre-interview activity materials and research questions produced by participants (P-RQs) in response

Contents

Email template

Dear name,

I hope you are well. This is a reminder of our interview for next week on date and time using this link: attach link.

I have attached a document with a description of what will happen during our interview next week so you know what to expect. If you wish to withdraw at this point or rearrange a time, please let me know. It is important that the interview takes place somewhere you feel comfortable to express yourself freely and where there are minimal distractions

If you recall from information about the study, I mentioned an activity to complete during the week leading up to our interview. This activity should only take a few minutes each day. What you produce will be used during the interview to guide our discussion on what you think research involving nonbinary autistic people should focus on.

For this activity I would like you to go about your everyday life considering 'research questions' relating to your **experience** and **identity**. These may be experiences that **puzzle** you or things you think need to be understood better and that research should address. This may also include **all** aspects of your identity, including but not limited to your gender and being autistic.

The experiences that inform your questions may be from **your own life** and also from your interactions with others in the **communities** you belong. As such, questions that you generate may represent both your own experiences and topics that you think would be relevant for your community. We will discuss between 3 and 5 questions during the interview, but you are welcome and encouraged to produce more than this. This way, you can then select from them those you think are the most important to discuss.

Please read both of the accompanying documents. The first document provides support on coming up with question ideas. The second document gives examples of how you may wish to record the questions. Please make sure to send me a digital copy of what you have created at least a few hours before our interview next week.

It would also be helpful if you could take a look at the activity for the second half of the interview (link: [here]). This activity involves ranking the statements about research that has been done so far in order of what you think is **most important to you and your community**. You can choose to either read through the statements and think about how you might order them OR you can choose to order them ahead of time.

Summary of points from this email:

- Confirmation of the time for our interview next week
- Introduction and explanation of activity to complete in the week leading up to the interview
- ○ Please return this at least a few hours before our interview
- Preview of ranking activity to look at and/or complete before our interview

All the best,

Charlotte Brooks

If you require screen-reading software to access any of the emails or documents, NaturalReader is a free app available on android and iOS (https://www.naturalreaders.com/app/)

Research question support

Below are some examples of different types of research questions that you may wish to use. Please take a **few minutes** every day to record questions relating to your everyday experience and identity. These may relate to your own life or your interactions in the communities in which you belong.

What might ___ mean?

What is the cause of ___?

What is the relationship between ___ and ___ ?

How does ___ influence ___ ?

What is the difference between ___ and ___?

What should be done about ___?

How good is ___?

What happens when ___?

What makes ___ good/effective?

What happens to ___ when ___ happens?

Why does ___ get more/less of ___?

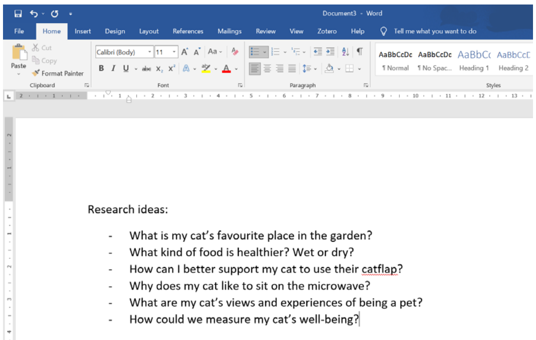
Please remember that the questions you generate should relate to your own experiences and identity, and also the experiences of others in your community. These may include aspects of your life other than being autistic and your gender. Please see the next document on recording your questions.

Source: Adapted from, Thomson, P. (2014) *Thinking about research questions*. Available at: https://patthomson.net/2014/09/08/thinking-about-research-questions/ (Accessed 16 Dec 2021)

Recording questions support

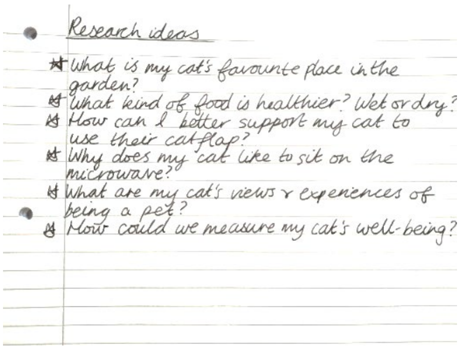
Please make sure that you have first read the first question on ‘research question support’, which will describe this activity further.
Below are some ideas of how to record your questions. Ideas can be recorded using a single method or a mix of methods.

As a list – either handwritten or in a document:



Research ideas:

- What is my cat’s favourite place in the garden?
- What kind of food is healthier? Wet or dry?
- How can I better support my cat to use their catflap?
- Why does my cat like to sit on the microwave?
- What are my cat’s views and experiences of being a pet?
- How could we measure my cat’s well-being?

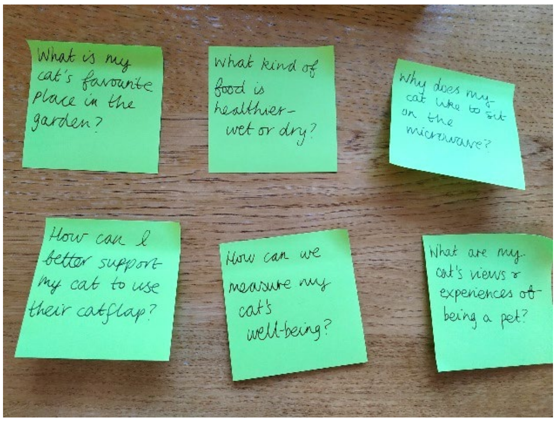


Research ideas

- What is my cat's favourite place in the garden?
- What kind of food is healthier? Wet or dry?
- How can I better support my cat to use their catflap?
- Why does my cat like to sit on the microwave?
- What are my cat's views & experiences of being a pet?
- How could we measure my cat's well-being?

Photographs either annotated or just by themselves:

Post-it notes:



Feel free to get creative – you could draw, paint, sculpt! Use whatever way you are more comfortable to express your questions and ideas!

Interview description

Overview of what to expect during the interview

1. The interview will be a bit like a one-sided conversation. First, we will get to know each other a little and I'll cover some admin to ensure you've understood your rights as a research participant.
2. Next, we will discuss the things you've created during the pre-interview task and why you think they're important
3. After that, we'll do an activity online that involves clicking and dragging statements about what current research involving nonbinary and autistic people has focused on
4. Finally, I'll ask if there's anything else you want to say before we wrap up. I'll then ask if you're still comfortable for me to use what you've said for my research, and whether you're happy to be contacted about my interpretations of what you've said (as part of the research process). Then the interview will be over.

Participant Research Questions (P-RQs)

Kay

Is being ADHD more socially acceptable than being Autistic?
Are autistic people more likely to become addicted to substances due to our sensory differences?
Does regularly playing D&D improve someone's social skills?
Do Autistic people need more sleep than non-autistic people to function?
Does everyone lie on their CV? If so, how many lies is the average?
Has covid 19 changed people's GP usage?
How many students leave University in their second year?
Why / what makes fashion trends cylical?

Rae

What do autistic people present like without ADHD?
What do ADHD people present like without autism?

What is the difference between autism and ADHD?
What link with associated comorbidities does ADHD carry? Autism? Both ADHD with autism?
Specifically, I want to know which specific condition carries what risks ultimately.
When do the NT training courses begin on neurodivergent people? How can we collectively make those lessons contain as little ableism as possible while still being informative enough to improve ND/NT relationships?
Why is neurodivergence still stigmatized and labelled?
Does autism and ADHD really actually belong in the DSM 6? Like, legitimately. What are we doing to disabled people by having a DSM compiled ON OUR BEHALF by NTs?

Sam

What accounts for the heterogenous presentation of autism beyond biological factors?
Might the complexity of autism be explained by cooccurring /comorbid conditions?
Other than diagnosing autism, how can we best identify and analyse the needs of different autistic people?
What is the role of education in equipping autistic people with the skills required for adulthood and living meaningful lives?
How can we develop holistic approaches to supporting autistic people i.e. considering the whole person rather than simply viewing them through one or another lens?
How can we better define the nature of the social difficulties autistic people face, especially when we take into account the problem of double empathy?
How does autism affect the inner experience of identity and the relationship to the self?
What kind of societal shift and changes in mindset would be necessary to accommodate autistic people socially and ensure their inclusion in social life?
How does autism affect a person's sense of community and personal relationships?

Tas

How do different cultures relate being non-binary and Autistic to their Spiritual practices?
How much distress does being non-binary and Autistic cause the diagnosed person if they are properly supported by community vs if they are not?
How does the non standard sensory perception of non-binary Autistic people compare to Neurotypicals?
What does being non-binary and Autistic mean to the person experiencing it? What do they find to be unique about themselves?
How do non-binary Autistic people relate to Spirituality? (Specifically not religion, but spirituality)
How do non-binary Autistic people relate to the paranormal via their non standard sensory perception?

Lauren

4/18
Why can’t I mean what I say? Why can’t I come up with the words I want? Why did he have to pick on me? What did I do to him?

4/19

Why people like car so loud?

4/20


Why doesn’t he go down all the way? Isn’t this harder?

4/21
Am I seen as this oblivious or mean when I didn’t know someone was flirting with me?

4/22

What would a bee be looking for up on the third floor? How high do bees fly?
What do I talk about with friends? I'm glad my one friend understands what types of things to ask when the talkative person leaves.
Do other people feel this exhausted after meetings?
Do other people feel like they have the flu after a sugar/caffeine high?
Why does everyone from my committee hate me?

4/23
Why does she think she has control over my body? Why can't I have my hair like I want?
Why do people think it's good drama to have characters not believe each other or not tell each other things in shows?
Why does my mom think that's even remotely okay to feed a dog? Why does she feel like she has to scare her into eating?

4/24
Why do mothers think they should be listened to when it comes to their child's own style? Why do I have to look straight?
Why is the city removing the asphalt but then not repaving the street for weeks? What are they doing in the meantime?

Appendix D

Ranking statements activity

Statements were shortened to reduce executive demands

Figure 1

Original statements for Ranking Statements activity

The following statements describe the aims of research that has involved non-binary autistic people.

Click and drag the statements in order of which you believe to be the more relevant to your own experiences and those of the communities you belong. At the top would be the most important:

to explore autistic experiences of sex and relationships, including sensory experiences and facilitators or barriers in romantic and sexual relationships

to explore autistic experiences in the workplace, including strengths of autistic people at work, disclosing identity labels, and facilitators and barriers to succeeding at work

to understand experiences of identity and how multiple identities are experienced at once, including being autistic, being non-binary or transgender, or having a minority sexuality (e.g. being gay or bisexual)

to examine and measure negative events experienced by autistic people, including stigma-related stress and unwanted sexual encounters.

to develop tools for supporting autistic people to participate in research and find out what autistic people think about participating in research

to investigate experiences of autism acceptance, including its relationship with well-being, responses to being diagnosed as autistic, identifying language preferred by the community, and stimming

to investigate the physical health needs of autistic people, including binge-drinking, sexual health, and sleep

to advance our understanding of autistic masking including how masking is experienced, developing ways to measure masking, and looking at the relationship between masking and mental health problems

to examine the nature of friendships in autistic people and how to develop satisfying friendships

to measure the relationship between being autistic and having a non-binary gender identity

to enhance our understanding of the mental health of autistic people, including measures of well-being, rates of mental health problems in the community, masking, and autistic burnout

to assess experiences of services, including schools, gender clinics, other healthcare services, university/college services, and psychological therapy

Figure 2

Adapted statements for Ranking Statements activity

The following statements describe the focus of research that has involved non-binary autistic people.

