

FULL-LENGTH ARTICLES

Participatory Research With Autistic Students in Higher Education: Experiences and Recommendations From Developing a Training Programme

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Keywords: autism, higher education, participatory research, community research

<https://doi.org/10.35844/001c.137307>

Journal of Participatory Research Methods

Vol. 6, Issue 3, 2025

Participatory approaches, which seek to involve affected community members in the research process, remain uncommon within autism research despite numerous potential advantages. The current work describes the process of co-designing autism training for university staff with an advisory group of autistic students and other stakeholders. The advisory group were involved in the project from the outset, including contributing to the funding application, training design, evaluation, and research dissemination. Here, we demonstrate the feasibility of participatory research in a higher education context, detail the approach taken, and provide recommendations for researchers seeking to undertake this kind of work. It is hoped that this example will encourage the uptake of similar practices in future projects.

Introduction

Autism is a neurotype associated with differences in social communication and interaction, sensory processing, and executive function skills (American Psychiatric Association, 2013). Autistic people have historically been dismissed in the production of autism research, with projects failing to align with their needs and priorities or those of the people close to them (Crane et al., 2019; Keating, 2021; Pellicano et al., 2022). This can be seen, for example, in the differing priorities of autism research funders who have, to date, largely focused on biological “cause” research, compared to many within the autism community who wish to prioritise mental health and daily living support (Pellicano et al., 2014). Research in this area often takes a medicalised or deficit-based view of autism and autistic people (Heraty et al., 2023; Milton, 2014; Vincent et al., 2017). Participatory work, which actively involves community members as equal partners, challenges this norm, allowing autistic people to advocate both for themselves and others (Pellicano et al., 2022; Vincent et al., 2017).

This work can foster a more accessible research environment for autistic participants (Crane et al., 2019) and lead to more meaningful and impactful research (Crane et al., 2019, 2023; Jose et al., 2020), that goes beyond interpretations of autism as simply an impairment (Heraty et al., 2023;

Nicolaidis et al., 2011). For the collaborators¹ themselves, this work can be empowering (Pellicano et al., 2022; Vincent et al., 2017). It provides mutual learning opportunities, the chance to share their experiences and builds relationships between peers (Cumbo & Selwyn, 2022). It can also allow opportunities to build trust between researchers and communities (Rodriguez Espinosa & Verney, 2021).

Participatory research approaches and co-production remain uncommon in autism research (den Houting et al., 2021; Hotez et al., 2018), despite recent published guidance aiming to promote further inclusion of autistic people in research processes (Fletcher-Watson et al., 2019; Nicolaidis et al., 2019). Fletcher-Watson et al. (2019), for example, co-produced a seminar series to develop a framework for collaborative research, identifying five key topic areas to build on: respectfully representing lived experience; autistic communities authentically shaping research agendas; best practice in leadership and advocacy; supporting and encouraging autistic researchers and activists through infrastructure; and building effective working partnerships. . Currently, where participatory work does occur, issues such as tokenism and unbalanced power dynamics remain and can be worsened by negative assumptions made by academics about their community partners, such as placing blame on their autistic partners' "impairments" when disagreements occur within partnerships (den Houting et al., 2021; Fletcher-Watson et al., 2019; Nicolaidis et al., 2019).

Demonstrating good practice and the feasibility of participatory research is of growing importance as autistic people are increasingly more open about their diagnosis. This includes being openly autistic in settings such as higher education, which they were historically thought not to be part of due to assumptions of co-occurring learning difficulties. As more autistic people are known to be in these spaces, there are calls to improve the ways in which higher education supports and enables them to succeed. Some of these calls have been answered with participatory research, discussed below, but these are by far in the minority.

Within a higher education context, Hotez et al. (2018) created a programme to help autistic students transitioning to university (Project REACH). They used a participatory approach which took the needs of these students into account by basing the curriculum on the experiences of prior students, focusing on skills such as self-advocacy. The course was run before students began university so that it was more effective at helping them prepare for the transition and adjustment, again based on earlier student experiences. The project also allowed autistic mentors to develop skills that would be beneficial for later employment, as well as demonstrating leadership roles for new students. Similarly, Gillespie-Lynch et al. (2022) designed two versions of a training course, with and without a participatory approach, and

¹ The term "collaborators" will be used to refer to non-academic partners in the research process (in the present paper, autistic students)

both versions successfully achieved the aims of reducing stigma and increasing autism knowledge in their university student sample. The participatory training, despite being similar in structure, was the most effective at achieving these aims and was also more engaging, according to trainees, as it allowed them to learn from autistic people themselves. The authors also suggest that the inclusion of personal stories and experiences were more interesting than the fact-focused information provided in the non-participatory version. Aside from the potential benefits of the training, autistic co-authors felt that their experience of working on the training had helped them become better advocates, for themselves, other autistic people, and other minority groups.

