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Trying to solve the 'worst situation' together: participatory autism research

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ABSTRACT
The importance of participatory autism research is discussed in relation to a project involving six autistic researchers and five non-autistic university researchers collaborating to investigate anxiety in autistic adolescents. The paper describes the process of establishing a research partnership and the values and philosophy behind this inclusive method of research. Lessons were learnt about neurodivergent thinking and the benefits it brings to the development of research questions and analysis of data.

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Autism; participatory research; neurodiversity; anxiety

Introduction

This paper is a reflection on the process of establishing a research partnership including autistic and non-autistic co-researchers. We came together to investigate the ways in which the organisation of the secondary school system in the UK contributes to the social and emotional difficulties for autistic adolescents through the organisation of the secondary school system as an agent of cultural reproduction (Apple 2017). A full description of the research undertaken by the co-researchers has been published separately (Costley et al. 2021).

The project was funded by a Research Development Grant from the School of Education and included researchers from Education and Psychology within the University of Nottingham as well as co-researchers from a range of backgrounds. The aim was to work together (co-production) to design a project that would privilege the views of autistic adolescents over the non-autistic adults who are normally the contributors to autism research and mediators of autism knowledge (parents; teachers; medical professionals). We wanted to understand the situations that cause anxiety for autistic boys and girls and to find out whether these are the same or different situations. Based on what the adolescents told us we hoped to identify the strategies they use to cope with anxiety in school with the aim of producing a resource that will share those strategies with other autistic students. In this way we were meeting the stated needs of participatory autism research (PAUR) that it should include the autistic voice and that it should have an aim to make the lives of autistic people better (Chown et al. 2017).

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Why partnership is essential in autism research

The exponential coverage of autism by academic researchers and other professionals can make us all think we know what autism is, what it feels like, and what autistic people need. However, much of the research continues to have a medical focus, looking for a cure or intervention; and most is carried out by non-autistic academics (Gillespie-Lynch et al. 2017). This situation accords with Goodley et al. who, when discussing Critical Disability Studies, comment "that disabled people are drawn in as interesting objects of inquiry rather than as arbiters of knowledge production (2019, 981). Pellicano, Dinsmore, and Charman (2014) found a disparity between the views of UK autism researchers, who believe they are engaged with the community, and the views of the community who do not feel included. This paper offers a critical examination of a project attempting to include autistic co-researchers in studying anxiety in autistic adolescents to consider both facilitators of participation and barriers. The project attempted to put the experience of autistic people at the centre from the beginning, as partners not just participants, to co-create knowledge about the autistic experience (Crane et al. 2019). In this paper the term 'autistic person' is adopted as the preference of co-researchers when discussed during the second focus group meeting.

Autistic spectrum conditions

There are multiple conceptions of autism that need to be considered from the medical model to social-constructivist theory, via neurodiversity, to claims that autism is not a valid description at all (Robertson 2010; Singer 2016; Silberman 2015; Timimi 20112011). The medical model predominates as it lays out the deficits of autism, such as lack of social communication, restricted and repetitive patterns of behaviour and sensory challenges (American Psychiatric Association 2013). This model describes the difficulties as belonging to the disabled person; what is 'wrong' with them and what we can do to 'fix' that. Not surprisingly, this definition is often rejected by members of the autistic community. In contrast, the social model of disability/autism views the disability as being exacerbated by the way society is organised, as opposed to the problem being with the individual themselves (2017; den Houting, 2019). This model, first used by Oliver (1996), seeks to make changes to society to remove barriers to participation for autistic people.

The latest thinking in autism studies uses the term neurodiversity to highlight the diverse nature of human beings; to encourage respect for neurological differences such as autism and ADHD as natural phenotypic variations in humans (Robertson 2010; Silberman 2015; Singer 2016; Prizant 2016). The adoption of the social model, and the concept of neurodiversity influenced the research design and underpinned the importance of co-creation of this research project that sought to understand the lived experience of autistic secondary school students.

Participatory autism research

(The acronym PAUR has been adopted for this paper to distinguish between participatory research (PR) and participatory action research (PAR)).

