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Participatory autism research: Early career and established researchers' views and experiences

Hannah Pickard[1], Elizabeth Pellicano[2], Jacquiline den Houting[2,3] and Laura Crane[4]

Abstract

Despite more autism research taking place than ever before, there is a disconnect between the current landscape of autism research and what autistic people and their allies want from research. While participatory research has been proposed as a potential solution, we know little about how researchers (particularly, early career researchers) employ this approach. We interviewed 25 researchers (14 early career and 11 established researchers) about their views and experiences of participatory autism research. Through reflexive thematic analysis of interview and focus group data, we identified three themes. First, our participants emphasised the flexible nature of participatory research, and the many forms it can take; yet noted that this flexibility could cause confusion. Second, our participants highlighted the importance of building relationships with research partners, while commenting on the challenges around effective communication and working with diverse groups of people who may have limited research experience. Finally, participants described the challenges of working within academic environments that are not conducive to participatory research (e.g. due to limited time, funding and support). We discuss these issues with regard to changes required at both an individual and systemic level, ensuring that efforts are made to meaningfully involve autistic people and their allies in all stages of the research process.

Lay abstract

'Participatory autism research' refers to ways of involving autistic people and their allies (e.g. family members) in making decisions about research. These decisions can include what research gets done, how it gets done and how research findings are used. While there is more and more interest in participatory autism research, we know little about how researchers at different stages of their careers use this approach. To find out more, we discussed these issues with 25 researchers. Fourteen of these were at an early stage of their careers, and 11 were more senior researchers. We spoke to people in individual interviews or in groups. We then used a technique called thematic analysis to analyse our data, which involved us looking for common topics or 'themes' discussed by our participants. What did we find? Our participants told us that participatory autism research was a flexible approach, meaning that autistic people can be involved in research in many different ways. While people viewed this flexibility in a positive way, it also caused some confusion about what does or does not 'count' as participatory research. Our participants also spoke about how important it was to build relationships with those involved in their research, but they also said it could be difficult to communicate well with diverse groups of people who may not have much experience of research. Finally, our participants said it was hard to do participatory research when there was not much time, funding or support available to researchers. In this article, we discuss these findings, focusing on what needs to change to ensure that autistic people and their allies are meaningfully involved in autism research.

Keywords

autism, co-production, early career, engagement, participatory research, researchers

[1]King's College London, UK
[2]Macquarie University, Australia
[3]Cooperative Research Centre for Living with Autism, Australia
[4]University College London, UK

Corresponding author:
Laura Crane, Centre for Research in Autism and Education (CRAE), UCL Institute of Education, University College London, London WC1H 0NU, UK.
Email: L.Crane@ucl.ac.uk

Over the past few decades, an increasing amount of autism research has been funded and published (Goldstein et al., 2015; Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee, 2019; Pellicano et al., (2014a, 2014b)). Despite the opportunities that this may bring to autistic people and their allies, there is a striking disconnect between the research being conducted and the research that the community wants to see conducted (den Houting & Pellicano, 2019; Pellicano et al., (2014a, 2014b)). Consequently, autistic people and their allies have – quite rightly – been critical of autism research: research tends to be guided by the interests of researchers and funders rather than autistic people and their allies (Cusack & Sterry, 2016), and there is often a lack of involvement from autistic people in the research process (Pellicano et al.,, 2014b). With increasing calls for autistic people to be 'at the centre of the autism conversation' (Ne'eman, 2011), participatory research has been proposed as one potential solution (Chown et al., 2017; Fletcher-Watson et al., 2018; Nicolaidis et al., 2011; Parsons et al., 2013; Pellicano & Stears, 2011; Raymaker & Nicolaidis, 2013).

Participatory research refers to 'incorporating the views of autistic people and their allies about what research gets done, how it is done and how it is implemented' (Fletcher-Watson et al., 2018, p. 1). A key principle of participatory research is an acknowledgement of the power imbalance between researchers and community partners (Gaventa & Cornwall, 2008; Nelson & Wright, 1995). As conceptualised in Arnstein's (1969) ladder of participation, power varies across different types of participation: from no power (e.g. therapy), through tokenism (e.g. consultation), to shared power (e.g. partnership). A move towards levelling the power balance in research has been evidenced by increasing interest in approaches such as citizen science, crowdsourcing, co-production, participant-led research and community-based participatory research (Wallerstein et al., 2017; Woolley et al., 2016). Irrespective of the specific terminology used, or specific methodological approaches taken, participation – beyond being a research participant – can take many forms, with the distribution of power in the decision-making process being key (see also Hickey, 2018; Tritter & McCallum, 2006).

Collaborative ways of working can improve the quality, relevance and impact of resulting research (Forsythe et al., 2019). Yet, as Redman et al., (2021) explain, there are several factors that can complicate attempts to adopt collaborative practices. First, they emphasise the individual, context-dependent nature of sharing power in research, as what works in one project may not work in another. Second, they discuss the need for the development of trusting relationships, based on honesty and effective communication, for fostering genuine co-produced research. Third, they highlight practical requirements such as equipping researchers with the necessary skills, but also ensuring that universities value and incentivise participatory practices. Finally, they call for greater investment to support the complex and long-term partnerships needed for effective and genuine collaborative research (i.e. co-production, as opposed to faux production). With growing interest in participatory research, Redman et al., explain that participatory practices will likely evolve even further over the next few years.