In light of the need for more participatory work in the higher education sector, and the lack of current recommendations for how to work well with autistic students when designing and conducting research, the current work describes the participatory approach we took in a higher education context, for the design and evaluation of a training course for university staff.

Previous work has found a lack of autism knowledge from academic and support staff at universities (Cage et al., 2020; Goddard & Cook, 2022; Van Hees et al., 2015), which could, in turn, have a negative impact on autistic students' mental health (Scott & Sedgewick, 2021). Thus, our group aimed to create a training course specifically centred around the concerns of the autistic student community. The online course itself and its evaluation are detailed in Jenks et al. (2023). Here, we will describe the approach we took to developing the course, working in partnership with autistic students at every stage of the project, and providing recommendations for how these experiences could inform participatory higher education research design more broadly. See [Appendix A](#) for a summary of who was involved in each project stage. It should be noted that some of our collaborators are multiply neurodivergent, but all identify as autistic and are referred to as such for the purposes of this work.

Project planning

A participatory advisory group (PAG) was formed with four autistic students from three different UK universities as well as representatives from the National Autistic Society (a leading UK autism charity) and Spectrum First (a company specialising in autism training and support which has a high number of autistic and neurodivergent staff). As the idea for the project arose from the findings of a previous project of the PI, autistic students who had contributed to that earlier project were initially invited to be PAG members. Adverts for PAG members were also sent out via university autism/neurodiversity society mailing lists, and via Disability Services mailing lists, at relevant participating institutions. When reflecting on the project, Miriam, one of our student collaborators, said that *“the diversity within the PAG was also key in my view, allowing multiple voices to be heard”*.

Once expressions of interest were received, students were offered information about the potential level of commitment and timeframe for this kind of academic project, and given the chance to opt-in to being involved.

"I really appreciated the flexibility we were given in choosing which aspects of the research we wanted to be involved in. It meant everyone could work to their strengths and PAG input was spread across the project without it being overwhelming trying to do everything" (Freya)

The first draft outline of the proposal was then shared with these students, and they contributed to refining and developing the funding bid. This included discussions about proposed training formats, goal numbers for recruitment and the breadth of which staff should be targeted for recruitment, and the types of in-kind benefit the students themselves would value getting out of their involvement beyond monetary compensation for their time. Once the funding had been awarded, PAG members were also included in the process of shortlisting and recruiting the post-doctoral research assistant for the project, resulting in the recruitment of a candidate who was themselves neurodivergent and therefore reinforcing the participatory nature of the overall project.

"As a PAG, we were integrated into the project from the beginning, consulting on the development, delivery, analysis, and dissemination of the project" (Miriam)

How-to steps for future projects

- Involve collaborators from the beginning of the project where possible (e.g. funding applications)
- Lay out clear expectations (e.g. time commitments) for autistic collaborators and allow for flexibility in their level of engagement

Training design and development

The PAG were responsible for developing a list of concerns that they wanted the training course to address, or things that they wish university staff had known about them from the beginning of their studies. The neurodiverse team of academics then separated this list into five topic areas that were used as training session titles: "What is autism"; "Stigma and stereotypes"; "Autism and mental health"; "Autism and the university environment"; and "Practical strategies for working with autistic students". These topic areas were reviewed and approved by the PAG before materials were developed, and they further contributed specific ideas for what should be in each of the sessions, in a two-way checking process. This was carried out both through live online meetings and through asynchronous shared documents which every member of the research team had access to. The materials themselves, including the presentation slides and resource lists, were written by the neurodiverse team of academics, based on these discussions and documents. Final versions of the planned content were approved by the PAG. Robert, a PAG member,

said that a strength of the project was in “...*encouraging autistic people to come forward with issues, and making reasonable adjustments to deal with these issues*”.

Lessons lasting approximately 20 minutes were created for each topic, using information from the PAG, supplemented with current research literature and online material from autistic creators. In addition, each session had a resource list including a range of media, again largely from autistic and neurodivergent creators. Resources included blog and social media posts, journal and news articles, online videos and podcasts. Once these had been compiled, the PAG were asked to read the slides and go through the resources to ensure that the materials accurately reflected their views and to make any changes or additions. This work mostly took place through asynchronous sharing of files, using tracked changes and comments to discuss ideas and suggestions. This worked well for the neurodivergent team, as it allowed PAG members to engage when they had the capacity and in ways which worked with their executive function profiles, rather than demanding on-the-spot responses to ideas or adding the pressure of social interaction to the work.