Click and drag the statements in order of which you believe to be the more relevant to your own experiences and those of the communities you belong. At the top would be the most important:

Identity and experiences as a member of multiple minority groups	embracing autistic differences (e.g. language preferences and stimming)	autistic experiences in the workplace	tools to support autistic people to take part in research
mental health and wellbeing (including autistic burnout)	statistical relationship between being autistic and gender diversity	friendships and how to have satisfying friendships	access to services (e.g. education and health)
physical health needs (e.g. binge drinking, sexual health and sleep)	sex and relationships	autistic masking	negative life events (e.g. prejudice and unwanted sexual experiences)

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12.

Appendix E

Interview guide development

Contents

Original interview schedule (pre-pilot)

I Opening

A. (Establish Rapport) I'm so glad you could make it, are you feeling well today?

B. (Purpose) So, I know we've been talking over email, but I'd just like to go over the purpose of the study again, if that's ok?

So, for one of my first pieces of research, I did a small study in the autistic community and lots of nonbinary autistic people responded to my study. That was the first time that I realised what a big part of the community nonbinary people are. I then realised that there's been no research out there to look at what nonbinary autistic people want from research, so this project is hopefully going to see what you think of research that has been done so far involving nonbinary autistic people and what you think future research should focus on. Is that clear?

C. (Admin) So, just to go over a bit of admin and make sure you realise your rights as a participant in this study. Do you realise you don't have to be here and this whole process is completely voluntary?

Do you realise that you can stop the interview at any time and nothing bad would happen?

Ok, and if you decide after the interview that you weren't comfortable and you don't want to take part any more, you can contact me and I will remove all your information, up until a month after this interview.

Is that all clear? Do you have any questions about the study at this time. Ok, I also just wanted to let you know that if any of my questions seem obvious at any time, please don't worry - I'm interested in your understanding of these issues and what they mean for you as an individual.

II Body

A. Before we start the first activity, I'd like to first get an idea of what 'research' means to you.

a. Prompts: What do you think is the purpose of research? How does that relate to you and your experiences?

Transition: Let's look at the documents you've produced. Do you have them in front of you?

II.I Activity 1

A. Which one would you like to discuss first? Can you tell me some more about [artefact]?

a. Prompts: How did you come up with that question?

b. How do you think it's relevant to your own life and identity?

c. How do you think it relates to others in your community?

d. Do you think this would be relevant to children or young people in the community?

(repeat questions until all artefacts or 5 most relevant ones to the participant have been covered)

B. How you think the issues that are important or relevant to you have changed across your life?

C. What do you think would have been more relevant to your younger self when you were a child or young person?

Transition: I'd now like to move onto the next activity. Are you happy to keep going?

III Body – Activity 2

A. (Explain activity) – In this activity, you're going to be presented with 12 statements that describe the aims of research that has been done so far involving nonbinary autistic people.

When the document opens up, you'll be able to click and drag them into order depending on what you think is most important and relevant for your life and the life of the communities you belong to. I'll also be able to see what you're doing and what you're moving where.

If you're comfortable, I'd like you to 'think out loud' and describe what you're doing and why you're ordering them the way you are, if that's alright? Alternatively, I can ask you questions after the activity - what would you prefer?

Have a read through of the statements first and let me know when you're ready to start – [post

Google Jamboard link into chat]

B. (Prompts throughout if needed) What were you thinking when you placed that there? Why was that one ranked higher/lower? Can you tell me more about what you've just done there?

C. (Follow up) Would you mind explaining why you have ranked the statements in the way you have?

D. How do you think the statements in this activity are relevant to your own life?

E. How do you think the statements in this activity relate to the experiences of the communities you belong?

F. Are there any statements you think would have been more or less relevant to you as a child or young person?

   a. If so, how?

Transition: Before we move on, is there anything else you would like to say about this topic?

IV Closing

A. (Summarise) We've talked through your thoughts on current research involving nonbinary autistic people and what you think research should focus on.

B. Have you been comfortable with everything we've talked about? Are you still ok for me to use what you've said for my research?

C. Do you have any feedback for me on our conversation and my role as an interviewer?

D. Would you be happy to be contacted when I've written up the interview to comment on the interpretations I make from what you've just said?

E. Thank you for your time, this has been really valuable, and let's hope this will hopefully one day influence the future research! Thank you again.

Annotated interview schedule with community feedback comments

V Opening

(Establish Rapport) I'm so glad you could make it, are you feeling well today?

(Purpose) So, I know we've been talking over email, but I'd just like to go over the purpose of the study again, if that's ok?

So, for one of my first pieces of research, I did a small study in the autistic community and lots of nonbinary autistic people responded to my study. That was the first time that I realised what a big part of the community nonbinary people are. I then realised that there's been no research out there to look at what nonbinary autistic people want from research, so this project is hopefully going to see what you think of research that has been done so far involving nonbinary autistic people and what you think future research should focus on. Is that clear?

(Admin) So, just to go over a bit of admin and make sure you realise your rights as a participant in this study. Do you realise you don't have to be here and this whole process is completely voluntary?

Do you realise that you can stop the interview at any time and nothing bad would happen?

Ok, and if you decide after the interview that you weren't comfortable and you don't want to take part any more, you can contact me and I will remove all your information, up until a month after this interview.

Is that all clear? Do you have any questions about the study at this time. Ok, I also just wanted to let you know that if any of my questions seem obvious at any time, please don't worry - I'm interested in your understanding of these issues and what they mean for you as an individual.

VI Body

A. Before we start the first activity, I'd like to first get an idea of what 'research' means to you.

a. Prompts: What do you think is the purpose of research? How does that relate to you and your experiences?

Transition: Let's look at the documents you've produced. Do you have them in front of you?

II.I Activity 1

A. Which one would you like to discuss first? Can you tell me some more about [artefact]?

a. Prompts: How did you come up with that question?

b. How do you think it's relevant to your own life and identity?

c. How do you think it relates to others in your community?

d. Do you think this would be relevant to children or young people in the community?

(repeat questions until all artefacts or 5 most relevant ones to the participant have been covered)

B. How you think the issues that are important or relevant to you have changed across your life?

a. What do you think would have been more relevant to your younger self when you were a child or young person?

Transition: I'd now like to move onto the next activity. Are you happy to keep going?

VII Body – Activity 2

(Explain activity) – In this activity, you're going to be presented with 12 statements that describe the aims of research that has been done so far involving nonbinary autistic people.

When the document opens up, you'll be able to click and drag them into order depending on what you think is most important and relevant for your life and the life of the communities you belong to. I'll also be able to see what you're doing and what you're moving where.

If you're comfortable, I'd like you to 'think out loud' and describe what you're doing and why you're ordering them the way you are, if that's alright? Alternatively, I can ask you questions after the activity - what would you prefer?

Have a read through of the statements first and let me know when you're ready to start – [post Google Jamboard link into chat]

(Prompts throughout if needed) What were you thinking when you placed that there? Why was that one ranked higher/lower? Can you tell me more about what you've just done there?

A. (Follow up) Would you mind explaining why you have ranked the statements in the way you have?

B. How do you think the statements in this activity are relevant to your own life?

C. How do you think the statements in this activity relate to the experiences of the communities you belong?

D. Are there any statements you think would have been more or less relevant to you as a child or young person?
   a. If so, how?

Transition: Before we move on, is there anything else you would like to say about this topic?

VIII Closing

a. (Summarise) We've talked through your thoughts on current research involving nonbinary autistic people and what you think research should focus on.

b. Have you been comfortable with everything we've talked about? Are you still ok for me to use what you've said for my research?

c. Do you have any feedback for me on our conversation and my role as an interviewer?

d. Would you be happy to be contacted when I've written up the interview to comment on the interpretations I make from what you've just said?

e. Thank you for your time, this has been really valuable, and let's hope this will hopefully one day influence the future research! Thank you again.

Updated interview schedule with tracked changes

In blue are additions, in ~~red~~ are where words have been removed

~~Opening~~
~~(~~Prompts throughout: Can you tell me more about what you mean by x? Can you describe a time that's been particularly relevant to you? I wonder why/how/what that must have felt like?

I Opening
(Establish Rapport) I'm so glad you could make it, ~~are you feeling well~~what have you been up to today?

(Purpose) So, I know we've been talking over email, but I'd just like to go over the purpose of the study again, if that's ok?

So, for one of my first pieces of research, I did a small study in the autistic community and ~~lots of nonbinary autistic people responded to my study. That~~that was the first time ~~that~~ I realised what a big part of the community nonbinary people are. I then realised that there's been no research out there to look at what nonbinary autistic people want from research, so this project is hopefully going to see what you think of research ~~that has been done so far involving nonbinary autistic people~~so and what you think future research should focus on. Is that clear?

(Admin) So, just to go over a bit of admin and make sure you realise your rights as a participant in this study. ~~Do you realise you~~You don't have to be here and this whole process is ~~completely voluntary?~~ Is that clear?

You can stop the interview at any time and ~~nothing bad would happen?~~ there will be no negative consequences. You can also choose not to answer any particular questions and we can move on. Is that clear?

Ok, and if you decide after the interview that you weren't comfortable and you don't want to take part any more, you can contact me and I will remove all your information, up until a month after this interview. Is that ~~all~~ clear?

Do you have any questions about the study at this time?

~~Ok, I also just~~ Before we start I wanted to let you know that ~~if any of my questions seem obvious at any time, please don't worry -~~ this process might feel a little unusual to start with because it will be like a one-sided conversation.
I also want you to know that I'm interested in ~~your understanding of these issues and what they mean for you as an individual.~~ all aspects of your identity and experiences, not just those related to your gender and being autistic. I realise that we don't lead single issue lives, and I really want this research to reflect that.
I also might ask you to tell me more about particular words you've used to describe your experiences - that's just because I want to get a feel for your understanding of something

II Body RECORD

Before we start the first activity, I'd like to first get an idea of what does 'research' ~~means~~mean to you~~.~~ in general?

Prompts: What do you think is the purpose of research? How does that relate to you and your experiences?

Transition: Let's look at the documents you've produced. Do you have them in front of you?

II.I Activity 1
~~A. Which one would you~~
Do you have one you'd most like to discuss first? Can you tell me some more about [artefact]?

Prompts: ~~How did you come up with that question?~~

~~How do you think it’s relevant to your own life and identity?~~

What made you think to ask that question?

Can you describe a particular time where that would have been relevant to your life? It might be something that’s happened to you…

How do you think it relates to others in your community?

Do you think this would be relevant to children or young people in the community?

(repeat questions until all artefacts or 5 most relevant ones to the participant have been covered)

~~How~~ Do you think the issues that are important or relevant to you have changed across your life?

How might that be?

What do you think would have been more relevant to your younger self when you were a child or young person?

Transition: I’d now like to move onto the next activity. Are you ~~happy to keep going?~~ comfortable continuing or do you need a break?

III Body – Activity 2

(Explain activity) – In this activity, you’re going to be presented with 12 statements that describe the ~~aims~~focus of research that has been done so far involving nonbinary autistic people.

When the document opens up, you’ll be able to click and drag them into order depending on what you think is most important and relevant for your life and the ~~life of the communities you belong to~~community. I’ll also be able to see what you’re doing and what you’re moving where~~.~~

~~If you’re comfortable, I’d like you to ‘think out loud’ and describe what you’re doing and why you’re ordering them the way you are, if that’s alright? Alternatively, I can ask you questions after the activity - what would you prefer?~~

You have a choice on how to respond to this task. You can either ‘think out loud’ and describe what you’re doing and why you’re ordering them the way you are during the activity, OR you can choose to have me ask you questions about how you ordered the items after the activity. Which would you prefer?

Have a read through of the statements first and let me know when you’re ready to start~~-~~, or I can read out the statements for you if that would be helpful? – [post Google Jamboard link into chat~~]~~

(Prompts throughout if needed) What were you thinking when you placed that there? Why was that one ranked higher/lower? Can you tell me more about what you've just done there?