Despite participatory research having a long tradition in other fields (e.g. Beresford & Croft, 1993; Kiernan, 1999; Macaulay, 2017; Minkler & Wallerstein, 2011; Ottmann et al., 2011), such practices have been slow to reach the autism field. Pellicano and colleagues (2014a, 2014b) sought to understand researcher and community members' experiences of participation in research at three levels: dissemination (informing community members about research), dialogue (consulting with community members about research) and partnership (collaborating with community members as research partners). Their data revealed that while researchers often reported efforts to engage autistic people and their allies in research at different levels, this was not always perceived to be the case: participants felt that there were very few opportunities to engage in research beyond dissemination and dialogue Pellicano et al., (2014a, 2014b). Furthermore, all stakeholder groups commented on how active research partnerships, whereby decision-making power is shared between autistic and research communities, were rare (Fletcher-Watson et al., 2018; Pellicano et al., (2014a, 2014b)); when they do occur, the details of such partnerships are rarely reported in published articles (Jivraj et al., 2014).

To support autism researchers in making their work more participatory, best practice guidelines have been proposed (Fletcher-Watson et al., 2018; Nicolaidis et al., 2019; Pellicano et al., 2017) and several innovative participatory research projects (Crane et al., 2019; Nicolaidis et al., 2013; Parsons et al., 2013; Pellicano et al., 2020; Vincent, 2019) and partnerships (e.g. https://aaspire.org/, https://participatoryautismresearch.wordpress.com/) have been shared. Yet, participatory practices are not commonplace in autism research and criticisms levelled at this approach may stem, at least in part, from a lack of familiarity with implementing these practices. For example, researchers have reported that they are often apprehensive about involving autistic people in research, expressing concerns that it could either dilute the scientific rigour of the research (see Pellicano et al., 2014b) or that it will only involve 'vocal minorities' that do not speak for the community as a whole (see den Houting et al., 2021; Fletcher-Watson, 2017). These concerns have also been highlighted outside the autism research field, along with broader challenges for researchers around managing relationships and time investments (Oliver et al., 2019; Redman et al., 2021, but also see Williams et al., 2020, for reflections).

Despite the various opportunities and challenges inherent in participatory research, to our knowledge, only two other research studies (aside from Pellicano et al., 2014a,

discussed above) have specifically examined autism researchers' views regarding community participation in research. den Houting et al., (2021) examined participatory research in the context of Australian research projects funded by the Autism CRC (https://www.autismcrc.com.au/). Using an online survey, they gathered quantitative and qualitative data from 64 academic researchers and 15 community members, all with research experience. Encouragingly, their sample of academic researchers was overwhelmingly supportive of participatory research and had positive experiences of employing participatory research practices. Yet, the authors reported that the academic researchers lacked a genuine understanding of participatory research and held views that could obstruct the implementation of successful participatory research (e.g. with academic partners retaining power throughout the research process). Furthermore, community partners discussed the limited opportunities for involvement in the research process, which were largely confined to consulting on research projects (as opposed to, for example, collaborative partnerships). den Houting et al., (2021) suggested that both academic and community partners would benefit from further training to develop a better understanding of participatory research, and to aid in the implementation of participatory practices in autism research.

In a related study, Hollin and Pearce (2019) interviewed 20 academics (seven postdoctoral researchers and 13 researchers with permanent academic positions, e.g. lecturers/professors) about their understanding and experiences of stakeholder and public engagement in autism research. From these data, the researchers identified three themes. First, participants felt that disagreements existed between stakeholders in the autism field due to the heterogeneity of autism. This was thought to result in difficulties generalising between different autistic voices, or from one autistic voice to the broader community. Second, participants felt that conflicts arose between the research and autistic communities due to the socio-communicative difficulties of autistic people, which they felt limited their ability to form relationships with researchers. Third, despite these challenges, participants recognised valuable traits in autistic people that they felt could benefit research (e.g. to enhance discussion of the social and ethical consequences of their findings). Taken together, the authors called for greater efforts to promote dialogue and engagement between researchers and autistic people, calling for autism-specific modes of engagement with research (e.g. online spaces to promote discussions).

Both studies provide clues as to why the autism research field has been slow to adopt participatory practices. Specifically, researchers' comments highlight the pathologising, deficit-based approach that has permeated autism research for decades (see Fletcher-Watson & Happe, 2019, for an overview). Even if implicitly, these attitudes may result in difficulties perceiving autistic people as equal partners who deserve shared power in the research process. This is further complicated by an apparent tension in researchers' responses. For example, researchers emphasised the need to diversify the pool of autistic people who contribute to research studies, but also appeared to expect all autistic stakeholders to provide consistent input and/or reach consensus.

While these studies provide a helpful starting point, they either focused on public engagement in a broad sense (i.e. not participatory research specifically), only elicited the views of certain subgroups of the research community (e.g. established, but not early career, researchers), or used methods that did not allow for more in-depth discussion to be generated (e.g. an online survey rather than interviews). The aim of the current research was to build on these existing studies by gathering views and experiences of participatory research from both early career and established autism researchers, via in-depth interviews and focus groups. Including both these groups enabled us to gain an understanding of the challenges and opportunities participatory research poses across different career stages, to examine areas of convergence and divergence. It also allowed us to examine potential differences in how the groups viewed and used participatory research, which was important given that established researchers (ESRs) and early career researchers (ECRs) may hold different levels of power in the research process (e.g. with ESRs potentially holding more power than those earlier in their careers) (Muhammad et al., 2015). Finally, it enabled us to identify strategies for supporting participatory research, tailored to specific career stages and needs. Our specific aims were to determine (1) researchers' views of participatory research and its perceived benefits and challenges; (2) researchers' experiences of participatory research, reflecting on any barriers and facilitators and (3) researchers' support or training needs, particularly for those at an early stage of their careers.