PAG members were also given the opportunity to be involved in the delivery of the course and have their voices directly heard by trainees, if they wanted and were comfortable doing so. For this, the students took part in an online panel discussion around each of the session topics.

“Being part of the training programme alongside other autistic people meant we had the chance to bridge the gap between our experiences as students and university staff becoming better allies” (Sarah)

These sessions were led by an autistic researcher, and questions were made available to the students ahead of time. This was done to increase their comfort level, as it is common for neurodivergent people to find it easier to communicate with other neurodivergent people (Crompton et al., 2020), and to reduce anxiety and accommodate their processing style by allowing them to think about and prepare their responses ahead of time (Maras et al., 2021). The students’ interviews were included alongside the recorded lectures as required viewing to complete the course and, according to trainee feedback, became the most valuable aspect of the training.

Once the training was launched, the PAG were consulted regularly with updates and plans for the project, usually via online meetings or email. Updates included adaptations of the training into a short course and an independent online training module to make it available to more staff. PAG members again were invited to review and approve the adapted materials as the content developed over the course of the grant, ensuring that their voices and opinions remained genuinely and actively represented in the project outputs.

How-to steps

- Provide multiple opportunities for engagement (i.e. at different time points)
- Allow for reasonable adjustments to participation and multiple methods of engagement (e.g. additional information ahead of time for discussion, both verbal and text-based options for providing feedback)
- Treat collaborators as equal partners in the research, with control over outcomes, regular update meetings, and continued involvement in project development

Evaluation

The training was evaluated via two approaches, again detailed in the paper presenting the results of the project (Jenks et al., 2023). The first was quantitative analysis of scores on the Autism Stigma and Knowledge Questionnaire (Harrison et al., 2017), which was undertaken by the academic staff. The second method consisted of interviews with trainees, which were conducted and transcribed by an autistic academic staff member.

After the transcription was complete, three students from the PAG participated in the triangulation process of the thematic analysis. *“Being involved in data analysis and getting an insight into how research works”* was a particular benefit of being involved in the project for Freya. Each of these students had prior knowledge of thematic analysis from their studies and so no formal training was provided to them by the project, though this was offered to any PAG member who wanted it. Two members of the research team (one autistic and one non-autistic) read and analysed all the transcripts, while the remainder of the group (both academics and PAG members) were given a random subset of transcripts. This was done to avoid over-burdening PAG members who were all enrolled on full-time courses or in full-time employment outside the project, in response to their expressed desire to contribute without feeling overwhelmed with the project work. Each member of the team was given the opportunity to send their individual analyses to the lead researchers, who established an initial list of four themes. The entire group met to decide on the final themes, rewording the original list and adding an additional fifth theme suggested by the PAG members as being especially important in their reading of the data.

How-to steps

- Involve collaborators in all aspects of the research, including data analysis
- Offer training opportunities to collaborators to ensure greater equality of skills and confidence contributing to the project outcomes
- Be considerate of collaborators’ workload to avoid undue pressures or overwhelm

Research dissemination

The three students who took part in the data analysis were also co-authors on the resulting research paper, contributing with edits and additions to a draft produced by the neurodiverse academic team. PAG members have also had an active role in producing the present manuscript, sharing their views and experiences of being involved in the participatory research process, and again editing and adding to the final paper.

“One of the standout moments for me was the feedback from participants of the research on the value of lived experience. Words such as “rare” and “powerful” were used, highlighting the importance of the PAG.” (Miriam)

The work was also presented at international conferences and our funding covered expenses for each of the student PAG members to attend one of these events. Three of the PAG members attended Autism Europe’s 2022 International Congress in Krakow, Poland, while the final PAG member went to the INSAR 2023 Annual Meeting in Stockholm, Sweden.

For most PAG members, this was their first experience of a research conference, and it was the first international conference experience for all PAG members who attended. It was hoped that participation in both the conferences and the creation of the paper would be beneficial for their individual career development. For Robert, the conference in Krakow *“gave me a brilliant opportunity to become better educated on autism”*. This was a benefit of participation which was costed into the grant from the outset, following conversations with PAG members as to what would be useful to them to get out of being involved – several are planning to seek either clinical or academic psychology careers, so publications and conference experiences are key to their long-term goals.