Participatory Autism Research (PAUR) is both a philosophical, ideological, and moral imperative, and a set of methodological approaches (Searle et al. 2019). It is based on a set of values and moral beliefs that research about autism is best conducted with the involvement of autistic people. Despite efforts to describe the inclusion of autistic people in research there is no agreed standard or description of what makes research participatory. Given the amount of funding spent on autism research that autistic people feel is irrelevant or unnecessary (Pellicano, Dinsmore, and Charman 2014) it is essential that more emphasis is put on PAUR, particularly in relation to education (Milton 2019). Despite the call for more PAUR and the publication of research that claims to be participatory, at the time of this research project there did not appear to be any consistent evaluative categories that demonstrated whether a project was actually participatory. There is increasing interest in this area of work and some studies have sought to identify guidelines for the inclusion of autistic adults (Nicolaidis et al. 2019) in meaningful participation. Fletcher-Watson et al. (ibid.) describe meaningful participatory research as 'relevant to the community, consistent with their values, and not tokenistic in delivery' (945). These themes were central to the PAUR project described in this paper.

Participatory disability research in general is more established in the fields of health or social care (Smith-Merry 2017). A meta-analysis of research purporting to involve people with neurodevelopmental disorders including autism found only 7 of the 636 studies actually had adults with neurodevelopmental disorders as research partners (Jivraj et al. 2014). Only two of those studies involved autistic people. In many cases the researchers did not report the extent to which partners were involved in all stages of the research and therefore a judgment could not be made as to whether the projects were participatory or not. As a result of this meta-analysis Jivraj et al. developed an evaluative framework for researchers to assess the 'breadth, depth, and outcomes of participatory research (PR) partnerships with individuals with ASD and other neurodevelopmental disorders' (2014, 790), for use as a guide for future researchers, and presented here as an evaluation tool for this project.

Chown et al. (2017) describe the Asperger's Consultation Group that they established to discuss the concepts of participatory research and emancipatory research to promote research with autistic adults rather than on them. Although there is not universal agreement on the distinction between participatory and emancipatory research, Chown et al. (2017) suggest that it extends the participatory research paradigm to include ownership of the research by the autistic researchers; a requirement for results to lead to social change; and reciprocal accountability between the autistic and non-autistic researchers. Chown et al.'s approach was based on the social model of disability and the assumption that autism research should be aimed at improving the lives of people with autism. They contend that autistic people need to be included in research to enrich the process; increase understanding of what is important and why; and to reflect the different cognition of autistic people. Chown et al. developed a framework for emancipatory research that includes autistic adults and aims to make a difference to the lives of people identifying as autistic. This takes the idea of a framework further than Jivraj et al. (2014), as it sets out the steps that should be taken from the outset of a project rather than evaluating the level of participation within a project, which is why the latter fits better with our approach.

Increasingly, autistic adult advocates are questioning the value of research that is about them without their involvement. The 'autistic voice' is made 'invisible' within the current culture of how knowledge is produced about 'autistic people' (Milton 2012, 885). Milton defined this lack of understanding as the 'double empathy' problem, suggesting that non-autistic individuals fail to appreciate the lived experience of those that identify as autistic; whilst common theories suggest that it is autistic individuals who lack empathy in relation to those they interact with socially (*ibid*). The different lived experiences of autistic and non-autistic people mean that we cannot truly understand what life is like for each other, which reinforces the need to include the autistic voice in research about autism.

Ecological systems approach

Accepting the social construction of autism makes imperative the link between the individual and their environment, which means the ecological systems approach or social ecological theory can also be linked to participatory action research (PAR) (Wright et al. 2014). The principles and concepts that underpin PAUR clearly link to social ecological theories, which in turn can be applied to the social model of disability and the study of autism. The ecological systems approach acknowledges that the autistic individual who is involved in developing research methodology is also embedded in their family and community, including schools, where interventions are carried out, clearly illustrating the dynamics of the autistic individual and the 'social and cultural forces of influence across the life course' (ibid, 6). Vincent et al. (2016) go further and describe PAUR as an emphasis on the 'construction of expertise and validity through the life stories of those who experience oppression, rather than by the professional researcher or expert' (Vincent et al. 2016, 303). Joss, Cooklin, and Oldenburg (2016) analysed inclusive research studies and found the main reasons for including disabled people was to draw on their expertise, experience, and relationships (which could be seen as tokenistic). The researchers involved in the project reported here wanted to move beyond these elements of participatory research to develop a partnership approach.

Setting up the project

This paper reports on a research project that included six autistic researchers and five non-autistic researchers working together to investigate anxiety in autistic adolescents. From the outset it was important to work collaboratively. The initial discussion about anxiety and how it impacts upon autistic people's lives was part of a seminar for International Autism Month that included autistic presenters. Their description of how they had to carefully plan their week to accommodate activities that they knew would cause anxiety was the stimulus for further discussions about what we knew or did not know about how autistic people cope with anxiety. It was clear that this was an area we wanted to investigate together, which would make the project meaningful and participatory at the level of the researchers, but we also wanted to involve adolescents in the research to explore issues such as when they become self-aware enough to recognise they are becoming anxious and what strategies they develop to cope.