Methods

Participants

Two groups of participants were recruited: ECRs and ESRs. A different recruitment strategy, and data collection methodology, was used for each participant group. These strategies were chosen based on our research teams' experience as members of these groups. With regard to ESRs, we felt that they would be less likely to volunteer for the research without personal invitations, that it would be challenging to coordinate the diaries of busy academics for focus groups, and that participants might speak more openly in individual interviews. Conversely, we felt that ECRs might struggle to discuss participatory research in individual interviews (since many potential participants

were likely to have relatively limited practical experience of participatory research). We also felt that ECRs would be forthcoming to more open calls for research participation (as opposed to the need for individual invitations).

ECRs were eligible to take part if they: (1) worked within the autism research field and (2) were less than 1 year into their first permanent academic position (full-time equivalent). They were recruited via social media and word-of-mouth. Fourteen ECRs (10 women and 4 men) took part (mean (M) age = 31.21 years, standard deviation (SD) = 7.59, range = 22–51 years). Eight were full-time PhD students, three were postdoctoral researchers, two were research assistants/administrators and one was a visiting lecturer.

ESRs (i.e. at least 1 year into a permanent academic position) were recruited via email, with invitations sent out to researchers in the United Kingdom at recognised university institutions (see: https://www.gov.uk/) who worked in the autism research field (identified by searching for academics who listed autism as a research interest). A total of 76 personal invitations were sent, along with nine invitations to broader autism research groups. We specifically requested participation from those with participatory research experience. In total, 21 (29%) ESRs expressed an interest in taking part (55 did not respond) and 11 (14%) completed an interview (3 male, 8 female; M age = 43.1 years, SD = 8.46, range = 30–56 years). Of the ESRs, four were lecturers (equivalent to assistant professor), four were senior lecturers/readers (equivalent to associate professor) and three were professors. ECRs were largely based in/around London, whereas ESRs were dispersed across the United Kingdom. Almost all participants reported being of White ethnic background (ECRs 93% and ESRs 100%). Two participants identified as autistic (one ECR and one ESR).

Procedure

Ethical approval was obtained via the Research Ethics Committee at UCL Institute of Education (REC991). ECRs took part in one of two in-person focus groups ($n = 11$) or a one-to-one interview ($n = 3$; one via video call, one via phone and one in person). ESRs participated in a one-to-one semi-structured interview over video call. Focus groups were chosen as the most appropriate method of data collection for ECRs to help facilitate discussion among a group with potentially limited experience of participatory research. Individual interviews were used when ECRs were keen to participate but unable to attend the focus groups. Individual interviews were used for all ESRs, as they were less able to come together for focus groups and were anticipated to have in-depth participatory research experiences to share. An ECR (H.P.) conducted all focus groups and interviews, which ensured consistency and that the ECRs felt comfortable disclosing their views and experiences. Prior to the focus groups and interviews, all researchers completed a consent form and demographic questionnaire that elicited information about gender identity, age, ethnicity and academic roles. During the focus groups, the facilitator ensured that the group discussion remained on topic and provided intermittent summaries to the group, particularly to check the interpretation of key discussion points. Focus groups ranged from 62 to 74 min (M = 68 min), while one-to-one interviews ranged from 36 to 75 min (M = 53 min).

Materials

Focus group and interview schedules were created by three members of the research team H.P., E.P. and L.C. based on their own experiences as ECRs/ESRs (see Appendix 1). ECR focus group schedules covered: (1) definitions and views of participatory research; (2) the benefits and challenges of taking part in participatory research; (3) experiences of participatory research and any barriers faced and (4) training and support needs. The interview schedules for ECRs followed a similar overall format. For ESRs, interviews covered the following topics: (1) definitions and views of participatory research; (2) a brief overview of their experiences of participatory research; (3) in-depth examples of participatory research and (4) advice for ECRs. Both the focus group and individual interview schedules followed a similar format. Specifically, a series of primary (open-ended) questions were always asked, followed by secondary (open-ended) questions that were used to probe on specific points where elaboration and/or clarification was needed.

Community involvement

While one of the research team members identifies as an autistic ECR, autistic community members from outside of academia were not involved in producing this work.

Data analysis

Focus groups and interviews were analysed using reflective thematic analysis as described by Braun and Clarke (2006, 2013, 2019). Analysis was led by one ECR (H.P.) and one ESR (L.C.), neither of whom identify as autistic, but both engage in and advocate for participatory autism research practices. Analyses involved identifying semantic meanings in the data set following an inductive approach, whereby themes were generated in response to interview data, rather than trying to accommodate data within predefined themes or research questions (Braun & Clarke, 2013). H.P. and L.C. recursively proceeded through Braun and Clarke's six stages of (1) familiarisation, (2) coding, (3) generating themes, (4) reviewing themes, (5) defining and naming themes and (6) writing up. Focus groups and