How-to steps

- Discuss collaborators’ motivations for involvement in the project and provide opportunities in line with their goals
- Ensure that collaborators are properly credited for their work

Recommendations

First and foremost, our team recommends, alongside other work in the field (Fletcher-Watson et al., 2019; Nind, 2011), that higher education research takes a participatory approach, seeking to involve autistic people in all stages of the research process, or as much involvement as the research type will allow.

“A unique element of this project was the value placed on the participatory advisory group (PAG). All too often in research, co-creation is seen as a tick box exercise leading to tokenistic involvement opportunities” (Miriam)

Levels of participation and autistic researchers

It is important to note that there are barriers to access within academia for autistic people, for example difficulties with managing course load, sensory overwhelm within university spaces, and a lack of adequate support can lead to increased pressure on autistic students (Cai & Richdale, 2016; Goddard & Cook, 2022; Van Hees et al., 2015). Within research projects, autistic people may fall victim to marginalisation or an assumed lack of competence in research skills (Botha, 2021). Researchers should carefully consider the sensory environment of meeting spaces, their expectations of social communication (e.g. making eye contact, or participating in social events), and the workload assigned to collaborators to make projects more accessible (Jones, 2021).

While these issues may sometimes prevent a fully participatory approach – and the level of participation may change across phases of the research – the goal should always be for far more than tokenism. “Tokenism” can have varied definitions, but here we define it as only consulting with autistic people after the research has been planned or designed (Keating, 2021) or involving autistic people as a “tick box exercise” without giving them any measurable control or decision-making power (den Houting et al., 2022; Fletcher-Watson et al., 2019). It is important to acknowledge that there are multiple approaches to participatory work, with different goals, from having collaborators in advisory positions through to direct leadership from the community (Brown, 2022; den Houting et al., 2021; Tritter & McCallum, 2006). Researchers should carefully consider the level of participation that is most appropriate and feasible for their project and make this clear to collaborators from the outset.

Our project is an example of having varying levels of participation, with some phases being consultative of the PAG (deciding the general content to be included), and others having more active and in-depth involvement (developing video materials). The fact that the Research Associate running the project day-to-day was also autistic meant that stakeholder insights were built into all decision making. It is important to remember that many autism researchers are themselves neurodivergent, and part of the community they work with (Botha, 2021; Jones, 2021). There is no automatic separation of these groups, and these identities cannot, and should not, be treated as exclusive, or as interfering with each other in a negative way. Lived experience and professional academic training can be complementary and enhance research, and should be seen as a positive when recruiting to academic positions.

Participatory research can be particularly valuable and accessible for collaborators when the academics they are working with are also autistic because it demonstrates that autistic viewpoints will be understood and respected (Pellicano et al., 2022). While the systems within academia create barriers for autistic people and need to be addressed on a much wider scale (den Houting et al., 2021; Fletcher-Watson et al., 2019), this project

deliberately employed an autistic researcher (with two PAG members involved in the shortlisting and interviewing process) and sought to provide practical research experience for our collaborators.

Collaborator recruitment

Academics can often approach the recruitment of collaborators in the same way they would for research participants, seeking a representative sample (Fletcher-Watson et al., 2019; Nicolaidis et al., 2019), which is often not feasible nor desirable in a participatory approach (den Houting et al., 2021). In their guidelines, Nicolaidis et al. (2019) note that this can devalue the role of community partners in the work, reducing them again to a participant role and over-valuing demographic characteristics. Instead, recruitment should be based on expertise, as with other research staff, or specific lived experience relevant to the research topic at hand (Fletcher-Watson et al., 2019; Nicolaidis et al., 2019). This was part of why students who had contributed the insights from the previous project were invited to be PAG members for this project – it gave them the opportunity to be actively involved in developing training based on their own original recommendations.

Data analysis and training

For this project, it is important to note that many of our autistic student collaborators came from a Social Sciences background and already had experience with the research methods being utilised, in addition to their lived experience of autism. Therefore, they did not need further training to take part in data analysis and were familiar with the research process. This is not likely to be the case for other similar projects (Hotez et al., 2018), and so it is the responsibility of the lead researchers to ensure that adequate training is provided to allow collaborators to make equal contributions in this area.