Why do you think it's difficult to choose between those two?
Support strategy first look at two and decide which of the two you think is more relevant to your own life and the life of your community, then pick another and think about how that compares to the two you've already looked at and continue that way

~~(Follow up) Would you mind explaining why you have ranked the statements in the way you have?~~

~~How do you think the statements in this activity are relevant to your own life?~~

(Follow up) Would you mind explaining why you have ranked the statements in the way you have?

Could you tell me more about the one you've put at the top/bottom?

Can describe a particular time where that would have been relevant to your life? It might be something that's happened to you...

How do you think the statements in this activity relate to the experiences of the communities you belong?

Are there any statements you think would have been more or less relevant to you as a child or young person?

If so, ~~how?~~ can you tell me more about how?

How do you think your choices this section relate to the questions that we discussed earlier?

Transition: Before we move on, is there anything else you would like to say about this topic?

IV Closing

(Summarise) We've talked through your thoughts on current research involving nonbinary autistic people and what you think research should focus on.

Have you been comfortable with everything we've talked about? Are you still ok for me to use what you've said for my research?

Do you have any feedback for me on our conversation and my role as an interviewer?

Thank you for your time. Would you be ~~happy~~willing to be contacted when I've written up the interview to comment on the interpretations I make from what you've just said?

Thank you ~~for your time, this has been really valuable, and let's hope this will hopefully one day influence the future research! Thank you again.~~ again for taking part.

Appendix F

PETs for all participants

Contents

Kay

RQ1 + 2

This combining of views on current research and future research represent Kay's tendency to jump from past to future research, recognising the links between these

A. GENERAL VIEWS ON CURRENT AND FUTURE RESEARCH	
i. Past research	
ii. The future is community-led	This sub-theme discusses K's views on involving community members in research
B. Experiences of members of minority groups	
i. Intersectional identities	This sub-theme discusses K's views on the poor representation of marginalised groups in research
ii. Prejudice	This sub-theme conceptualises Kay's views on the nature of prejudice as the result of societal structures that define what is 'socially acceptable'
iii. Educating children and young people – how prejudice is learned and can be unlearned	Kay's perceptions on how prejudice is taught and how they believe children and young people should be educated to embrace, appreciate and respect human diversity
iv. Healthcare	Views on access to healthcare for disabled and/or neurodivergent people (combines physical and mental health because Kay saw these as indistinguishable)
C. WORK	
i. Getting into work	This sub-theme include K's views on barriers to getting into work and difficulties faced in the job application process
ii. At work	This sub-theme discusses difficulties that neurodivergent people face in the workplace
D. UNIVERSITY	Views on stress and pressure of undergraduate courses, reflections on the experiences of mature students and particular struggles for autistic students
E. SEX AND RELATIONSHIPS EDUCATION	This discusses K's views on the importance of SRE for disabled people and what should be included
F. STATISTICAL RESEARCH	Mainly compromising of negative views towards research that is purely statistical, K also reflects on some ways it could be used positively

RQ3

A. PERSONAL UNDERSTANDINGS	'Personal understandings' looks at how Kay's personal experiences have influenced their outlook

i. Family and growing up	
ii. Neurodivergence	
iii. Work	
B. NEGATIVE PERSONAL EXPERIENCES AND CONFLICT	Describes experiences where Kay experiences a conflict between their expectations, understandings, drives and needs and those of others, at an interpersonal, organisational and systemic level. It is also acknowledged, however, that both interpersonal aspects may reflect organisational factors and both interpersonal and organisational experiences may reflect larger systemic issues
i. Interpersonal	
ii. Organisational	
iii. Systemic	
C. COMMUNITY	Kay's understanding of community experiences and what's important or relevant for the community is influenced by interactions with online communities, support groups, their work, and friends.
i. Characteristics of community understanding	
ii. Perceptions of community experiences	
iii. Conflict and incongruence between personal and community understandings	
iv. Role as a contributor in the community	
D. REFLECTION	As an interaction between personal and community experiences, 'Reflection' demonstraTas how Kay looks beyond themselves to imagine the experiences of others

Rae

RQ1

A. GENERAL VIEWS ON RESEARCH	Rae talks about how they understand research, the impact of centring of non-disabled voices in research and how better research about autistic and neurodivergent people is necessary

RQ2

A. TRAINING COURSES	In this theme, Rae discusses their ideas for courses to teach 'human classes' on all aspects of diversity

RQ3

A. ABLEISM	This theme describes Rae's experiences of prejudice
B. SELF-DISCOVERY	This describes Rae's experiences of self-understanding resulting from discovering their neurodivergence, gender and sexuality
C. LOOKING OUTWARD	This theme describes Rae's tendency to reflect on their own experiences to consider those of others

Sam

RQ1

A. PURPOSE OF RESEARCH	Sam provides a critique of current research involving autistic nonbinary people. They believe research should inform practice and be relevant to the immediate needs of those involved
B. HOSTILITY FROM RESEARCH COMMUNITY	Sam goes on to say that some areas of research are actively hostile to autistic people and may be limited by stereotypes
C. POOR REPRESENTATION	Sam recognises that research is often not representative of racial and cultural diversity, including their experience of living in Singapore. Nor does it reflect those with communication difficulties.

RQ2

A. UNDERSTANDING	Research relating to components and complexity of issues and what lies behind behaviour
B. HOLISTIC AND INDIVIDUALISED EDUCATIONAL APPROACHES	Focused on researching approaches that consider individual differences and holistic educational processes that consider the whole person

RQ3

A. BALANCE	This describes experiences where Sam sought balance by negotiating competing forces, which can create tension.
B. PERSPECTIVES	This PET describes experiences where Sam reflects on their experiences from different perspectives, such as within communities, as an educator or as someone with personal experience

Tas

RQ1

A. PURPOSE	Tas talks about how research should improve people's lives and focus less on negative experiences
B. A WESTERN PROCESS	Tas sees research as a Western process influenced by researcher biases and reflects on how knowledges from their culture are not represented

RQ2

A. PURPOSE OF FUTURE RESEARCH	T felt strongly that research efforts should focus less on negative experiences of people and instead on how to improve those people's lives
B. METHODS	T had clear ideas about how research should be conducted, drawing on their knowledge of participatory and collaborative research frameworks
C. RESEARCH ON SUPPORT	
i. Sex and relationships education	Tas' own experiences surviving abuse and their knowledge of psychology give them clear ideas about how SRE should be supported
ii. Empowerment	Research should focus on helping individuals to become empowered and empowering others
iii. Therapy	Tas believes therapeutic techniques should address trauma in a way that supports individuals to become integrated wholes

RQ3

A. TRAUMA	
i. Generational	The forceful separation of Tas' father from his Native American community created a rift between Tas and their heritage, which they are now trying to piece together.
ii. Child abuse and toxic environments	Tas experienced abuse as a child an in some of their environments and relationships since, which has caused them to reflect on how these aspects impacted their identity and expression
iii. Doing the work	Tas has a powerful drive to 'do the work' to empower themselves and support others to become empowered
B. CULTURE AND IDENTITY	
i. Culture and community	Connecting to their Native American heritage has given Tas a strong sense of community, cultural connectedness and place, pulled together by a shared spirituality

ii. Identity	Tas' change in perspectives on events in their life has given them a newfound sense of identity around aspects that make them unique (specifically, their autistic traits, hypersensory perception and gender)

Lauren

RQ1

A. CONDUCTING RESEARCH	This sub-theme includes Lauren's reflections on the ways different research areas may conduct research
B. MASKING	Lauren talks about their views on masking in opposition to embracing autistic differences
C. MENTAL HEALTH	Lauren explains why they think this area of research is important, especially for autistic nonbinary people

RQ2

A. AREAS FOR FUTURE RESEARCH	Lauren discusses future areas of research relating to tools for social situations, education and embracing differences

RQ3

A. FOLLOWING THE FAMILY LINE	This theme addresses the struggle between Lauren's wish to express themself authentically and familial pressure to be brought back 'in line' with social conventions
B. NAVIGATING SOCIAL SITUATIONS	Describes situations that have caused Lauren to reflect on their own understanding of social situations including those that have proven difficult, situations where their needs weren't respected as well as those that created a positive environment
C. PHYSICAL NEEDS	This theme describes Lauren's difficulties with aspects of their physical health and relationship to their body
D. COMMUNITY	This theme describes Lauren's interactions with others in the community and how their experiences may compare to others
E. EMBRACING DIFFERENCES AND STANDING UP FOR THEMSELF	Lauren talks about their journey of embracing their differences and advocating for their needs

Appendix G

Group Experiential Themes (GETs)

Feedback from participants can be viewed as comments to the right of the document

Table of Contents

RQ1 - What are participants views on current research involving nonbinary autistic people?

The nature of research and autism research

This theme first addresses how participants come to understand ‘research’ and its purpose before looking at some critiques of autism research

Research draws from various sources to improve understanding Rae, p. 2

> *Research could mean a lot of different things, really. There’s peer reviewed journals, internet searching, books, history, story telling from oral traditions*

Research as a Western process influenced by who and how its used Tas, p.1

> *it's the way that <u>Western</u> society has of collecting information to try and find patterns? And it can be negative or positive depend on the- depending on who's doing it and how they're using it?*

Research should be oriented towards improving people's lives Tas, p.2

> *I think it <u>should</u> be to make people's lives better. And it should be for the greater good. I think that <u>my</u>- like, the research that I'm doing right now, and that I hope to do in the future is very much oriented towards that. I think that... uh, that's not <u>always</u> the case with everybody else? Or that sometimes they <u>mean</u> for it to be and it's not?*

Research should be timely and important by informing people's actions and being relevant to today Lauren, p.2

> *‘Important’ being that it could be used for by other <u>people</u>? Or, um, maybe it'll be useful for <u>future</u> research, um, ‘timely' being that, uh, it's kind of... like you're, you're doing things that are relevant to <u>today</u>. And that could be because like, just of the way that things have accumulated up <u>until</u> now? Or because something's about to happen and you, um, you kind of are trying to...*

> *anticipate.*

Current research should inform how we do things and the decisions we make Sam, p.2

> *research has kind of a relationship with, with, um, how we do things in the world, I suppose. Um, it should inform, um... it should, inform us*

Kay conceptualises ‘autism research’ as pathologising and removed from the practical needs of the autistic community Kay, p. 33

> *Because for me, like 'autism', autism research is always about, “Oh, that's what's wrong with these bunch of people. They're really weird…What's that all about?” And then, no, “Oh, this is how it would be really helpful to support these people in school,” or “This is how the health system is really messing-“*

Research focus is limited by stereotypes around the abilities of autistic people in terms of metacognitive awareness Sam, p.12

> *What we don't see a lot of research on is, like, research that even, that even assumes that autistic people have some kind of, like, [laughs] metacognitive awareness, I suppose [laughs].*

Ableism and centring of abled voices results in autism being considered a low priority and a low quality of research Rae, p. 6

> *Autism funding was just at the bottom of the heap… NTs don’t bother themselves with things that don’t affect them. Additionally, BAD research in mental health issues!! Ableist, poorly thought out, ill considered, and frankly gross assumptions…They assume that they know what we do and why we do it.*

Approaches tend to look for a ‘one size fits all kind of solution to everything’ to meet administrative demands Sam, p.7

> *what people want from an administrative perspective, most of the time is like simple clear-cut solutions, where you can sort of say, 'Okay, this person's autistic then then this is what we do.' Because that's easier in a lot of ways because it doesn't require expertise. It doesn't require big systemic shifts. Um, so that's what people want to do, right? People want to kind of like have a one size fits all kind of solution to everything.*

Research should focus on how identities can be embraced so that less research on negative experiences is required Lauren, p.25

> *if we talk about how autistic people can be embraced and how their identities can be looked at then, then hopefully these negative life events will be lessened and wouldn't be need- needed to research as much?*

Research should focus on the success stories of those who have overcome hardship and trauma as opposed to those who are 'treading water and drowning' Tas, p.23

> *people being empowered in their research, like in research, like once they have a success story? Like I'm, it's so frustrating to see the research focused on people who... are just like, treading water and drowning? And that's sort of how we've gotten into this bad cycle of research where everybody just looks down on us, because we aren't identifying the people who've succeeded*

Representation

This theme considers the representation of marginalised groups as research participants. The theme is organised into the subthemes Autistic, Transgender and Racial and Cultural Diversity. It is important to note, however, that participants' responses considered how identities intersected

Autistic

This sub-theme talks about the importance of research including the voices of a wide range of autistic people. Participants talked about the erasure of particular autistic identities, including those who are nonbinary, people of colour and those who communicate differently. Kay then talks about how research papers themselves use language that is inaccessible.