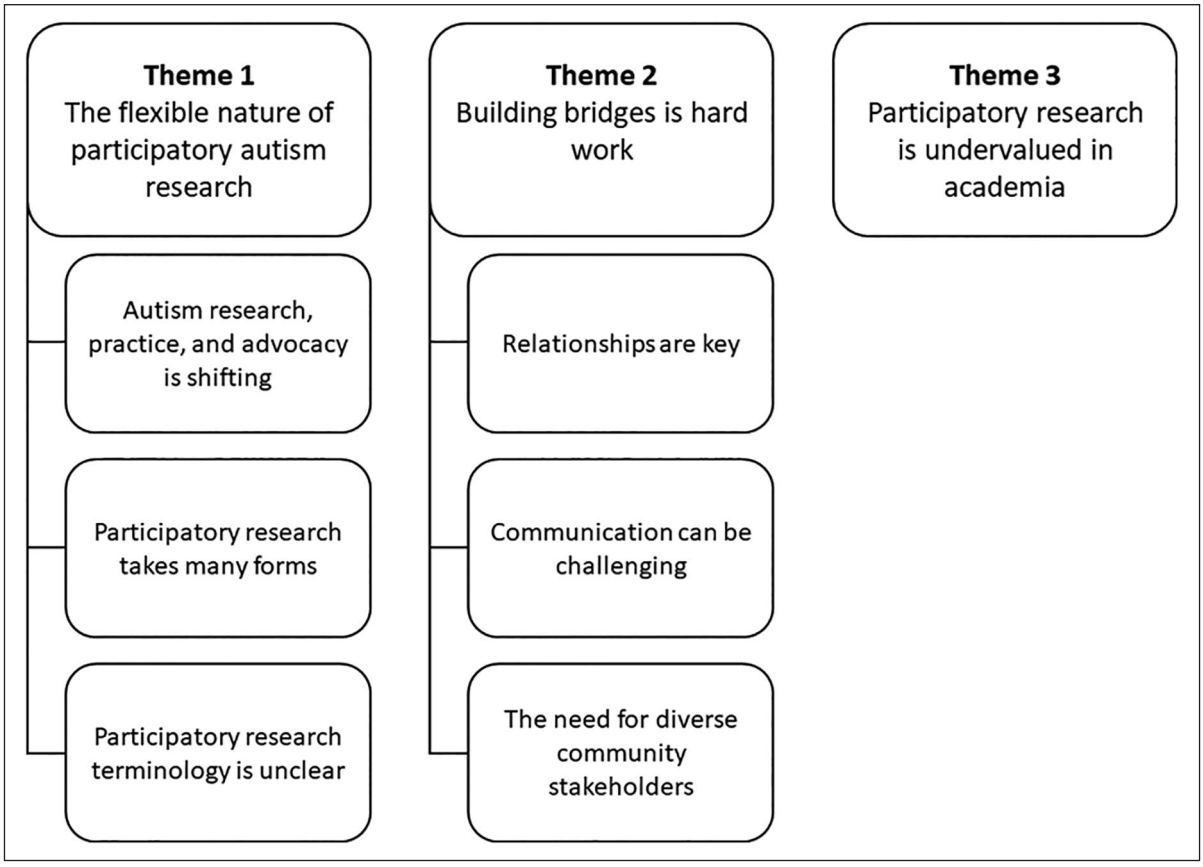

Figure 1. Participatory research views and experiences from ECRs and ESRs: themes and sub-themes.

interviews for ECRs were analysed together, as the same schedule was used across both formats. Data from ECRs and ESRs were coded separately. During the process of data familiarisation and coding (i.e. stages 1 and 2), similarities were noted, so data from ECRs and ESRs were merged prior to theme development (i.e. prior to stage 3). While developing themes, we considered whether the findings applied to ECRs, ESRs or both. Themes were reviewed (separated or merged where required) following several detailed discussions with the other members of the research team: J.d.H. (an autistic ECR) and E.P. (an ESR who does not identify as autistic), both of whom engage in and advocate for participatory research practices. Following these discussions, the final themes and sub-themes were confirmed.

Results

Three themes were identified from the interview and focus group data: (1) the flexible nature of participatory autism research, (2) building bridges is hard work and (3) participatory research is undervalued in academia (see Figure 1). Quotes from individual ECRs and ESRs are indicated using numbers (1–9) and letters (A–K), respectively.

Theme 1: the flexible nature of participatory autism research

Sub-theme 1: autism research, practice and advocacy are shifting. Researchers emphasised the effectiveness of autistic community members campaigning for their voices to be heard in research: 'I think [autistic] people feel a lot more empowered because they're able to get together in communities and, therefore, they're able to have the confidence, maybe, to pose questions to the research community' (ESR-C). Online platforms were seen as a particularly powerful way for the autistic community to vocalise their views in this regard: 'through online channels, they are something of a coherent group, there's lots of communication going on about various issues that affect them' (ECR-8). Researchers reported that participatory research practices were 'massive at the moment' (ESR-E); noting that this was potentially 'part of a broader autistic rights movement, which is in itself part of a bigger socio-political agenda about expanding our definitions of civil rights to include the disability movement' (ESR-F).

Interest in participatory autism research was felt to have emerged recently and gradually: 'I think autism research has been very slow, mostly because it's been driven so strongly by a medical model of disability rather than a

social model, and, unsurprisingly, that has inhibited wider participation at a much earlier stage' (ESR-B). Yet, researchers also commented on the slow uptake of participatory practices in autism research, relative to other research fields:

> autism researchers think they have so many brilliant new ideas but participatory research has been around for decades, and I would say autism research has been exceptionally slow, as it often is, in getting smart to stuff that's going on with this. (ESR-B)

Researchers added that 'we're very far away from any sort of model of participatory research that is acceptable in autism research' (ECR-8).