The best way to be sure that we understand anxiety and how it manifests in autistic adolescents is to ask them. At this stage we considered asking autistic adolescents who were still in school to be part of the research team but on further discussion with the Nottingham City Autism Team this did not seem like a feasible strategy. The ethical and practical issues would have been difficult to justify. Two of the autistic researchers were teenagers who had left school for an apprenticeship or specialist college course, so we felt they could represent an adolescent perspective in the group.

Ethics

Ethical approval was applied for in two stages; first to set up the co-researcher relationship and meetings, which we conceptualised as focus groups; and second to conduct the interviews with autistic adolescents. Approval was given by the School of Education Ethics Committee. There were particular ethical issues to consider at each stage. First, in setting out to establish a co-research relationship we had to be cognisant of potential power relationships between university researchers and autistic researchers, some of whom were studying at our University. We had to ensure that everyone's views were sought and that each person was given the opportunity to contribute where they wanted to. We also discussed issues of confidentiality and anonymity and the use of their real names in any presentations or publications and all were keen to have their contribution acknowledged. Previous researchers have discussed the difficulties of involving autistic individuals in research, some of which were based on their susceptibility to anxiety and depression (Gillott and Standen 2007). This discussion echoes Vincent et al. (2016) when they discuss the tension between giving a voice to potentially vulnerable people, where their ability to give fully informed consent may be in doubt. In the second ethics application we considered the role of outside adults going in to schools to interview 'vulnerable students' and worked very closely with the school special needs coordinators (SENCOs) to ensure we understood the needs of the students who volunteered to talk to us. The term 'vulnerability' is contested by scholars involved in qualitative research (see Aluwihare-Samaranayake 2012, for a discussion of the issues) and bioethics (Ten Have 2015) and is used here as the terminology used in the procedural ethics policy of the University. The autistic adolescents are considered vulnerable because of their age and ability to give informed consent, rather than because they have a diagnosis of autism per se.

Establishing the co-researcher relationship

The autistic co-researchers were recruited from a range of organisations, including the University, and through connections with other groups that support and work with autistic young adults. Initial information about the project was sent via email and when individuals showed an interest in participating they were sent the information sheet and consent form. Further questions were asked by some of the young people themselves and in two cases by the parents of younger potential partners. Six people agreed to join the group. The group consisted of two males and four females; the university researchers were all female. The co-researchers all had a diagnosis of autism spectrum disorder/Aspergers apart from one who was exploring his autism. The autistic co-researchers were mostly studying: one at a FE college; one undergraduate psychology; three post-graduate (PhD, Masters in Counselling, PGCE); one plumbing apprenticeship. They agreed to take part in three meetings at the University and to read and comment on outputs between meetings. The project funding included an amount to pay them an 'inconvenience allowance' (this was the only category the Finance team had for us to pay people not on contract) for their time plus any travel expenses and catering of their choice at meetings. Paying external research collaborators in this way was a first for the School of Education and the most suitable way to pay people who were not on the payroll had to be negotiated with the University Finance team (Fletcher-Watson et al. 2019). We felt strongly that this was extremely important to the project as it illustrated the value of all researchers' time and contribution and was very much appreciated as part of the participatory principles underpinning the project.

> 'It is important because of the financial recognition of the autistic voice, which so rarely happens in research' (Autistic co-researcher).

Autistica, the UK's leading autism research charity, endorses the National Institute for Health Research's INVOLVE guidelines for payment of fees for research contributions. It is unusual to be able to pay people for their participation in Education research and for many autistic individuals their main hope is that their participation will benefit others. One of the participants in the participatory research project with MacLeod et al. illustrated this point, *'So the feeling of helping others was rewarding in itself'* (2013, 10).

Method of co-production

In this project co-production refers to autistic and academic researchers working together. The meetings took the form of three flexible focus groups, each with a different focus depending on the stage of the project.