Embracing autistic differences means embracing a wide variety of autistic experiences Lauren, p.29

> *And, and how, like, there's, like, when you think of people being autistic, it's just like this, like, cis het, white boy, like, like a Rain Man or whatever, I don't*

> *know. And, and I think that it's important to - yeah, to recognize that different types of people can be autistic. And that's okay.*

Research tends to focus on views of more vocal members of autistic community and should be concerned with representing all views, especially those who have difficulties communicating Sam, p.26

> *there is this idea that we focus too much on, on the autistic people who have no problems communicating? Which, which I think, I there's two ways to look at it, right? One way is, like, like definitely, I think it's not wrong to say that, like we should [↓] people, autistic people who are capable of communication do have a right to say certain things. And a lot of the time a lot of us are, are concerned about the people who are less able to communicate. So I don't think we should be dismissive of that. But on the other hand, I also think that there is some truth, right? That if we're not careful with, with the research that we also end up over representing certain views? Because certain people are more able or willing to communicate and take part in research, Where as, like, um.. whereas, like, like, like, how do we- how do we at the same time get the experiences of autistic people who have, um, more significant language or cognitive disabilities. I think, figuring out how we should be- can do that would be pretty important*

Kay is critical of academic language in papers that is inaccessible to the ND community Kay, p. 53

> *the plain language summary is just…you know, is that- I mean, some of the work you think, Well this is being read by academic people, but like, there's some serious word-wank here.' [It's hard enough to] work out what's going on, let alone can the lay man know that? Or, or, you know, people with reading comprehension is a bit different? Like, it's just...yeah, so I think that's, that's mega important*

Transgender

This sub-theme looks at the representation of nonbinary and transgender autistic people. This includes erasure of these identities in research and how this may be enabled through reliance on strict participant selection procedures.

Mental health may be a particular issue for those 'marginalised in different ways', including both autistic and nonbinary people as neither group are 'given a platform', leading to erasure of experiences Lauren, p.28

> *I, I've, I think burnout is a really big issue. And I think mental health is already a big issue, but it's especially bad for people who are marginalized in different ways …cuz I think, um, like, nonbinary people and autistic people are... like, I feel like neither group is really kind of... given... given a platform? And I think that people don't, because they're not given a platform, people don't... think of these people as people? And so they're, they're not thought of as multi dimensional because of that.*

Most of current research erases the experiences of marginalised groups, such as nonbinary autistic people Kay, p. 43

> *as you know, everything's like cis white boys…so that's like, crap. And then...yeah, there's just, it's just a complete- And even, like, when you were saying about nonbinary, autistic-specific research, like…that doesn't exist, because everything that- You've probably found this as well - everything I've read around my work is like, still very binary, like, but it's just trans binary now [laughs] So like, "What do trans men and trans women feel about this?" And you're like, Well, where are the nonbinary folk? Like, Where are the agender folk? Where are the genderfuck folk? Where are the gendervagues?*

Research relying on clinical samples erases the experiences of transgender autistic people who do not access those services Kay, p. 47

> *"So, we're only going to talk to trans people who are going through gender identity healthcare." Okay, well, that's assuming that people have access to it and need it in the first place. That's possibly discrediting all the people who are on waiting lists, which are like four or five, six years long now. Um…and all the people who are at gender identity health care, who are autistic, but not known to be autistic, or are autistic, but self-realized*

Racial and cultural diversity

This sub-theme looks at how research is limited to the experiences of white autistic people from Anglocentric countries, erasing the experiences of people of colour and those from other cultures. Tas then considers this through the lens of colonialisation with epistemic implications.

Anglocentric research does not represent racial or cultural diversity and what it means to be autistic for those from other cultures/ethnicities Sam, p.24

> *a lot of the research tends to be focused on white, white people, whether male or female, usually people I see in the community as well as the research- all tends to be focused around white people. I suppose, like, the nature of it [↓] a lot of research being English kind of just makes it that way to a large degree? But even in, like, Anglocentric countries or English-speaking countries, there's quite a large racial diversity. So I think, I think it's quite important to account for that.*

Relying on traditional diagnostic procedures and tools disadvantage and misrepresent autistic individuals from minority ethnic groups, Kay p. 48

> *And then it's things like "Oh, and then we're not going to have any self-realized autistic people." Okay. So, you need to have diagnosis. Okay. So that's loads of white people then, because, you know, people from the traveller community, homeless people, black, brown, Asian people, uh, queer people, like we just don't have access to the same- they don't have access*

Research should consider Indigenous knowledges, perspectives and wisdom while seeking to understand how such knowledges have been disrupted by colonisation, Tas p.22

> *I think that we, there's so much to gain from...understanding how minorities view it? And, um, in addition to that, how like minorities view it after they've been colonized? And how minorities just view it in general, like in their traditional ways? Because there definitely are like some Native American cultures that have... harshly turned against their TwoSpirit people because the Catholic Church would like come in and murder everyone for trying to protect them?*

Ranking statements activity

Table X shows how participants agreed and disagreed about the importance of different issues, however it is important to note that many participants saw patterns between the different research areas and found it challenging to rank some issues as more important than others. This means the table should not be used to make more general statements and should instead be illustrative of how participants approached the task.

Overall, participants felt differently about a number of the statements, which is indicated in the large spread of rankings for some of the statements. Some areas were more comparable, however. All participants rated the 'statistical relationship between being autistic and gender diversity' as less important and 'access to services' and 'mental health and wellbeing (including autistic burnout)' as more important. These findings reflect the views expressed in response to this research question, especially those regarding the purpose of research and which issues are critically important.

Critical importance of certain issues

This theme draws on how participants made sense of the Ranking Statements activity and how they chose to approach issues they felt were most important

Issues that are important reflect a 'hierarchy of needs' including identity and mental health Lauren, p. 21

> *so I think somewhere in the top will have to be kind of like this... Like, I feel like kind of low-level hierarchy of needs kind of stuff? Where it's like, identity and like, mental health, just like basic needs kind of, in a way?*

S believes the most important issues reflect the 'most basic needs that autistic people need' and likens this to Maslow's hierarchy Sam, p. 24

> *so I guess the first thing is mental health and wellbeing, including autistic burnout because… [↓] That, I think, that's- that should be one of the major angles, right? Then physical health needs are pretty important, as well? So, I think those two are like, kind of like Maslow's hierarchy [laughs] is where, like, it can go with the most basic needs that autistic people need? And, like, I think they can be quite different from, from neurotypical, allistic people. For that reason those two things come first?*

Some research areas are more foundational (e.g. mental and physical health), without which other areas, such as work, are not viable Kay, p. 38

> *I feel like it's all wrapped up in this as well. Like, if you sort out someone's mental health needs, and their physical needs, like…work- working becomes like, a much more viable option. So like, yeah, and if your 'tools to support autistic people to take part in research,' then then that's, you know - oh! – 'CV building'. But it is, you know, and then there's community within that. And then that's like, self-confidence and self-awareness*

Rae sees poor life expectancy the ultimate cost of systemic prejudice Rae, p. 4

> *Non straight people die at higher raTas than straight people. Disabled people die at higher raTas than able bodied people. Whether it's suicide, a hate crime, police brutality, or disease: dead is dead…If you're not straight or able, then you experience trauma to your different status. Related to your trauma is life expectancy.*

RQ2 - What do participants think future research involving nonbinary autistic people should focus on?

This question was addressed primarily using data from discussions around the questions that participants produced prior to the interview (a full list of the P-RQs can be viewed in Appendix X). As not all questions were discussed, not all questions are addressed in the themes for this question. Responses to the Ranking Statements activity are also represented in this section as most participants moved seamlessly from considering current research to looking at future possibilities within the interview. Themes generated for this question were: The Future is Community-Led and Education.

The future is community-led

Participants were knowledgeable about community involvement in research and had strong views about how individuals should be involved in decisions made as part of the research process.

Research should focus on the voices of participants and put the people who it impacts the most in control Tas, p.11

> *I <u>think</u> that the <u>voices</u> of the- [long pause] it being like, <u>participants</u> versus subjects, is, is a, is something that needs to change…<u>Things</u> like that put the people who impacts the most in control. And that is <u>really</u> important to me*

Autistic people should be involved in directing the topics of research about them Lauren, p.24

> *Okay, so I'm gonna put this up pretty <u>high</u> because I think it's, it is really important for autistic people to be more involved in their own research and kind of <u>picking</u> what they want? What they want <u>research</u> to be in like what <u>topics</u> and stuff?*

What it will add

Kay sees participatory research as the key to a gradual improvement in the focus of research involving autistic and transgender people p. 53

> *And I think, if the, the researchers found- has a foundation in actual <u>lived</u> experience, like- [coughs] I've been talking too much [laughs] Um, then I think the rest of the things on this list will actually improve, like, <u>not</u> straightaway, <u>not</u> overnight. But if research underpins policy, then, then yeah, I think that's a winner. So that's <u>why</u> I put the first one because I thought it can very- not very*

> *easily, but it would be a big step towards addressing the other issues.*

Implementing participatory research

This sub-theme expresses participants' thoughts on how participatory research should be implemented with consideration for research design, practicalities and representation in research teams.

Kay calls for a reform of research involving autistic transgender people to include community terminology Kay, p. 43

> *until someone brings it into academics, it's almost like… someone's got break the mould. Someone's got to go through like, the forbidden door between like, society and academics. And bring forth like, you know, the idea of neurogenders or autigender or autisexual*

Research teams should comprise a majority of community members, tokenism is not enough, Kay p.50

> *I think it's really important to have people…if not all of the research team, then at least like, depending on how many people are there, but like, you know, three out of four people four, out five, something like that being- Even if you're not like trans and autistic, like, you better be one. You better be one of those things, you know [laughs]*

Although they would rather be paid for their participation, Rae recognises the value of contributing to develop "better research" about autistic and other ND people Rae, p. 15

> *it depends on if I were being paid for participation. I wasn't able to afford to not get paid for my time. Another part of the reason why research costs so much money. I'm giving you my time now because I identify that better research about autistic people and other ND is necessary*

Tas has clear ideas about the design of research into supporting groups of individuals that is collaborative and actionable 'right there' Tas, p.30

> *if I had my way with it? Like, it could just be, like, Okay, well, so it's a thing that exists. And we could just, like, get a support group together and put, you know... 12 people together to talk about it from all these various cultures, or whatever? And it could just be like, an hour over tea? And we come up with some ideas and write it all up. And... and put it in a book. Like that, like*

> *collaborative research?*

Education

This theme is organised into three sub-themes: Educating and Supporting Autistic People, (un)Teaching Prejudice and Sex and Relationships Education.

Educating and supporting autistic people

This sub-theme addresses participants' thoughts on how autistic people should be educated and supported. Participants talked about different aspects of education - schools, academic learning spaces and empowering individuals. As such, the views of participants in this section are disparate and express their various viewpoints.