Sub-theme 2: participatory research takes many forms. Researchers discussed the need for research to include some form of autistic involvement but had diverse views regarding levels of involvement that were 'appropriate'. While some suggested that community members should be 'fully involved, start to finish' (ECR-5), others felt that the level of involvement could 'vary quite a lot from just having people involved as part of an expert group that might be advising on the research, right through to autistic people defining research questions' (ESR-J). Researchers emphasised the need to tailor involvement to the specific research project: 'I don't think it's always appropriate that an autistic person can decide the full research design of a project design – I think that [participation] needs to be individualised' (ESR-J). Furthermore, researchers mentioned that community members having full control of a research project was often not a viable option:

> I know there's a lot of debates and discussions about participant-led research, where the participants actually take control of the research . . . which is interesting, but I'm not sure you can ever fully achieve that if you have an agenda, and all research has an agenda. (ESR-D)

Flexibility was emphasised, noting that the level of involvement should be driven by discussions with community members, rather than striving to meet arbitrary standards of what participatory autism research 'should' be:

> I had at the beginning quite a dogmatic view of what participatory research was and that it should be people who engaged in all parts of the process etc. I think probably now I'm a bit less dogmatic and I think it's about being involved in as much or as little as they want to be. (ESR-A)

Discussions regarding involvement were seen as essential on a study-by-study basis: 'You can't assume that every project is going to be the same or that you can apply the same things, you have to work that out with the people that you're working with' (ESR-A). 'Levels of participatory research' (ECR-5) were emphasised, as was the need to consult with community members regarding their preferred level of participation in research: 'We can't expect or assume that people all want to be involved or lead research . . . people want to be involved on their own terms' (ESR-B).

Sub-theme 3: participatory research terminology is unclear. While researchers acknowledged that participation is 'a very broad concept . . .' (ESR-D), they discussed the lack of clarity in commonly used definitions of participatory autism research: 'it's one of those things that people define in different ways, and the level of participation can vary' (ESR-J). Participants perceived the language commonly used to describe participatory autism research to be vague or ill-defined: 'words like "meaningful" and "engagement" are not black or white terms' (ESR-G). The vague use of common terminology used to describe participatory research contributed towards a lack of confidence surrounding research practices, both from ECRs and ESRs. As a potential solution, ECRs reported that having 'a standardised definition or guidelines for participatory research' would be 'really helpful', since 'I don't think I would know how to go about having a fully participatory study at this point' (ECR-1); 'a big challenge for me was to think how can I start to do participatory research' (ECR-6).

Theme 2: building bridges is hard work

Sub-theme 1: relationships are key. Researchers discussed how 'you have to build bridges with other people' (ECR-7) to make connections, build trust and incorporate a range of views into research. Yet, researchers highlighted the 'costs' of relationship building in terms of time:

> if you want to do it properly, you have to invest time and effort in working with these communities, and helping them, and doing things with them that simply isn't of benefit to you in research terms, but actually builds a relationship and a rapport, and getting to know them better. (ESR-D)

Despite the costs, relationship building was viewed as a key component of participatory research:

> that took a lot of work in terms of how we communicated to how we enabled their participation, the things that they wanted to bring to that, but at the heart of that was an extremely powerful interpersonal connection or relationship with people for whom participation had never been very meaningful. (ESR-B)

Sub-theme 2: communication can be challenging. Researchers mentioned 'the challenges surrounding the different ways in which autistic and neurotypical people communicate' (ECR-8) and how communication with autistic people requires experience:

> communicating with autistic people is not the same as communicating with people who are neurotypical; it's a huge spectrum condition, so you can't have experience with, say, three children who've got autism, and say that you know autism, because you don't! I think experience counts for everything. (ESR-D)

Differences in communication styles were often reported to lead to misinterpretations: 'sometimes in discussions there can be a degree of heat to them, or what we can perceive as heat when you're reading on a computer screen that isn't actually there' (ECR-8); 'you often do find that after about an hour of talking, you realise you are both meaning the same thing! That is one of the challenges and why things take so long' (ESR-K).

Researchers discussed the challenges around communicating with audiences unfamiliar with research:

> if you are involving people that have no experience of research, then there is a massive language barrier to get over. . . it can be very challenging to word things and present things in a way that is accessible to people that have never come into contact with academia. (ECR-7)

Researchers commented on the difficulty of getting the balance right when deciding the amount of information to communicate when working with people who may not (yet) be research literate:

> I don't want to give someone only a partial picture of what the project is going to be about or what the findings were or what the methods are or what the psychological theory is but then equally, if they're not an expert, I can't – it's not fair to just bombard them with a bunch of technical stuff, pages and pages of writing. (ESR-F)

Researchers highlighted the need to meet the communication needs of everyone involved:

> if you're genuine about inclusion and participation that takes a lot of time and that's about making sure that we're communicating in a range of ways, communicating in the right ways, taking time to step back and explain and to work with people in different ways in order to have meaningful engagement and input (ESR-B).

Broader benefits were also emphasised: 'learning how to communicate with autistic people better had sculpted how I communicate with everybody, like with everybody all the time' (ECR-8).

Sub-theme 3: the need for diverse community stakeholders. Researchers commented on the need to look beyond the 'core group' of autistic people who often contribute to research, to find those who may have differing perspectives:

> The easy thing to do would be to just involve people that we know . . . autistic people who we know have got quite a bit of experience of participatory research. I think we need to look to involve people who may find it difficult to participate, but want to contribute, and want to be part of it. (ESR-J)

Yet, researchers commented on the challenge of eliciting too diverse a set of views from community stakeholders, expressing concerns about how this could impact on decision-making processes in research: 'people do have different views and how do you then, as a team, decide on how to move forward with those different views because sometimes those views are absolutely diametrically opposed to each other' (ESR-B). Researchers also highlighted the barriers around connecting and representing the views of people within the autistic community who may not be as vocal and easy to reach:

> Again, this is the problem with finding diversity, right? You're only seeing people who are willing to collaborate and do stuff, which many people on the spectrum don't want to do. So, how do you find those people? Because you can't just send an email! You can't just send a request, or an invite. That's why you need to be in the field meeting people. (ECR-9)

ECRs suggested that large organisations could help support this process:

> collaboration with organisations that have contact with lots of different types of people that are on the spectrum would help, because then you would know that you are getting a much broader range of people that are taking part in it. (ECR-7)