Meeting one

During the first meeting we had to establish a relationship between the team members who attended (Fletcher-Watson et al. 2019). Two of the autistic researchers knew each other but no one else had met before. The academic team members who attended were each known by some of the participants. We started by introducing ourselves, where we came from, what people were studying, and why they wanted to be part of the project. Although some people were shy at first they all contributed and having at least one of the academic team members they had met before gave them a person to focus on when they were speaking. This was valuable in the initial stages of the meeting and would have potentially taken much longer to develop a rapport if no one in the group had met before. As Fletcher-Watson et al. recorded *'mutual respect between autistic and non-autistic members grew from meeting to meeting'* (2019, 947). After introductions and discussion between the group we had to carry out the University based research protocols; we reviewed the information sheets and everyone signed the consent forms; we supported the co-researchers to complete the expense forms provided by the University and filled in as much as possible with details about the project (leaving just personal and banking details to be completed). We were conscious of the different ages and experience within the group and wanted to minimise any embarrassment or stress with form filling; the younger group members were dropped off by parents and so they completed the details on the forms leaving the young people to sign for themselves. We then went on to discuss the ideas behind the project, including the importance of us all being co-researchers, and agreed with the focus on anxiety in adolescents in mainstream schools. Once the administrative tasks were completed, we sought and received permission to record the meeting to help us to capture the important issues raised in the discussion. As it was the first meeting the University researchers had prepared some questions to open the discussion about anxiety in order to understand the experience of the co-researchers and to give them the chance to share their knowledge and feelings on the subject.

Frankena et al. (2015) carried out a systematic review of inclusive research and identified some of the key benefits to the co-researchers, which included an element of empowerment and an opportunity to contribute, which gave them the opportunity to develop skills and self-confidence whilst feeling respected. As one co-researcher commented:

> 'It was important to me so I could spread awareness to other students in schools and also to have a voice and to make my feelings known. I was glad to be asked to take part' (Autistic researcher).

The success of the first meeting of our new research team can mainly be attributed to two elements. First, it was due to the ability of the academic researchers, who had all worked extensively with autistic people, to ensure that appropriate adaptations were made, relationships built and comfort and safety prioritised. Second, the confident and articulate young people who joined the team were willing to engage with each other from the start. Their participation in the group went against all the received wisdom about the deficits of autism (the medical model) and highlighted the importance of respecting the individual and considering the environment (the social model and neurodiversity). The aim of the first discussion was to start to identify the questions we would want to ask autistic adolescents in secondary schools.

Discussing anxiety

The first meeting helped the members of the group get to know each other and bond over shared experiences. Autistic and non-autistic team members discussed their own experiences of secondary school as a method of understanding the issues that may be specifically relevant to the autistic experience. The discussion recordings formed the first element of the research and were used to summarise the key issues raised by the research team enabling direct quotes from autistic team members to be used to illustrate those issues. They raised the difficulty of meeting new people; of talking to people especially of their own age; worry about fitting in; not wanting to admit to having autism or trying to supress autistic behaviour; uncertainty; dislike of change; school specific issues such as reading out loud in class; and sensory issues caused by noise or light. For more than one group member anxiety was described as thinking about the worst situation they could encounter.

> 'An overwhelming feeling of fear and nervousness that makes me think of the worst possible scenario'.

> 'Thinking of the worst situation and trying to solve it'.

> 'I'm worried about every situation and about everyone else and how things affect them'.

The outcome of these feelings for one group member was described as feeling

> 'Like I want to disappear into a black hole and that there is no escape'.

The group discussed how these feelings of fear and anxiety would make us behave or react at school and what we could learn from that for the questions we would want to ask autistic adolescents. We talked about trying to fit in at school, and the impact of supressing autistic traits on behaviour when people got home at the end of the day.

> 'At school, I would excessively fidget and was very anxious about sitting in assemblies where it was silent. I stopped attending them in year 10. Then I needed to sit against a wall to do my GCSEs or in lessons. I couldn't concentrate in lessons because I was constantly anxious and trying to suppress 'autistic behaviour' and appear normal to everybody else. I was not diagnosed in school'.

> 'I would meltdown at home after school as I could keep things together and "act normal" to an extent at school. This would come out as door slamming, 'tantrums', self-harm and not being able to deal with any small changes at home (e.g. a change in planned food for supper)'.