Schools

Sam believes educational approaches should strike a balance that helps the individual as an adult Sam, p.10

> *so, so that's the difficult thing of like, how do we balance out the picture for every single child, when their [indecipherable segment] are so different, right? …you're going to need a completely different set of interventions or different- a different concept of how, how do we educate this person, so that they can, you know, achieve what they want to achieve. And, and ultimately, I think the most important thing is that, um… it helps the autistic person when they are adults? That whatever we teach them to do, or however we... like the skills we give them, or the academic qualifications, we help them to get - all those things must ultimately kind of... help them as an individual to be the individual that they want to be.*

Sexuality and gender should be considered as part of a holistic approach to supporting autistic people Sam, p.32

> *we talked about, a little bit, about this idea of looking at autistic people*

> *holistically, right? So, so I think this is not something that we should ignore. Um, it still comes very, it can be very core to a person's sense of self, right? Gender, sexuality, and relationships. Um, so these are still areas that we need to look at.*

Only qualified professionals with Tasts should make ability assessments, not teachers Rae, p. 10

> *Teachers are wholly unqualified to be able to judge another person’s ability and inability. Full stop.*

Academia

Learning spaces should be open to answering questions at any level and not hostile by being combative and 'gatekeeping knowledge' Lauren, p.16-17

> *An open learning space is... like, you let people ask their questions, and you answer them and you... Like, at whatever level they're at? …Yeah, it's meeting people where they're at. And... and listening…I think the... like... like, a reading group, especially [laughs] is, is specifically made for learning. Like, it's supposed to be- like, you're, we're all going there because we want to know more about this paper or whatever? And so it's, um, I think, yeah, it's really important to, to make sure that the people who go to it are aware of how to, um, keep it like... um, oh, like not gate keep knowledge like this guy was.*

Empowering individuals

Nonbinary autistic individuals should be encouraged to 'hold space' for themselves and others by 'unapologetically being yourself, taking up space' Tas, p.25

> *there's a part where you need to just, like... hold space? Like holding space, learning how to hold space for yourself and to, like, hold space for the others around you that are autistic. To have those things, like being able to, like, speak for yourself and justify it? And, like, explain why you need it? Like that's a that's another step that I think is, like, just the nat- next natural, like part of the process there…Like learning to just be like, yeah, sometimes I talk in... TV show quoTas to express what was happening, like what the general feel of the room was in that TV show like, right in this moment, especially when things are awkward. Like [laughs] to just be like that is... holding space is like, um, this is going to happen, and there's nothing you're going to do about it? Like this is, this is life, this is how it's going to go. Um, just, like... just*

> *unapologetically being yourself, taking up space*

(Un)teaching prejudice

This sub-theme speaks to the fact that participants saw prejudice as a learned process that is reinforced by society. Participants considered ways in which children, professionals and parents could be taught to ‘champion differences’ rather than stigmatise.

Kay views interactions between parents and children - when disability is not spoken about - as communicating wider societal attitudes and prejudices that miss out on key learning opportunities Kay, p. 56-57

> *But instead of taking that opportunity to like [sighs] humanize the person that you're talking about, or you- the person that your child's recognized. Like you'd much rather just get embarrassed about it…because then it just tells children that, you know, “Oh we don't talk about disability,” “Oh, no, it's really rude to talk about that,” or, or that these people are unapproachable? Or don't have their own stories? Or way to say about things?*

Courses should be co-designed and taught by ND people on ableism with the goal of improving ND/NT relations and helping NTs to understand ND experience Rae, p. 9

> *This class would contain anti ableism training and awareness. Trauma informed people, teaching normies how it is really for the rest of us. Anti stigma training too.*

Educational interventions challenging children's attitudes and supporting friendships should start with parents Tas, p.34-5

> *I would want the intervention to be on their parents to teach them to not pass on unnecessary biases. Because that's definitely a behavior... that, like, people teach their kid to walk away from people doing a certain thing, or they tell their kid that they have to sit still. And that, like, if you don't sit still, people will think you're a freak or whatever. And then, so even, like, normal amount of movements in kids get, like, they pathologize it and so kids are like, Oh my gosh, that kid's moving a ton.*

Changing attitudes and empowering individuals would cause many other issues to 'fall away' and provide strong foundations to assert their rights Tas, p.23

> *the Māori people - I don't know if I'm pronouncing that, right, I've never heard it said out loud - they, just like, their definition of autistic is just like 'in their own time and space.' And like, that's such a, just like, a nice way to look at it that's like non stigmatizing. It's just like, Yeah, this person exists in a different reality than us. And so there's so much to learn, so much wisdom from all of these other cultures, that I think that, like ,if we could embrace that? Like, it's number one, because I think if we could just embrace that, that so much of the stigma, and then with the stigma, the masking and the negative effects, and all that stuff kind of just falls away*

Kay believes children should be taught how to embrace, appreciate and respect diversity through active and respectful learning Kay, p. 59

> *I just think as long as...as long as children are brought up, and are supported, cared for educated in a way that...that shows... and not just acceptance of things - I fucking hate the word acceptance, I think it's bollocks. But like, championing differences and like, appreciating like the rich tapestry of human diversity like, and I don't just mean that for being autistic or being gender divergent. But everybody if everyone's like, has the opportunity to talk and explore things together and there's no like, "Oh, I don't want to offend people," this politeness thing or shit like section 28. Like if people… starting from a young age, if children are allowed to be themselves, and also understand what it's like for other people to be themselves*

Sex and relationships education

Multiple participants spoke openly about their experiences of sexual abuse and abusive relationships. There was an understanding that their experiences were common for those in the community. This sub-theme expresses participants' views on why sex and relationship education is important for autistic people and how it should be implemented.

High quality SRE as preventative due to the impact of related trauma on mental and physical health Kay, p. 54

> *I feel like if I had had more help with understanding...consent, um, what toxic, kind of, relationships, people, behaviors look like, red flags for kind of like abuse and neglect, um…You know, I think I think it would have would*

> *have...Yeah, it would've stopped a lot of heartache, which then actually bleeds into mental health, and, you know, binge drinking and [laughs] everything else*

Individuals should be supported to learn to recognise the signs they're being used or abused in friendships and relationships Tas, p.26

> *it's really hard sometimes - especially if you don't have that connection to interoception - to tell like your body trying to warn you, um, about people's, like, bad intentions or whatever. Like you can't hear messages coming from your subconscious or your body that, like, you just get used. And it's such a common experience for autistic people that we just, like, end up in friendships, air quoTas, for the transcription [laughs] of people who are just using us because we're friendly, because we're good people, because we want to help. And so I think that, like, the work done on that specifically should... focus on like how to... help us identify when we're being used*

Own experience being abused as a child helps Rae to recognise the increased vulnerability of disabled people and the importance of safe methods to report abuse Rae, p. 13

> *Disabled people are taken advantage of by individual groups or people who are causing us harm actively. I think I want to see interviews with disabled people alone. The propensity is too high for abuse within families. A safe way to report abuse is needed, and to be taken seriously*

The vulnerability of neurodivergent and disabled people makes high quality SRE crucial Kay, p. 36

> *especially if you have like, quite um...complex needs, or you've got various things going on. Like you're actually an incredibly vulnerable person. And like, you are the person- If, if only one group of people could understand about consent, then like you are- especially if you're people who are being changed by other people. You're going into rooms and being- Do you know what I mean? Like, when people are taking you to the toilet like… yeah, it really worries me that sex education doesn't exist in in SEN schools really? It absolutely horrifies me*

Tas believes having candid conversations and answering questions in age-appropriate ways give children access to 'good information' and may prevent sexual abuse Tas, p.28

> *having those conversations could prevent a lot of the sexual abuse…, just like, being candid from the very beginning. I, like, with my daughter, I have*

> *just, um... like, my daughter was, unfortunately, sexually abused. So I, the route I took was, I am just going to answer all of her questions as they come up, because I believe if they're asking a question, they have a need for an answer? There's a lot of, like... nuance around like finding an age appropriate answer for them? And one that's not going to mess them up? But I believe that just, like, having those... questions answered is, is really important. Just like access to information, access to good information, access to- in particular, access to models of healthy relationships, and access to, um, understanding abusive and manipulative tactics.*

SRE should be tailored for ND people with impulse control difficulties Rae, p. 7

> *I believe ND people who struggle with impulse control need specifically tailored sexual education classes that include the poor impulse control aspect IN the presentation*

Kay recognises their pivotal role in teaching anatomical language to young children to give them tools for reporting abuse and autonomy over their own bodies Kay, p. 55

> *people were genuinely shocked that I was talking to this like two/three-year-old and saying 'penis'. But if something happens to him, then he can say, "and then this happened to my penis," or whatever it is. If you can't take autonomy over your body, if you don't know the different parts of your body, and if people are going, "Oh, your flower, your fufu," you're whatever like, it's just…yeah*

RQ3 – How do participants' views relate to experiences in their lives and those of their communities?

Influences of experiences growing up

This theme includes some of the experiences participants discussed from when they were children or young people that have contributed to their views and outlook in the present day.

Generational trauma and separation from Native American roots alongside and abusive counter-culture led to a sense of fragmented identities in Tas' earlier life Tas, p.3

> *My dad was, 'scooped' is the term they have for it when in the 60s and early 70s, a bunch of Native American children were forcibly taken away from their communities [gestures with hand away from body] and their families and adopted out to white families? And so, um, so he spent decades looking for his family, and I am now in, like, I've spent over a decade looking for them, because we still, like, I'm as close as anyone's ever been. But like, I am acutely aware, I'm Native American. I, like, m- my default is rejecting white culture [laughs] American culture. And, and like, I've always been drawn there and like, we know that they were Native American. And so like, that's home [hand makes arch movement). I unfortunately was raised... my mom and her side of the family were very into Christianity and Catholicism. And it was hugely damaging… to my identity. And like I... I didn't even allow myself to have such thoughts, until they were out of my life*

Tas put themself in a 'box' of being hyperfeminine after their gender identity was suppressed when they were younger, but they still explored some aspects within these constraints e.g. managing the boys' football team Tas, p.9

> *so like, when I started expressing, it was pushed down. You are a girl, you're to act feminine. And my autistic brain coped with that by hyper focusing on feminine roles... strictly following rules, making it my special interest to be able to do all of that- I can, I can sew, I can knit, I can cook and clean so fast. Like I can cook everything, I am super good at baking, like there's- every type of dessert you want, I can make it for you. I can get myself dolled up all pretty with, like, I can curl my hair four different ways, like I know how to, I know how to hyper feminine and behave. And that was... a safety strategy. Even though I've always, like, like, I've always had an- like, I managed the football team*

> *because that was the closest I could get to a boy activity safely. I, and I was stronger than so many of the boys on the football team, because I would lift weights with them and, like, would like, rough and tumble with them. And, um, I was always getting told, 'You're not like all the other girls,'*

Lauren made a conscious decision to 'sever' their sensory connection when tickled to avoid the extreme overstimulation, as their response was considered consent or enjoyment Lauren, p.19

> *I would, um... [?] like, kind of sever [chopping gesture] certain... um, uh... connections to my body, so that I wouldn't get this overstimulation or whatever? Which led to poor interoception later on, that I'm dealing with and trying to reform those connections. But anyway, um, one of the connections I did, I mean, one of the severed, severings I made, which I actually kind of like [laughs] is that I am not ticklish anymore, because I actually remember making a conscious decision to kind of turn that part of my brain off. When people were tickling me. I, I kind of, treat- would be like, I don't know. I remember the sensation of just kind of like, shutting that off. Because I learned that if I react? Or if I, uh, like, yeah, if I react, people will keep doing it. And it'll continue on, and so I learned, just don't react. And that kind of led to a... Like, don't pay attention to that signal. It's not a good signal. Um, and... um, yeah, so now I'm not ticklish [laughs]*