Theme 3: participatory research is undervalued in academia

Researchers noted the positive impact that participatory practices can have within research: 'reducing that gap between what is being printed and what is actually helping people, which is a very big gap at the moment' (ECR-9). They commented on the value of involvement at both a personal level: 'The benefits to me personally, are constantly learning and improving my understanding' (ESR-I); and a professional level: 'By giving some control over to [autistic people], you learn things that, if you had completely directed the research yourself, you would never have got' (ESR-D). Researchers mentioned that participatory practices had direct benefits on their research, providing insights that would not otherwise have been realised. For example, they mentioned that their research is held to a high standard, that it provided opportunities for two-way learning, and that it was better informed by the lived experience of the autistic community:

> So of course our research is better informed by including a wider range of views and we would hope therefore that

> whatever we're doing is more aligned with and better suited for meeting the needs of the people who are at the centre of our research. (ESR-B)

Nonetheless, researchers noted several challenges that make it difficult to co-produce research within academia. The restrictions and demands of academia were discussed as key barriers:

> the academic context expects certain things from you, you know, papers, grants, PhD supervision, teaching, you know, they're so essential to what you're doing that trying to make participatory research top of your personal to do list is very, very hard. (ESR-F)

In addition, two challenges were noted by our ECRs specifically. First, the absence of support from senior academics was reported as a key challenge for ECRs: 'it can be really hard to do [participatory research] if the more senior people in your research group don't value that, if they don't see it as a priority' (ECR-3). Second, ECRs felt that their lack of seniority within the research environment often constrained their ability to employ participatory research practices, particularly when their views did not align with those of their broader research team: 'I can come in with all these good ideas, but if they've already got the project well underway and it's their idea, there's not much I can do' (ECR-8) and 'I don't feel I have much control over whether the research is participatory' (ECR-2).

Time constraints inherent in pressurised academic contexts were seen as a significant challenge to conducting participatory autism research: '[participatory research] is hard work and it takes a lot of time, and from the research perspective that's time that isn't necessarily valued in terms of the things that progress your career' (ECR-8). Some ECRs felt that time constraints limited their ability to involve autistic people and their allies during the early stages of their research career:

> while you're doing a PhD there is a lot of pressure to do as much as possible, produce as many results as possible, publish as soon and often as possible and it doesn't necessarily give you the time to say, 'I want to do a focus group[1] or, I want to spend a bit of time reflecting on people's responses to the study, before I write it up' (ECR-3).

ESRs expressed similar views: 'a challenge for us as researchers in doing participatory research is that everything takes longer, so if you're genuine about inclusion and participation that takes a lot of time' (ESR-B). Both groups also commented on the lack of funding resources available within academic structures to involve autistic people and their allies in research:

> how does someone like me get to be able to pay people for their time properly, like get . . . little research assistant contracts for somebody who might help out with stuff, and not just be doing it on their own goodwill (ECR-8).

As an ECR, a lack of control was thought to contribute towards funding constraints: 'I think particularly with PhD projects or if you're a post-doc, projects where you're coming in and the funding has already been assigned . . . There is no money built in to pay for people to come to a focus group' (ECR-3). Some researchers also feared it was somewhat of a luxury, only accessible to those in certain research groups or institutions: 'I think it's quite a privileged thing to be able to do participatory research' (ESR-C).

Discussion

It is perhaps unsurprising that researchers who engage with, or have an interest in, participatory research are enthusiastic about such practices. Yet, conducting interviews and focus groups with researchers at different stages of their careers presented a nuanced picture. Even though researchers wanted to make their research participatory and felt that these methods afforded benefits to their work, researchers at all stages of their careers reported experiencing considerable challenges in incorporating meaningful participatory research practices within their work. Specifically, we identified three themes relating to participatory autism research practices across both ECRs' and ESRs' data. First, researchers emphasised the shift towards a participatory research framework, which they perceived to be largely driven by autistic advocacy and broader societal changes. However, they felt there was an inherent lack of clarity around the terminology used to define participatory research, which led to confusion among ECRs in particular. Second, researchers identified tensions around key features of participatory autism research. In one example, they emphasised the importance of building bridges with autistic people and their allies, but also commented on the challenges around communication that could hinder such relationships. In another example, researchers called for greater diversity of community partners in research, yet also highlighted the difficulties around incorporating diverse views. Finally, researchers spoke about the challenges of working within an academic environment that was not conducive to participatory research, emphasising issues associated with time, funding and support. In what follows, we discuss these findings with regard to existing literature, while also highlighting crucial areas where change is needed.

The researchers in this study expressed a range of views around how autistic people could or should be involved in research. Despite stressing the need for flexibility when conducting participatory research, ECRs also expressed a need for clear guidance on what constituted 'genuine' participatory research. In line with den Houting et al., (2021), we suggest more in-depth, ongoing training

on the underlying philosophy of participatory autism research, with the recognition that 'participatory experience is not simply a method or set of methodologies, it is a mind-set and an attitude about people' (Sanders, 2002, p. 1). Teams with considerable experience in participatory research have made available resources that address both the philosophical underpinnings and real-world practicalities of participatory autism research (e.g. Nicolaidis et al., 2019). There is, however, a paucity of such resources, at least in the field of autism research, and more examples of high-quality participatory research are needed to guide those new to participatory research. One means of addressing this issue may be to encourage more explicit reporting of participatory practices in published work (see Jivraj et al., 2014; Nicolaidis et al., 2019; Price et al., 2018), as opposed to only reporting the outcomes of the research. Importantly, these examples should not be treated as templates for how participatory research projects *must* be conducted, since what works well in one project may not work well in another (Pellicano & Stears, 2011; Redman et al., 2021). However, these examples should serve as useful exemplars of how things *could* be done, providing those new to participatory autism research greater insight into the considerations and practicalities of this kind of research.