Most of the autistic co-researchers discussed looking for a safe place and taking themselves out of situations whenever they could. They differed in their views about relaxation techniques, with some people able to describe how they would calm themselves in stressful situations, and others discussing techniques taught by others (such as mindfulness) that did not work for them. We did try to end the discussion with speculation about how autistic teenagers might feel in mainstream schools and whether this was different for boys and girls, but some group members felt that we could not possibly know what other people might feel. This highlighted a difference in thinking style between academics who are willing to extrapolate from what they know and offer hypotheses and the autistic researchers who were only willing to comment on what they had directly experienced or witnessed themselves. Again, this further underlined the value of different thinking styles and why we needed to listen to and incorporate the views of autistic people. After this detailed and very open discussion at our first focus group we had an idea about the areas we wanted to explore and the method we would use. The University researchers agreed to draft some questions and send them to the whole group for comment. Co-researchers contributed comments about language and meaning of questions, which was incorporated in the next iteration.

Meeting two

The second meeting focussed on the research methods and refined the questions to be asked in secondary schools. We agreed to use semi-structured interview questions in order to guide the interviews whilst also allowing the opportunity to follow any interesting line of discussion raised by the participants. At this point a fifth University researcher joined the group, with everyone's agreement, to use the adolescent research as the basis of her MSc Psychology dissertation. We discussed the possible use of a standardised measure of anxiety but the autistic members of the team were very much against it as a tool designed by non-autistic academics to measure autistic people's behaviour. Some team members felt strongly that we should not be using a measure that we had not designed, did not know how it had been developed and tested, and could not prove that it measured what it said it did. Overall, there was agreement that autistic adolescents had probably been tested and measured enough (medical model of diagnosis) and if they said they experienced anxiety then that should be evidence enough for us (individual and social model of experience). The group dynamics were very important and we had to be careful that discussions were not dominated by people studying post graduate degrees that had involved them reading more academic literature that led them to question theories and processes. Those with less experience of academia or of autism theory were encouraged to offer their opinions and to agree or disagree with ideas put forward in the group. All group members were very supportive of each other and encouraged the quieter members by asking their opinions and showing genuine interest in their experiences.

The autistic co-researchers contributed to the design of the interview protocol, suggesting we provide fidget toys to relieve anxiety for student interviewees; grapes as a reward for taking part; and a traffic light system to take away the pressure of talking to unknown adults. The idea of the traffic light picture was that it would enable autistic adolescents to indicate by touching the appropriate colour when they did not want to answer a particular question (amber) or wanted the interview to stop completely (red). The fidget toys and traffic light system were put in place and their purpose formed part of the introduction to the interviews. The questions used to frame the school-based interviews included four specifically suggested by the autistic co-researchers' experience that the non-autistic researchers would not have considered. Some of these may appear to be leading questions, but we felt it was important to record both positive and negative feelings about school and that the autistic adolescents would not necessarily freely offer the more negative responses. The additional questions were; 'What don't you like about school and why?' to follow the positive form of this question; 'Does other people's behaviour bother you?'; 'Who do you most enjoy talking to at school and why?'; and, 'What do you do at break and lunch times?'

Data generation in schools

Semi-structured interviews were carried out in two mainstream schools with significant populations of autistic students. The interviews were carried out in three groups with two University researchers conducting each interview. The autistic co-researchers were all studying or working full-time, reliant on public transport (or parents) for travel, and for some, anxious themselves, so we considered it more appropriate for the professional researchers to carry out the data generation. In addition, the sensitivities around interviewing potentially vulnerable young people on school premises added to the complexity (DBS checks were needed for those going in to schools).

Eighteen adolescents between the ages of 12 and 17 were interviewed. There were eleven boys and seven girls. All interviews were recorded and transcribed in full (see Costley et al. 2021 for full details).

Meeting three

The third meeting was set up after the data collection and initial analysis in order to discuss the findings with the co-researchers and to achieve social validity of the thematic analysis. Social validity is a term that is normally applied to the evaluation of autism interventions (Wolf 1978) to engage with end users to ensure the procedures, goals and outcomes are acceptable (Kramer 2011). We have appropriated this term in our project to ensure the thematic analysis, and therefore outcomes of the adolescent research, satisfy the autistic co-researchers based on their experience. Prior to the final meeting data were analysed using thematic analysis to identify and code specific answers to interview questions using the framework developed by Braun and Clarke (2006, 2014). The interview transcripts were read in detail by two academic members of the team, independently, in order to identify and record patterns in the data. Every response to a question was tabulated and assigned a code depending on the semantic analysis of the student's main ideas.