Sam's difficulties as a teenager were overlooked and they see themselves on reflection as a 'forgotten child' p.10

> *For myself, I think as a student- okay, like I was in the gifted program, right, actually? But I was not... [laughs] I've always felt like, like almost like a forgotten child kind of? Like, like, um... I wasn't disruptive in class. I wasn't having any ma- major issues. Academically, I was doing okay …um... probably fairly well, I suppose. Um... but my teenage years were very difficult. And, um... like, there were so many different things.*

Sam reflects on their experiences as a student from their adult perspective of a teacher with limited resources p.11

> *I don't know how to pinpoint that, actually, because I am a teacher now, myself. So, like, I have a good sense of, like, how to identify a student's needs and try to, to, to um address them? But I suppose there are still kids who, kind of, go under the radar, no matter how hard we try, when it comes to academic support because, like, primarily if you're doing okay, then sometimes, um,*

> *teachers don't really have the bandwidth*

Rae was penalised for their ‘gift’ for ‘years on end’ when they were at school Rae, p. 10

> *I got marked down in math for not showing my work constantly even though I had the right answers. For years on end. I was penalized for being a mathematical savant. I didn’t NEED to work out those simple ass problems. I just had a gift, and I was made to feel badly about being gifted*

Kay’s understanding of friendship and interpretation of their disabled youth group draws on their own positive experience in a similar group growing up p. 57

> *I think the work that I do is working towards that anyways, because even just being in a group of other autistic children? Um... it just is, like, yeah, it would have been, like- On, on <u>reflection</u>, way, way, <u>way</u> before my autism diagnosis, um, I was in a scout group. And…<u>now</u> when I look back at the scout group, I think, yeah, there wasn't, there <u>probably</u> wasn't a single neurotypical one among us. Definitely - autistic, learning disabled, ADHD, like, <u>yeah</u>. But because, and <u>because</u> of that, I got so much out of my scout group.*

Balance and conflict

This theme includes participants’ experiences searching for balance and facing conflict and pressure from others in their lives

Sam feels the tension between the need to shape themselves into being who they 'need to be for other people' and a strong sense of self is not socially conventional Sam, p.15

> *So for <u>myself</u>, I've always felt that tension, I've always felt that tension between like, ‘This is who I think I need to be’? And, um, driven <u>entirely</u> by social identity for that. Versus, like, the <u>inner</u> sense of self, which is very strong and needs to be categorized and explained a certain kind of way? Which may not be… the more socially conventional.*

Lauren's unconventional haircut is a subject of debate in their family with some members trying to bring Lauren back in line with societal norms and others trying to diffuse the tension Lauren, p.4

> *And my aunt noticed my hair. Which was it was funny because it's actually been growing out. And, um, she's like, 'Oh, did you cut it short?' And I was like, I was like, No, I'm actually, it's actually a little longer than it usually is, but, but I guess so? And, um, and then I said, Like, my m- but my mom doesn't like it. Um, and she- my mom said something like, 'Oh, I'm only your mother.' Like, like, I... like her opinion matters so much. Um... that it, it should like, um... like, warrant, how I, how I, um, present. And then my aunt also spoke up and she- another aunt. And she said... like, how she didn't like it when her daughter had asymmetrical hair. And that, um, her solution to that was to shave her whole head. And so she said, 'Be careful what you wish for.' Um, I thought that was kind of funny. But, um, um... so she was kind of like, yeah. Then, then my, my dad made a joke about like [long pause] Uh, making, like, kind of making fun of my mom? In the end, kind of like, supporting... supported being more supportive?*

Rae feels alienated from the NT world as a result of their first-hand experiences of ableism and prejudice Rae, p. 16

> *I'm living autistic in a NT world. I experience the ableism and the prejudice first hand in my life. Dating is the worst as an autistic adult. Almost every single thing about the NT world bothers me, actually. From capitalism to politics. It's noisy, cruel, and not made for me*

Power imbalance between receptionists and patients leads to low expectations of patients and a patronising demeanour Kay, p. 20

> *was incredibly clear with what I wanted. And they still presumed, and not because of being autistic, I don't think because unless they'd got my medical records up, they wouldn't know that, but they just assumed that everyone whose ringing in there is, like a fool, like, we're just silly. We don't know what we're talking about, and therefore, must be patronized*

Kay's atypical relationship to work requires negotiating societal expectations regarding the nature of 'work' and being a mother Kay, p. 11

> *but then also people say, "Oh, so when did you stop doing that?" No, I haven't*

> *stopped doing that. “Oh, so you're doing this, this, this and this, but you're also going for this job as well?” And I think some people are kind of a bit…put off by that? Um, because, I don't know, they think, like, “Oh, well you have a baby, but you're also doing like 5 million other things.” But then you have to explain that it’s…ad hoc, but I also can't explain that because I don't have enough space on my CV [laughs]*

Tas is frustrated that they have had to wage a battle between their values and following other rules in order to gain qualifications to 'heal' others, which they would not have to have done if they hadn't been estranged from their culture p.10

> *So like I would, at this age, I could be almost like a full-fledged practicing medicine person. But at this age, I am stuck in the Westernized context of I'm having to get a PhD, in order to get acceptance into white society…To help people in this way. And I still don't, like, having been through this. I don't think a lot of what psychology and psychiatry has to offer is that good. I really don't, I don't respect it as a whole. I don't, like I... my PhD is a piece of paper to say, Hey, I played by your rules? And I don't like them. And so I'm going to shred them now. And I'm going to build something better. That's what it is. Which - if I could have just had my Ways from the get go that my ancestors had made and worked on for thousands and thousands of years - I wouldn't have to fight that battle. I could just be healing people.*

Self-discovery and empowerment

This theme includes experiences of empowerment, self-understanding and self-acceptance that participants have experienced since discovering and embracing aspects of their identity including culture, gender and being neurodivergent.

Tas finds a sense of purpose, place and community by connecting with their heritage and spirituality as a TwoSpirit person Tas, p.3

> *And I have a community of friends online who are like, yeah, no, you're definitely one of us. And like, and they- the term- since I've found the Native American community, the term I identify with now is TwoSpirit. And like there's a whole set of practices for people like me - all the way down to, like, our place in society as healers, like it's not an accident that I'm getting a degree to be a psychologist. That is, like, who people like me are in my culture. I make*

> *sense through and through and through in that context. And people love me and support me and prop me up for it. Rather than telling me that I'm bad and I don't exis-, or things like that don't exist, and I shouldn't be... and that I'm wrong. And so like, those are two very different experiences that, it just like it… Having that spirituality there to support it has just meant everything. Like I am a whole person now.*

Tas' new understanding of themselves as unique - as an earnt position of trust and work - is in contrast to their previous understanding of their unique traits as personal shortcomings Tas, p.19

> *I think that maybe someone who was raised in like a restrictive, like, situation like I was, um... might think that it made them bad? Or might think that it made them a freak? Or they might think that it made them an outcast? Or that they're not good enough? Or that they need to change themselves? Um, which is very different from the cultural context that I have now of I... am like this for a reason, it's a gift. I, um, have a responsibility because of it? I need to, no matter where I go in life, I am to use this gift to help others? Like when things come to me I have a responsibility to, to do my work to pass it forward? That I... a lot of people believe that you are like this like - if you believe in like Soul journeys and soul paths and like ascension? - that this is, like, a position of ascension? And that like you've attained it because you've done work and because you've been... not just, like, Good but because you've been Just and because you've overcome, you've shown to have, you've shown yourself to have character... And it doesn't make you infallible, it just means that, like, you've been trusted*

Rae describes the process of “unpacking my own ableism” as peeling back layers of trauma to spot problems by “getting closer to them” Rae, p. 14

> *I’m still unpacking my own ableism. Trauma and ableism have layers. It takes me years sometimes to figure out how I feel about certain things and events in my life. I have another common condition for ND people called alexithymia. I’m delayed even further from emotional processing by becoming stoic in my teens and twenties. It’s like you’re only able to spot so much of your own problems until you start getting closer to them. Your perspective changes, and then you are able to recognize more of the ableism for what it really is*

Recognising their gender and sexuality has allowed Rae to make sense of their experiences and be more honest with themselves Rae, p. 14

> *Things make so much more sense than before, and I’m being honest with myself about my sexuality and gender expression*

Lifelong experiences of meltdowns are a shared experience between Sam and their students that cause them to reflect on educational approaches Sam, p. 4

> *the most immediate thing, I think of, what causes meltdowns, right? Because, like, you see a lot of students have meltdowns. And for me, I, actually that's how I kind of figured out I was autistic. Because I was like, looking at the kids having meltdowns, I realized, 'Oh, okay, I have meltdowns too.' It's less frequent for me, I suppose and like, but it's been a lifelong thing. And uh... I've learned to... control it in certain ways? Like, um, I think, after discovering- having the self-awareness that I'm autistic has helped me to kind of, um… have more insight on how to manage and identify what's not done for myself?*

Realising they were autistic opened doors to consider how they could use alternative modes of communication to help them when they become situationally mute Lauren, p.27

> *especially since I've made this connection of being autistic, it has helped me and knowing that I actually become selectively mute when I get really depressed? Has actually... helped me realize that, like, Oh, I can use a tool to like, communicate when I'm feeling really bad. And I just never thought of that before, because I didn't put those things together.*

Drawing on the experiences of others

This theme highlights how participants made sense of their own experiences and topics of research through the experiences of others.

Kay's understanding of 'friendship' as an issue in the community draws on both experiences working with autistic young people and experiences engaging in online communities Kay, p.44

> *but I think about the kids I work with… And it's something that comes up*

> *in…actually, it came up in the [redacted organization] LGBTQ thing, was that earlier this morning? It might've been yesterday as well. And, uh, someone was saying about the fact that you know, "I really want to talk to people online. It's just really difficult and I don't know what to talk about." And like, you know, and I think so many of us - attached to the trauma that I've spoken about - you know… get laughed at, you know, we get confused we go situationally mute or we don't use mouthwords anyways, and like, there's just so many things*

Kay's understanding of access to diagnosis in the transgender community is informed by speaking to numerous people who don't seek diagnosis because it may impede their gender healthcare Kay, p. 47-48

> *And the amount of people you talk to who don't get their autism diagnosis, because they know that it's going to impede their trans healthcare and their, like, medical journey, is it's not like, there's enough people I've spoken to where it's not coincidental. Like, it's not just a one-off thing that that people either fear or- it's real, that, you know, being diagnosed autistic is a barrier to anything to do with medical kind of healthcare.*

Sam's experience seeing past students 'end up unemployed' has caused them to consider the importance of research that seeks to understand why that might be Sam, p.25

> *So, I have a lot of students who end up unemployed, simply because, I don't know, it's like the interview stage or that they work for a while and they can't, they can't cope with it. So better understanding why that's the case and whether it's something in the environment where they're not being properly supported? And, or whether it's really the case that they are, they are disabled in a way that, that prevents them from doing work.*

Tas reflects on their own experiences through the stories of friends and how those friends were supported in embracing their TwoSpirit identity within their community Tas, p.7

> *So there's...okay, I guess I have two stories. There's a person who I know who is TwoSpirit, autistic, non binary. And they, when they grew up in the culture, and when they were a child, they had a mentor, who was also… TwoSpirit, who, um, was given to them, like, was given to them by the, like, the Elders. She was an elder herself, who did a ceremony with the child to help them identify this in themselves, to help them, like, learn what it meant and, and all of these things. And they did this whole, like, presentation of objects in front of them. And they told them to pick the thing that they, that spoke to them. And so they chose this knife that had a bunch of like symbols*

> *on it and everything. And they were like, as we thought, you are, the TwoSpirit. And, the first time, like- and so that was like a transitional moment in their lives. They had that really young, they knew what they were, that helped guide them. And then from then on out, all of the TwoSpirit people in the community... shared their stories and supported them and all of this.*