In any training on or reporting of participatory research, it is essential to highlight the power dynamics involved. It was notable that discussions of power were lacking among our sample of researchers, yet power is 'one of the founding principles of participatory research' (Rose, 2018, p. 765; see also Arnstein, 1969). This finding mirrors recent work by den Houting et al., (2021), who surveyed academics and community members about participatory autism research in Australia. Community members reported a stark lack of power sharing throughout the research process and felt that researchers tended to remain in positions of control. Taken together, these findings suggest that – although there is an overall willingness to involve autistic people in research – considerable efforts need to be made to ensure that power sharing is genuine and not tokenistic (Pellicano et al., 2014a), with training for researchers needed to manage expectations around this (den Houting et al., 2021).

One way that expectations around power can be managed is through open discussions between researchers and community members. Yet, our participants highlighted challenges around communication, noting that differences in communication styles can often lead to misinterpretations, which can be time-consuming. This finding aligns with the work of Hollin and Pearce (2019), whose interviews with academic researchers also identified communication difficulties as a major barrier to community engagement in research. Our findings, however, diverge from those of Hollin and Pearce's, as our participants tended to describe communication difficulties as arising from differences between autistic and non-autistic people's communication styles, whereas Hollin and Pearce's participants placed the onus squarely on community members. Milton (2012) has reframed long-standing notions of an autistic deficit in social interaction within the Double Empathy Problem. This theory emphasises the reciprocal nature of communication highlighting that, although autistic people may lack insight into the social world of non-autistic people, the reverse is also true. Based on our findings, the Double Empathy Problem may certainly be evident in relation to participatory autism research. We therefore suggest that researchers need to make efforts to develop their interactional expertise and increase trust and communication within research–community member interactions, rather than expecting autistic people to change to fit in with academic norms.

In this regard, our results can be contextualised within the broader literature on ableism in academia (Bottema-Beutel et al., 2021). Disabled scholars have long noted that there is a push towards normalising and homogenising the way in which academic research is conducted (see Brown & Leigh, 2020, for discussion). This ableist bias may be particularly pronounced within the field of autism research, with deficit-focused accounts having driven autism research and practice for decades (e.g. Fletcher-Watson & Happe, 2019).

While the Double Empathy Problem and ableism in academia are two potential explanations for our findings regarding communication breakdowns within research teams, communication breakdowns did not always seem linked to differences in neurology. Rather, they appeared to be associated with more fundamental challenges with involving lay people in the research process, particularly around their often-limited research literacy; challenges also noted outside the autism field (e.g. Holland-Hart et al., 2019). In any academic-community partnership, whether participants are autistic or not, it is essential to have 'clear communication and . . . robust relationships' (Common Cause Research, 2018). This may be a useful focus of training for researchers and community members prior to entering research partnerships.

Our participants expressed much uncertainty regarding the amount of information they should share with autistic community members; that is, striking the right balance between giving the community enough information to be able to contribute meaningfully, but not overburdening them. Given that effective partnership is a two-way endeavour, a greater focus on relationship building and communication between researchers and community members may help reduce uncertainties around information sharing. Furthermore, educational opportunities may help to alleviate these uncertainties. In particular, training programmes could aim to extend beyond individual projects and build broader capacity to support participatory research, ensuring that researchers and community members are equipped with the skills needed to engage *with* and participate *in* participatory research (e.g. Autism CRC; https://www.autismcrc.com.au/sylvia-rodger-academy/research-program).

Beyond communication barriers, our researchers raised concerns regarding a perceived lack of diversity among the autistic people who contributed to research, noting that a 'core group' of people were consistently involved. den Houting et al., (2021), who observed the same phenomenon when surveying researchers in Australia, stressed the need for researchers to move away from equating participatory involvement in research with mere research participation. Echoing this call, we advocate for a move towards careful consideration of what each person brings to the research team (i.e. why they have been selected in the first place), and ensuring that people are involved in projects because of their experiential expertise relevant to each individual research study (Little et al., 2002). Indeed, this process should not be alien to researchers given that academic partners are usually selected to be involved in projects based on their skills and expertise, rather than how representative they are (Bozeman & Gaughan, 2011).

Arguably, the shift towards participatory research that our participants identified is no longer optional, with community engagement increasingly being mandated by funders and other organisations (e.g. National Institute Health Research Involve; www.invo.org.uk). However, our data suggest that academic researchers are not fully prepared for this shift. For example, our participants explained how the time investment needed for participatory research seemed incompatible with the demands of academic life; a particular concern for ECRs (see also Southby, 2017). While the efforts of researchers are increasing, with academics across many fields recognising and sharing the benefits of community engagement in research (e.g. Israel et al., 1998), this shift needs to be accompanied by systemic change to ensure that participatory practices can be accommodated within the current research frameworks. This systemic change needs to include recognition of the costs, time and other commitments inherent to participatory research, to ensure that these practices are supported within academic structures.