After consultation and consolidation of codes, five main themes were identified from the data. These themes, as well as the complete transcripts, were shared with two other non-autistic members of the team and three autistic researchers during the third meeting. Due to the success of some autistic team members, two were undertaking PhDs in other parts of the UK and one was starting a new teaching career, only three were available to take part in the final meeting. The six researchers worked in pairs to review some of the interview transcripts, so that they could identify themes themselves and also see where the themes already identified had come from. The autistic co-researchers had not been involved in any work like this before, but were able to work through some transcripts with the support of an academic co-researcher. The autistic team members highlighted the issues or words they thought were important in the adolescent student transcripts and discussed these with their partner. We discussed the coding of the participants' words in the interview transcripts in some detail to make sure everyone understood what the codes meant and how they had been identified, and to make sure we all agreed the final themes for the data analysis.

The themes discussed with the group of co-researchers were mainly consistent with those identified in the initial analysis. There were only two points of departure: one example was that the autistic co-researchers focussed on the difficulty the adolescents had answering some of our questions and the number of times they said 'I don't know' were highlighted. This was identified as a methodological issue by Lewis (2009) who suggested there was a particular risk of autistic participants giving 'don't know' as a default response. We did not identify this as a theme, but it is worth noting that it was discussed and added to our understanding of the difficulties of taking part in the interviews for some participants. This again highlighted the importance of paying attention to divergent thinking and interpretation and of taking account of the double empathy problem (Milton 2012). The autistic co-researchers could well have been identifying an important theme that previous researchers (Lewis 2009) have dismissed as a methodological issue. The social validation of the thematic analysis and interpretation of the views of the autistic adolescents were extremely important for our understanding of how to interpret the data.

Reflection on participatory research

The research team used the PAR Framework developed by Jivraj et al. (2014) to review and reflect on the participatory nature of this research (see Table 1).

Table 1. Using the framework for assessing breadth, depth, and outcomes of PR partnerships with individuals with ASD and other neurodevelopmental disorders (Jivraj et al. 2014, 790) to evaluate the autism and anxiety research project.

PAR Framework	Autism and anxiety research project
(1) Context	
a. Study purpose	To explore the impact of anxiety on autistic adolescents using a participatory methodology.
b. Study method	Discussed during a focus group and agreed.
c. PR purpose	Value of autistic voice discussed and supported by all researchers.
d. PR method	Agreed via email and initial information and consent discussions and reiterated during first focus group meeting.
e. Was PR required or inspired?	Inspired by previous work in Australia and the establishment of a Participatory Autism Research Network by the academic co-researchers; and stimulated by a co-presentation with autistic people at an autism month seminar.
f. What theory underpinned involvement as described by reports' authors?	Social model of disability; autism movement of 'nothing about us without us'; authentic voice.
g. Did partners share authorship?	Yes
(2) Breadth	
a. Which stages of the research did partners participate in?	All stages except data generation in schools.
i. Identifying or setting the research questions	Yes
ii. Setting the methodology	Yes
iii. Collecting data	No
iv. Analyzing data	Yes
v. Uptake or dissemination of research findings	Yes
b. How were partners involved in each stage of research?	Through focus groups; email discussions; sharing and commenting on written information; decisions about process and outcomes.
(3) Depth	
a. Which partners were involved?	Autistic co-researchers were involved in the first two focus groups; three were involved in the final one: University researchers were involved in all stages.
b. How were partners involved?	Through discussions during focus groups; commenting on drafts of questions; designing interview questions and protocol; reviewing data; agreeing themes; commenting on conference abstracts; journal paper drafts.
c. What was the direction of the approach/what was the degree of consumer involvement?	We were co-researchers at every stage: 6 autistic adults and 5 university researchers.
i. Researcher- or consumer-initiated	Joint generation of initial idea; development and funding initiated by University researchers.
ii. Consumers consulted	Yes
iii. Consumer collaborators	Yes
iv. Consumers in control	Methods and research questions were negotiated in the research team.
d. What were the forums for exchange?	Open discussions with autistic co-researchers; interviews with autistic secondary school students; joint review of data.
i. Committee membership	Yes
ii. Written consultation	Yes

(*Continued*)

Table 1. (Continued).