A force for change

This theme speaks of participants' involvement in their communities and highlights how those communities are co-constructed through the work and interactions of individuals

Lauren stood up for themselves after being treated poorly in an academic reading group - they investigated why it had happened and debriefed mentees that attended on how the way they were treated wasn't acceptable in academic spaces Lauren, p.15

> *So they're like PhD students, like first year, second year PhD students in the lab. And I went, I like messaged them later. And I was like, That is not acceptable behavior. Like this is, um, like what he did was wrong. And that's not the way academia should be*

Sam's perspective as an educator is informed by 'what was not done for myself' to improve the lives of their autistic students Sam, p. 4

> *knowing what was not done for myself is also, knowing... how difficult it was for adults to understand me when I was growing up? Then that also gives me a sense of like, um... why is it difficult for people to understand what the needs are as well as to, to sort of see for myself what I think the needs are*

Kay communicaTas values through their youth work by normalising neurodivergent behaviours and needs p. 57

> *whereas what I do now is, you know, "You're not the only person here," and "Okay, yeah, if you want to stim and flap, that's fine." And, you know, "We can have a bit of quiet time," and "This is what we're kind of generally doing today,*

> *but if we don't really get there, then it's not really a problem." Yeah… "I can understand why you'd have issues with that. I can help you with that," or whatever it's not- a lot, like a lot of kids don't get that at school. A lot of kids don't get that at school at all.*

Rae takes an active role in co-hosting Twitter spaces to connect with other and discuss community issues p. 6

> *I'm actually taking part in Twitter spaces now. I'm co hosting some mental health spaces and some LGBTQIA2S spaces too. We discuss all topics with those heavy experiences*

Tas' tendency to enter every relationship with their 'whole self' and support others with their knowledge is frequently abused and unappreciated by others, but T still chooses to put good out into the world p.27

> *so, I just like show up to every relationship with good intention, my whole self, warmth and love. And, like, I'm very much, like, until you prove me otherwise, I will... help you. Like I, if I see you in need, I will extend what I know that can help you? Like if there's knowledge I have, I will take the time to sit down and explain it to you? And I do that all the time. Like that's so much of what I do on social media. And there's, some people, take it and don't like they, they say, Oh, this will help so much. And they don't even ever say thank you? And then there's some people that I develop, like really long lasting friendships with over it? And then there's some people who will, like, long term treat me like a therapy service? And then just, like, decide to, like ghost me someday. And so there's like... like, we can't, there's always going to be people with bad intent. But I choose to move through my life in a way that's putting good out in the world? And, um, people can act how they want? And my job is to just, like, learn how to build better boundaries around that. So I'm not wasting my... energy on people who... won't value it, people who won't use it to do the work or people who will take it and hurt others with it.*

Appendix H

Materials used to ask for feedback from participants

Email template

Thank you very much for taking part in our interview earlier this year. I really enjoyed talking with you. As you may remember, I asked you at the end of the interview if you would mind giving some feedback on the interpretations I make as part of the research. The attached documents include the interpretations I've made, the demographic information I plan to include and a short questionnaire for you to provide feedback:

1. I have attached a copy of my interpretations of what you said during the interview. I used a data analysis method called IPA which looks for patterns and themes. You will, therefore, be able to see in the attached document a copy of themes I found in the interviews from all participants. Within these themes are extracts from our interview together with sentences describing my interpretation of what you have said.
2. I have also attached a copy of the demographic information that I plan to be including in the study. Please let me know if there is any information you would prefer not to be included or whether you would like to alter the description of you.
3. I have attached a document with a short questionnaire for you to provide your feedback. Questions are about the interpretations I made and your experience being involved in the research. If you disagree with the interpretations, we can negotiate changes and if we still disagree, I will report both our interpretations side by side when writing up the study. As always, this is completely voluntary so if you'd rather not provide feedback please let me know.

Finally, please let me know whether or not you are happy to be contacted about the overall findings of the study and any publications that result.

As I have a deadline fast approaching for a dissertation on this project, I would really appreciate if you could respond with your feedback within the next two weeks.

All my best, and thank you again,

Feedback questionnaire

1. Please write a few sentences about your thoughts on the interpretations I've made. You may wish to comment on the sentences that accompany the quotations from our interview (see the box below) you may also want to comment on whether you think they relate to the themes.

The highlighted sentence is my interpretation of what you have said

e.g.

Jake loved his dog, Jake p. 26

Ever since I first laid eyes on my dog Sandy, I knew we were going to be family

2. Please write a few sentences reflecting on your experience being involved in this research. You might want to talk about:
   a. Our interaction in the interview
   b. The process of being asked to take part
   c. The activities in the interview (coming up with research questions and the clicking and dragging activity)
   d. Being asked to reflect on the themes and your contributions (this questionnaire)
   e. The experience in general

3. Do you think being interviewed by an autistic researcher made a difference? Why?

Appendix I

Ethics form

MA SOCIAL RESEARCH DISSERTATION (60 credits)
ETHICS SUBMISSION FORM
NAME: Charlotte Brooks
STUDENT I.D: [redacted]
DEGREE PROGRAMME: MA Social Research Methods (Education Pathway)
BRIEF DESCRIPTION OF PROJECT: A project looking into the views of nonbinary autistic (NBA) advocates and researchers regarding current research involving NBA people, what they think research should focus on, and how this relates to experiences in their own lives and in the lives of those in their community.
SIGNATURE OF STUDENT [redacted] DATE 17.01.22

University of Birmingham:

MA Social Research

RESEARCH ETHICS REVIEW FOR POSTGRADUATE DISSERTATIONS

(Note: This checklist is adapted from Appendix A of the ESRC Research Ethics Framework)

This checklist should be completed for every postgraduate research project. It is used to identify the research ethics issues that will need to be addressed in the design of any research project. Your supervisor is responsible for exercising appropriate professional judgment in this review. This checklist must be completed before potential participants are approached to take part in any research.

Project Title: What should research involving nonbinary autistic people focus on? Views and experiences of nonbinary autistic advocates and researchers.

Name: Charlotte Brooks

Email address: [redacted]

Supervisor's name: Dr Prithvi Perepa, [redacted] and Prof. Karen Guldberg, [redacted]

Research Ethics Framework (REF)

SECTION I

Research Checklist

Please tick for yes in the appropriate box: Leave blank for no.

1. Does the study involve research with participants (people who are the research subjects), for example through surveys, interviews, focus groups or participant observation in non-public places? This includes participants that are recruited and/or researched remotely, e.g. over the internet.

☐ **YES**

2. Does the study involve participants who are particularly vulnerable and unable to give informed

consent, or might feel under pressure to participate? (e.g. children, people with learning disabilities, fellow students)

☐ **YES**

3. Will the study require the co-operation of a gatekeeper for initial access to the groups or individuals to be recruited? (e.g. students at school, members of self-help group, employees of an organisation)

☐ **NO**

4. Will it be necessary for participants to take part in the study without their knowledge and consent at the time? (e.g. covert observation of people in non-public places)

☐ **NO**

5. Will the study involve discussion of sensitive topics or of participation in illegal activities (e.g. sexual activity, drug use)?

☐ **YES**

6. Are there any safety issues involved for participants or for the researcher (e.g. will interviews take place in unfamiliar settings, or late at night)?

☐ **NO**

7. Could the study induce stress or anxiety, or cause harm or negative consequences beyond the risks encountered in normal life?

☐ **NO**

8. Will the study involve recruitment of patients or staff through the NHS, or involve people involved in social care settings operated by the Local Authority?

☐ **NO**

If you have answered 'yes' to any of the questions you will need to complete Section II of this

form, describing more fully how you plan to deal with the ethical issues raised by your research. If you answered ‘yes’ to question 9*, it is unlikely that you will be able to do the research.* ***If you have answered ‘no’ to all questions you need not complete Section II****, but you and your supervisor must complete Section III and sign the form.*

SECTION II

(This part of the form has been adapted from one developed by the Higher Education Academy Subject Panel for Sociology, Anthropology and Politics, C-SAP)

Briefly describe the rationale for your research with reference to the research literature (approx. 250 words).

Autism is often viewed as an impairment relating to social, cognitive and perceptual differences. Historically, non-autistic professionals have been considered experts on autistic people. Non-autistic researchers have, therefore, led the dialogue of what autism is and what autism research should address (Catala et al., 2021). Proponents of the disability rights movement have highlighted this issue and argued that disabled people should be authorities on issues that affect them – “nothing about us, without us” (Charlton, 1998). This has implications for research and indicates that autistic people should be involved at all stages in autism research.

Research has already looked at the views of the autistic community in relation to research in general (Frazier et al., 2018; Pellicano, Dinsmore and Charman, 2014); early autism research (Fletcher-Watson et al., 2017); sexuality and intimate relationships (Dewinter, Miesen and Holmes, 2020), transition and employment (Nicholas et al., 2017; Shattuck et al., 2018); and mental health (Benevides et al., 2020; Vasa et al., 2018). No research to date, however, has explored the views of the nonbinary autistic people, who represent a relatively large proportion of the community (16.4% compared with 2.2% in general populations; Cooper, Smith and Russel, 2018).

The proposed research will, therefore, look at the views of nonbinary autistic people regarding current research involving NBA people, what they think research should focus on, and how this relates to experiences in their own lives and the lives of those in their community. The findings of this research will be used to inform my future doctoral research and, hopefully, the larger research community more generally.

State the major research questions including the aim(s) and hypothesis(es) where appropriate.

1. What are NBA individuals’ views on current research involving non-binary autistic (NBA) individuals?
2. What do NBA individuals believe should be the focus of research involving NBA individuals

going forward?
3. How do these views and beliefs relate to the experiences of participants in their own lives and their perception of the lives of others in the NBA community?

Describe the method including the design, participants, and procedure.

Design

The design takes an interpretivist approach from the perspective of critical realism. As such, the current research will be interested in how reality is interpreted, and how meaning can be drawn from the subjective experience of individuals (Rosenberg, 2018). The critical realist interpretation will take into account an a priori objective reality that can exist independent of interactions with humans, recognising how our conception of reality is mediated through language, individual meaning and social context.

This will include some consideration of the power of institutions in shaping our views of reality (e.g. institutions of academia and the dominance of deficit-based models of autism and gender diversity). The methodology for the study will be interpretive phenomenological analysis (IPA; Smith, Flowers and Larkin, 2009), which will centre the experiences of individuals, allowing for a more in-depth exploration of phenomena at the level of the individual, and looking at how their view of reality can be contextualised by history, society and dominant cultural forces (Lopez and Willis, 2004).

The study itself will consist of a single phase of interviews, as this may the best way to facilitate participants to tell their own stories, in their own words, in depth and in detail. This will produce rich data necessary for high quality IPA research.

Participants

Ten non-binary autistic (NBA) participants will be selected opportunistically by contacting individuals directly on Twitter, although a snowballing approach may be taken if recruitment proves difficult. Participants will be identified based on their Twitter profiles with a focus on the selection of individuals from a diverse range of backgrounds. This sampling method will be used in line with IPA, which prefers purposive sampling methods in order to select individuals who may provide a particular perspective on an experience (Smith, Flowers and Larkin, 2022).

Procedure

Selected participants will be contacted through direct message on Twitter and asked about their interest in a study looking at the research interests of non-binary autistic people. Participants will be provided with the information sheet (in both written and audio-visual formats for accessibility), a consent form, and a demographic questionnaire (see document ‘consent and demographic questionnaire’). Participant will be asked to sent the questionnaire to the researcher’s university email address to express an interest. Understanding of study and consent information will later be assessed in the interviews. The researcher will then respond to arrange a time for the interview that is convenient for both the researcher and the participant.