Reflecting on the views of ECRs and ESRs, across focus groups and interviews, there was considerable overlap. Despite clear differences in their experiences of using participatory research practices, our findings suggested that, to some extent, ESRs and ECRs noted similar challenges. Support for participatory research (e.g. training in communication and relationship building) should therefore be implemented for researchers at all career stages. Greater support for ECRs, however, is particularly essential. Our sample of ECRs discussed several intrinsic barriers (e.g. limited knowledge of how to implement participatory practices) and extrinsic barriers (e.g. a lack of support from senior academics and not being involved in high-level decision-making) hindering their participatory research efforts. We therefore call for better education and support for ECRs by embedding participatory practices within the culture of research and giving ECRs the necessary support to make their work participatory (e.g. supporting ECRs to build wider community connections). While this requires top-down directives, ECRs also need to start taking positive action, akin to the drive for reproducible research practices led by early career researchers in the United Kingdom. In this regard, Orben (2019) notes,

> We need all those who care about better research to stay invested, and this will not happen by telling the next generation of scientists to just sit back and hope. Early-career researchers do not need to wait passively for coveted improvements. We can create communities and push for bottom-up change. (p. 465)

We advocate for the same approach to participatory autism research.

While this study was one of the first to explore the views and experiences of ECRs and ESRs with respect to participatory autism research, it is not without its limitations. First, this study was advertised to those who had been involved with (or, for ECRs, who had an interest in) participatory autism research. Future research should elicit the views of researchers who do not engage in participatory research to understand the reasons underlying this (i.e. do they *want to* make their work more participatory or are they *unable to* do so?). Second, while all researchers had experience of and/or interest in participatory research, we did not collect data on their level of community engagement (i.e. whether they were novices or experts, or how successful their engagement had been). Also, we did not define participatory research for our participants. Instead, we encouraged participants to share the experiences that they felt were participatory. Therefore, it was unclear whether some experiences shared were genuinely participatory in nature. Third, our sample included researchers only. As researcher and community perceptions of participatory research may diverge Pellicano et al., (2014a, 2014b), in future it will be important to triangulate these data with community perceptions (den Houting et al., 2021). Fourth, most of our participants were non-autistic autism researchers. Further research may benefit from specifically examining autistic autism researchers' experiences of participatory research, given their unique position as both academics and members of the autistic community. Fifth, our sampling strategy and data collection procedures differed for ECRs and ESRs. We adopted different approaches for pragmatic and ethical reasons, based on our personal experiences of what would be most acceptable to these groups; but these differing modes of data collection may have impacted the information shared by researcher groups (e.g. some ECRs may not have been comfortable disclosing sensitive information in a group setting). All focus groups and individual interviews were led by an ECR to promote consistency in data collection. It is possible, however, that being interviewed by a more junior researcher may have made it difficult for ESRs to disclose their views and experiences, particularly negative ones.

Finally, this study is limited to researchers working in the United Kingdom. While these findings do align with data from Australia (e.g. den Houting et al., 2021), it is important for similar investigations to be undertaken across a broader range of countries to examine any specific structural or cultural barriers affecting participatory practices (Nicolaidis & Raymaker, 2015).

To conclude, interviewing ECRs and ESRs provided an understanding of the challenges *and* the opportunities that participatory autism research can afford. We call for greater appreciation of the flexible nature of participatory research, since 'participation should be viewed as an expansive concept . . . any meaningful attempt to progress along a continuum of participation should be recognized and encouraged' (Southby, 2017, p. 128). Participatory research hinges on meaningful and trusting relationships with members of the autism community; relationships that may take time to develop but are essential for respectful autism research that aligns with community priorities. Change cannot just be at the level of individual researchers. Rather, we need broader cultural and structural shifts to enable participatory practices to become commonplace. Together, these efforts should foster a research culture that produces high-quality, well-funded collaborative research that genuinely makes a difference to the lives of autistic people and their allies.

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ORCID iDs

Elizabeth Pellicano https://orcid.org/0000-0002-7246-8003
Jacquiline den Houting https://orcid.org/0000-0002-9409-2035
Laura Crane https://orcid.org/0000-0002-4161-3490

Note

1. In this example, focus groups were being discussed as a way of consulting with the autistic community to discuss research project findings and their relevance to autistic people's lives.

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Appendix 1

Interview schedules

Early career researcher (focus group) interview schedule

1. First, I would like to start by asking you all, what do you think the term 'participatory research' means?
2. It seems that we are hearing more and more about participatory research with regard to autism – would you all agree? Why do you think that is?
3. What do you think are the benefits of doing participatory autism research?
4. What do you think are the challenges of doing participatory autism research?
5. Can you tell me a bit about your overall experiences, if any, of taking part in participatory autism research? We would like to hear about any good experiences, as well as any not so good experiences.
6. Can anyone tell us about the barriers that prevent you from doing participatory autism research?
7. Do you feel confident taking part in participatory research?
8. Are there any areas of participatory research where you do not feel as confident?
9. What do you think could be done to help build your confidence?
10. For those of you who have taken part in participatory autism research, how did you go about involving the autism community in your research?
11. For those of you who have not taken part in participatory autism research, how would you go about involving the autism community in your research?
12. What training would you like to receive to help support you with your participatory autism research?
13. What support would you like to receive to help with your participatory autism research?

Established researcher (individual) interview schedule

1. Tell me a bit about yourself.
2. What does the term, 'participatory research', mean to you? It seems that we are hearing more and more about participatory research with regard to autism – would you agree? Why do you think that is?
3. When did you first become involved in participatory autism research? Why did you decide to get involved in participatory autism research?
4. What do you think are the overall benefits of taking part in participatory autism research? What do you think are the overall challenges of taking part in participatory autism research?
5. Can you tell me a bit about your overall experience of taking part in participatory autism research?
6. Tell me about a time when you were involved in a participatory autism research project and it went well?
7. Please can you tell me about a time when you had an experience of taking part in a participatory research project that did not go quite so well?
8. Do you have any advice for researchers, especially those at the early stages of their career, who might want to involve the autism community in their research in a more meaningful way?