iii. Focus groups	Yes
iv. Public meetings	No
e. What methods were used for decision-making?	Discussion and consensus agreement reached in the group.
(4) PR Outcomes	
a. How did PR partnerships influence the research process and outcomes?	By contributing to design and analysis.
b. What were the intended outcomes of PR?	To value and listen to the autistic voice at two levels; the autistic co-researchers and the autistic adolescent school students. To produce authentic outcomes.
c. What outcomes were achieved	Successful participatory autism research. The autistic co-researchers gained research experience, which was highly relevant to those starting or applying for doctoral study.
d. What outcomes were not specified?	Consideration of how we might involve the autistic co-researchers in data generation.
e. How did involvement from individuals with neurodevelopmental disorders change research outcomes (vs. influence the world views/perspectives of the investigators)?	By their honesty during the initial focus group about what anxiety meant for them; design of interview questions; interview protocol; and analysis of results.
f. Which barriers to, and facilitators of, meaningful participation by consumers in PR partnerships are described?	Barriers: travel to meetings; ability to contribute to data generation; possibly the focus group method, although this specific group seemed to cope well in the group situation; inclusion of autistic adolescents as project participants. Facilitators: experienced university partners; genuine desire to listen to and include the autistic voice; sharing of decision making at all stages; confident and neurodivergent co-researchers; offer of payment for time and travel expenses.

Discussion

The participatory nature of this project has provided an insight into the ways in which a team of autistic and non-autistic researchers can collaborate to design and implement a meaningful research project. The first cycle of participation was the development of the project with autistic co-researchers; the second cycle was using questions developed in partnership to include the experiences of autistic adolescents; the third cycle was working in partnership to analyse and agree the findings using the concept of social validity.

The fact that this was a University of Nottingham funded project meant that the project was not participatory from the conception of the idea, but rather once funding had been awarded.

The University researchers were very keen to listen to and value the autistic voice but there were some things that as academic researchers we had to do, such as applying for funding for the project, completing and submitting the ethics application, liaising with Local Authority and school contacts to identify students to interview, organising University rooms and catering for focus groups, organising finance to pay autistic co-researchers, ensuring University processes were followed, and presenting findings at conferences. The latter point we have tried to organise as a research team, but the anxiety of the autistic co-researchers meant they withdrew from one presentation and funding constraints for overseas conferences meant they could not attend as a delegate. The move to online conferences as a result of the Covid-19 pandemic means that this might not be an issue in the future. It is important to consider the impact that the procedural leadership by University co-researchers had on the initial meeting with autistic co-researchers as the academics had arranged the first meeting, asked the autistic co-researchers to join them, and then had to ask them to sign participant consent forms to satisfy procedural elements of the ethics committee. There were obvious disparities in the power and control in this relationship at the beginning.

The framework proposed by Jivraj et al. ibid, was a useful tool to review the approach that we took to participatory autism research. The table was completed by the academic researchers and reviewed by the autistic co-researchers before being finalised. It does not exactly fit an educational context where the research also involved vulnerable school age students, but it provides a good overview of the different stages at which participation should be possible. In some places it refers to partners and in others to consumers, so we have completed all sections in reference to the autistic co-researchers. These terms could be clearer in the table. Most of the responses in the table have been discussed throughout this paper, but it did encourage us to consider barriers and facilitators to PAUR in this project. The main barriers were related to travel to meetings, which were all held at the University. Most participants were based locally but for some that involved parents in transporting group members, and for others there were train journeys between cities. Expenses were paid but this did not compensate for travel time or for the anxiety caused by having to use public transport. The second barrier could be seen as our lack of involvement of autistic partners in data generation. As the project was Participatory Autism Research, as opposed to Action Research, there are differences in approach that the table does not reflect. Autistic co-researchers are not always in a position to take part in data generation but still want to contribute to the other stages of the project. Jivraj et al. say the table is meant only as a guide,

> 'a balance needs to be developed, allowing partners to provide the necessary expertise to aide in the development, and implementations of the overarching academic agenda' (2014, 790).

Although there were positive facilitators to the design, development, and completion of a participatory project due to the experience and values of the university partners, the completion of the table did help to consolidate those and to point to areas for improvement. The table could be improved by adding a question about challenges posed by the process and how these were addressed, in order to make it more of a formative tool. This could be added to the section on breadth.

This paper reflects on the value of participatory autism research including a team of autistic and non-autistic co-researchers. The involvement of the autistic co-researchers gave us a greater insight into what their anxiety actually feels like. Through our discussions and the willingness of co-researchers to share so openly about their own experiences the research team were able to develop a set of semi-structured interview questions that enabled generation of more genuine and authentic data from the secondary school students. This fits well with the principles outlined by Pellicano et al. (2011), that in order to make the scientific study of autism relevant to those in the autism community we should ensure that key voices get heard, that the direction of the research is shaped by agreement and not based purely on power differentials of the participants, and that as many participants as possible feel their unique and vulnerable perspectives have been paid due concern (278).