Pre-interview activity and correspondence

One week before the interview has been arranged to take place, participants will be contacted with information about the interview (see document 'pre-interview email template'), including what to expect in the interview (see document 'Interview description') and a pre-interview activity with support documents (see documents 'Research question support' and 'recording your questions'). The activity will ask participants to go about their everyday life considering 'research questions' relating to their identity and both their own experiences and the experiences of other community members. The materials they produce (artefacts) will then support discussion in the first half of the interviews.

Interview

The interview will take place online and be recorded using Zoom, unless participant communication requirements/preferences require alternative arrangements. Zoom recordings will be stored locally on university servers, which means that Zoom will not have access to the recordings and these will be kept securely. If participants prefer or need alternatives to Zoom, additional platforms will be explored which include end-to-end encryption and secure data practices (such as Whatsapp). The ability for the project to accommodate communication differences within the limits of the study will be assessed when participants are asked about their communication needs and preferences in the email correspondence. The interview and pre-interview activity will also be conducted with a friend who is an NBA community member for feedback on my interview style (pilot). No recordings will be made of this pilot interview and no information about this individual will be included in any reports of the study.

Prior to the interviews, the interview guide will be shared within the community to ensure that it is open enough to capture rich data and does not limit responses. Before the interview starts (see document 'interview guide'), participants will be asked questions to ensure they have understood their consent in the study and the right for them to withdraw at any point until a month after the interview has taken place. After an initial question on the participant's understanding of 'research', the artefacts participants produced in the pre-interview activity will be discussed.

The second half of the interview will consist of an activity where participants click and drag statements about aims of research that has been done so far involving NBA people – they will be encouraged to 'think aloud' during this process, alongside prompts and follow-up questions (see document 'Interview – ranking statements' – note that this document needs to be opened in 'web layout', which can be selected on the bottom right corner of Microsoft Word). The ranking activity will take place on Google Jamboard, which allows both participant and interviewer to view and interact with the activity remotely and synchronously.

If participants struggle to 'think aloud' during the ranking activity, they will instead be asked questions after they have sorted the statements about their choices. Finally, participants will be asked if they want to contribute any further information and will be reminded of their right to withdraw. They will then be asked whether they agree to be contacted after the interview has been transcribed and analysed to provide a comment on the interpretations that have been made.

If participants choose to use a written format for the interview, the interview guide will need to be adapted for this purpose. For example, participants will need to be asked follow-up questions during the ranking statements activity, as it will not be possible to record their utterances during this activity. A written version may also be more time intensive for both researcher and participant to write their responses. The researcher will, therefore, gauge the energy levels of the participant before the second activity - if the participant is fatigued, it may be necessary to arrange an additional time to complete the interview.

Participant interviews will then be transcribed from recordings and/or extracted from instant messaging platforms. Audio recordings will be transcribed using Otter software, which is GDPR compliant. Once transcribed, all information will be deleted from Otter. Once data has been analysed, original recordings will be destroyed (they will not be deleted directly after transcription as they may aid in data immersion during initial stages of analysis). Transcribed data will be stored on secure university servers.

Data will then be analysed in line with guidelines for interpretive phenomenological analysis (Smith, Flowers and Larkin, 2022), which produces themes at both an individual and group level. The research supervisors will conduct a mini-audit on the analysis of the first interview transcript, to ensure that the account being produced is a credible one.

After Personal Experiential Themes (PETs; themes at an individual-level) have been produced for each participant, participants will be contacted to provide a commentary on the PETs for credibility (see document ‘correspondence email templates’). Participants will be informed that the themes may be subject to change due to the iterative nature of IPA, however, it is likely that interpretations will not stray too far from those provided. Participants will be asked to comment on any interpretations made. Occurring over a month from the initial interview and due to the time-intensive process of analysis, participants will be unable to withdraw at this point. This choice has been made due to the labour-intensive nature of IPA. If participants disagree with interpretations, both interpretations will be included in the write-up of the research. If this occurs, the situation will be handled sensitively and may involve negotiations between the researcher and participant, which will be supported by the researcher’s supervisors.

Participants will finally be asked whether they would like to be contacted with a summary of the study, once it has been written up, and with details on publications that may follow.

Describe the type of data analysis you envisage using.

This study will collect qualitative data consisting of responses to interview questions. Demographic information will be used to describe participants and develop a sense of the embodied context they inhabit in the report of the study. Although interpretive phenomenological analysis (IPA; Smith, Flowers and Larkin, 2022) will be used as the main method of data analysis, the first two research questions will be treated differently.

The first two research questions looking at what participants views are on current research involving nonbinary autistic people and what they believe should be the focus of this research. To answer these questions, responses will be extracted from the data to providing a descriptive account. This, in itself, is not IPA, however these descriptive accounts will inform the IPA process and illustrate the benefits of looking beneath the surface in the tradition of the phenomenological, hermeneutic and idiographic tradition of IPA.

The main focus of the IPA will be in the third research question, which will look at how research is experienced by participants, through their views, and how this relates to their lived experiences. To respond to this question, all data collected will be analysed following the guidelines for IPA (Smith, Flowers and Larkin, 2022). This approach will centre the perspectives of participants, valuing their interpretations of their own personal and social worlds. IPA also has a great reflexive tradition in looking at the ways researcher pre-conceptions may influence their interpretations. In light of this, I will be sure to consider my own role in this process throughout the study, keeping notes of how my own pre-conceptions change throughout the research process.

Additionally, if it seems useful, Q sort analysis may be conducted on the statements ranked in the second half of the interview, which is a mixed methods technique, and is complimentary to the idiographic focus of IPA. Ways of including and analysing the artefacts produced by participants may also be explored - e.g. Boen and Eatough, 2014, who provide protocols for describing and interpreting the process of image production and the features of image themselves. These descriptions could then be included in the material analysed using IPA.

Describe the arrangements for selecting/sampling and briefing potential participants. This should include copies of any advertisements for volunteers or letters to individuals/organisations inviting participation.

As detailed above, ten non-binary autistic participants will be selected opportunistically by contacting individuals directly on Twitter, although a snowballing approach may be taken if recruitment proves difficult (see document - ‘Twitter direct message’). Participants will be identified based on their Twitter profiles with a focus on the selection of nonbinary autistic individuals from a diverse range of backgrounds. This sampling method will be used in line with IPA, which prefers purposive sampling methods in order to select individuals who may provide a particular perspective on an experience (Smith, Flowers and Larkin, 2022).

Describe any possible negative consequences of participation in the research along with the ways in which these consequences will be limited. This should include details where appropriate of any withholding of information or misleading of participants along with a justification of why this is necessary.

Some aspects of the interview may ask participants to reflect on aspects of their identity, which may bring up difficult feelings or negative experiences. If this does happen, I will respond sensitively, remind participants that they don’t need to talk about anything that makes them uncomfortable (or can stop the interview), and I will also be able to signpost them to resources if they wish to seek support form a group or service.

Describe how participants will be made aware of their right to withdraw from the research. This should also include information about participants' right to withhold information.

Participants will be given this information as part of the information sheet. In order to make sure that this information is easy to understand, I will also provide an audio-visual version of the information sheet that participants can watch or listen to – this will help to ensure that participants understand their rights, including rights to withdraw. As part of the information provided, they will also be told that they will be able to withdraw with no penalties up until a month after the interview. After this point, they will also have the opportunity to comment on the interpretations that have been made.

Participants will also be reminded of their right to withdraw in all email correspondence with the researcher, and at both the beginning and end of the interview. Understanding of their rights will also be gauged at the beginning of the interview.

Describe the arrangements for obtaining participants' consent. This should include copies of the information that they will receive & written consent forms where appropriate. If children or vulnerable people are to be participants in the study details of the arrangements for obtaining consent from those acting in *loco parentis*, or as advocates, should be provided. For an example of how to provide an information sheet, and a consent form see: http://www.socscidiss.bham.ac.uk/ethics.html

Participants will be provided with an information sheet about the study and what is entailed in providing consent. Having read and understood this information, participants will provide written consent by completing a consent form questionnaire (see document 'consent and demographic questionnaire'). The researcher will further check that participants have understood what it means to consent at the beginning of the interview and their rights to withdraw their consent. If participants do withdraw from the study, I will destroy any information they have provided.

If you intend to undertake research with children or other vulnerable participants does the data collection involve you being alone with the participant(s)? Please provide details. If your data collection plans requires that you work alone with children or other vulnerable participants, you will be unable to undertake the research unless you have you undergone Criminal Records Bureau screening)

Study will take place online with recordings taken of all of my interactions with the participants. They will also have contact information for my supervisors, which they may use if they are concerned about my own conduct in the study.

Describe the arrangements for debriefing the participants. This should include copies of information that participants will receive where appropriate.

Due to the lack of any kind of deceit, a full debrief is not necessary for the current study. At the end of the interviews, I will summarise what we have talked about. After analysing participant transcripts, participants will be provided with a summary of what we discussed (in the form of Personal Experiential Themes) for comment. At this point, I will ask participants whether they wish to be contacted with a synposis of the overall study and information about any future publications.

Describe the arrangements for ensuring participant confidentiality. This should include details of how data will be stored and how results will be presented.

Although individuals will be initially contacted on Twitter, participants will be asked to respond to the researcher's university email address to express their interest in the study. This means no sensitive information will be included in messages on Twitter. Participants will also be asked to complete a consent form and demographic questionnaire at this point. Responses to this form will be stored securely in a separate document to the transcript data.

For the pre-interview activity and the ranking statements activity, participants will be given personalised links to documents on Google Jamboard. After the interview, copies of these documents will be retrieved from Google and stored on university servers with the other data. Copies on the Google interface will then be destroyed, though it is possible that Google may retain some of this information.

For the interviews, recordings will be made using local recordings on Zoom. This means that recordings will not be saved on the Zoom cloud, and will only be saved on the researcher's computer. These recordings will be stored securely on university servers. After analysis, the recordings themselves will be destroyed. Interviews will be transcribed into a written format using Otter software – this software is GDPR compliant. Once transcribed, information will be removed from Otter, though it is possible they may retain a trace of this information. Once transcribed, interview transcripts will be stored securely on university servers.

The results will be written up in the format of an academic report. Participants will be given pseudonyms to maintain anonymity. Inclusion of demographic information to describe participants will be chosen selectively for anonymity.

SECTION III

You are required to read one set of relevant research ethics guidelines, normally it will be those provided by C-SAP. Please confirm that you have done so, and that your research conforms to the principles they contain.

Relevant research ethics guidelines are:

> The Economic and Social Research Council (which has set a Research Ethics Framework to apply to all research, including that by students):
>
> https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/our-core-principles/

The C-SAP guidelines for undergraduate projects (applicable for postgraduate projects):

http://www.socscidiss.bham.ac.uk/ethics.html

The Social Research Association:

http://the-sra.org.uk/wp-content/uploads/SRA-Ethics-guidelines-2002.pdf

The British Sociological Association:

https://www.britsoc.co.uk/ethics

The Association of Internet Researchers

http://www.aoir.org/reports/ethics.pdf

Any significant change in the question, design or conduct over the course of the research should be notified to your supervisor, who has the responsibility of contacting the Department Research Governance Committee for advice.

Signed (Student): [redacted]

Date: 17.01.22

Supervisor: Please tick the appropriate boxes. The study should not begin until all boxes are ticked:

x The student has read the statements of good practice and the relevant codes of practice as indicated above.

x The topic merits further research.

x The student has the skills to carry out the research.

x The participant information sheet or leaflet is appropriate.

x The procedures for recruitment and obtaining informed consent are appropriate

Signed (Supervisor): [redacted]

Date: 20th January 2022

The form, together with information sheets and examples of consent forms, are to be returned to Cate Gahan in the PGT Office (socialresearchmethods@contacts.bham.ac.uk). This must be submitted prior to beginning the research.