Large scale research by Pellicano, Dinsmore, and Charman (2014) found that academics have some difficulty with how they might involve autistic people in research and the extent to which they should be involved. Participants felt they were not always valued, or were in unbalanced relationships with researchers where they provided evidence, attended steering groups, or read documents, but never found out what happened to the data. As a result of these and other challenges the resulting research was often found to be 'indigestible' and of no benefit to the partners (Pellicano, Dinsmore, and Charman 2014, 5). We were determined that our project would be a partnership and we made every attempt to include all researchers at all stages, as can be seen in Table 1. No researchers in Pellicano, Dinsmore, and Charman (2014) suggested that autistic individuals could be co-researchers. This is a very different attitude to that held by those who see the benefits of participatory autism research (Haas et al. 2016).

Researchers' reservations about taking a participatory approach focus on the challenges of working with autistic adults; the time it might take to support them; the funding required; how to work with their different cognitive styles; social and emotional difficulties of taking part in research; and their lack of objectivity (Pellicano, Dinsmore, and Charman 2014; Jivraj et al. 2014; Haas et al. 2016; Nicolaidis et al. 2019). The academic researchers were lucky to have good networks that included autistic individuals who were keen to join the team and that the academics were able to make the case to the School of Education funding committee that paying autistic co-researchers for their time was an important element of the study. This was complemented by an academic team each with ten to thirty years of experience of working with autistic individuals, which meant they were not worried about different cognitive styles, rather they embraced them as adding originality and focus to the project. The research team wanted to hear the authentic voice of autistic individuals within our project and therefore expected them to be subjective/personal. On reflection the research team is concerned that 'participatory' still infers that the academics conceived of a project and then invited the autistic researchers to join. Chown et al. (2017) suggested that for research to be participatory it should ensure autistic researchers feel ownership. This research achieved a level of ownership during the project and afterwards as conference papers were produced and delivered, and although early drafts of papers for publication were shared, the level of involvement of the autistic researchers reduced over time.

When the research project was originally conceived the aim was to establish a precedent for including autistic adults as co-researchers in a University of Nottingham funded project. We were pleased to be able to work with autistic adults as paid researchers thus establishing a precedent for the School of Education. At that point we did not consider also including the autistic adolescents as co-researchers in the same way. We wanted to give them a voice, rather than taking evidence from teachers or parents, but acknowledge that their involvement was not participatory. This was a pilot project and therefore what we have learnt from this experience will feed into the development of a larger scale project proposal.

Limitations to the approach taken

The focus on anxiety in adolescents in mainstream schools was already established in order to apply for funding, which meant that early discussions with potential co-production partners were already focussed on that as an area of interest. The academic researchers acknowledge that focus groups might not be an accessible method for all autistic researchers and they would therefore be interested in looking for more creative ways of involving autistic co-researchers in future projects, such as online chat groups. Participatory autism research is not a simple option; 'enabling participants to develop the skills they need to take an active part in research necessitates adaptations' (MacLeod, Lewis, and Robertson 2013, 12), which include understanding their sensory, social, emotional, and cognitive needs. Future participatory projects would ensure this level of adaptation is included prior to discussions about details of aims and methods. This would facilitate another of the recommendations of Chown et al. (2017) that there should be reciprocal accountability between autistic and non-autistic researchers in participatory research.

It would be interesting to carry out research with autistic researchers who could be fully involved in all stages of the process but the caveats listed in the methods section would still pertain and strategies would have to be put in place to ensure the researchers themselves had appropriate support in the same way that the needs of the adolescents interviewed were considered. We would also have to ensure we did not confound the results due to the double empathy issue, so the make-up of each team of interviewers would be very important.

Other limitations include the barriers to inclusion of autistic adolescents as co-researchers and the inability to pay them for their time and contribution to the project.

Conclusion

The research team that planned and undertook the participatory research discussed here would argue that in order to understand what the 'worst situation' might be for autistic people, and to offer support and solutions to help them to cope, the authentic voice of autistic people is crucial. The approach was *meaningful* in that the discussion of anxiety is relevant to autistic people; the way in which the project was developed was consistent with their values; and it tried very hard not to be tokenistic in delivery (Fletcher-Watson, 2019). This approach enabled the research team to produce some new insights into the experience of anxiety for autistic secondary school students (Costley et al. 2021), which was much richer due to the initial conversations between autistic and non-autistic researchers. Of course this only works if the social model of autism, or better still neurodiversity, is accepted as the only defensible position in autism research, particularly in an education context.

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Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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