All our community partners were given the opportunity to collaborate in qualitative data analysis, which directly challenges traditional views that autistic people are incompetent or incapable of doing this type of work effectively (Nind, 2011; Vincent et al., 2017). In the current project, our autistic partners recognised the presence of an additional theme within the interview data, that of systemic barriers for autistic students. This directly demonstrates the importance of involving people with lived experience in interpreting data from projects they are involved in – different perspectives can generate additional insights and improve the quality of the final research outputs. This supports our recommendation that community members are genuinely involved in all stages of research, not just in early design phases or in tokenistic ways. As higher education institutions will have research methods training options already in existence, lack of previous experience should not be a significant barrier to inclusion. Indeed, offering access to these kinds of courses can be an integral part of developing PAG members' skills and should not be limited to instances where the collaborators already have, or are in the process of completing, degrees at university. Access for collaborators from the wider autistic community means that they can be

more genuine partners in the research process, as they share knowledge that previously may have been limited to the academic members of the team, and enables them to engage with future research on a more equal footing.

It should be noted that the PAG were not directly involved in the quantitative data analysis, which was instead conducted by an autistic member of the academic staff. Participatory approaches align best with collaborative analysis of qualitative data over quantitative (Kidd & Kral, 2005), although the latter can include shared input into the design of the materials (Nicolaidis et al., 2019) and data interpretation (Fletcher-Watson et al., 2019). In the current work, the PAG were involved in decisions regarding the choice of measures and were able to adjust the interpretation of the data throughout the report writing process, which was possible due to their prior experience with these methods. Future participatory studies should explore deeper involvement for collaborators in quantitative approaches, including the provision of adequate training for full participation in data analysis and interpretation, as the feasibility of this has not been extensively explored. Some research has involved indirect engagement with quantitative approaches, for example by having collaborators select the measures used (Kidd & Kral, 2005) or through involvement in data collection (Main et al., 2012). Another approach is to provide lay summaries of the data to collaborators to allow them to participate in interpretation (Cashman et al., 2008). As with qualitative data discussed above, collaborators may be able to provide insight into quantitative data interpretation that the academics cannot (Fletcher-Watson et al., 2019; Israel et al., 2005) and so it is essential that they are given the tools to engage with these data.

Accessibility

When working with autistic and neurodivergent students as partners in research, conversations should be made as accessible as possible (Collins et al., 2018; Cumbo & Selwyn, 2022; Fletcher-Watson et al., 2019). Robert stated that “...*running the meeting in manner suitable for autistic people, by including people trained and experienced with autistic people*” was of particular importance to him.

In our case, we held discussions with the team through online meeting software. This meant that our collaborators could choose whether to be seen on camera and whether to communicate vocally or using the chat function. Being able to access the conversations remotely also allowed them to control their own sensory environment and take breaks as needed. These are all features which have been identified by autistic people as enabling them to engage more authentically in communication in a range of situations (Howard & Sedgewick, 2021). It was also possible for PAG members to send their suggestions by email if they preferred not to attend, or were otherwise unable to attend, meetings. Other research groups (Nicolaidis et al., 2011) have taken an entirely text-based approach to communication, and these preferences are something which we recommend are established early on in any participatory research project. We also suggest that it is good

practice to check in with PAG members at regular intervals as to whether their preferences have changed or if anything can be done to make their involvement and communication easier, as individuals' needs are dynamic rather than static.

The decision to conduct meetings online was also dictated by other practical reasons. Our PAG members lived in different parts of the country and the project was run amid the coronavirus pandemic, with these conditions limiting our ability to run in-person discussions. For many of our students, this was a familiar approach due to their experiences of studying and having academic meetings during the pandemic. However, it was a concern for one of our PAG members, who expressed that they would have been more comfortable in a face-to-face setting. While this was not possible for every meeting of our project, we did have some chances to meet in-person to try to support the different preferences of team members. We would recommend, again, that this is discussed early on in participatory projects and clear plans made to try to accommodate a variety of preferences, including hybrid options, within reason.

Respect and compensation

Recommendations from previous participatory work include needing to show clear and overt respect for one another, ensuring that everyone is heard (Fletcher-Watson et al., 2019).

“Right from the beginning of the research project, I felt welcomed and that I was an equal member of the research team despite not having a PhD and ‘only’ bringing my lived experience” (Freya)

Many autistic people have criticised that they are asked to share their lived expertise by traditional researchers without proper compensation, which can all too easily feel like this is the equivalent of being treated without true respect (Benevides & Shore, 2020; Dwyer et al., 2021; Michael, 2021). To prevent this feeling, and to demonstrate our appreciation for the work the PAG members put into the project, they were compensated monetarily for their time at the equivalent hourly rate to employed Research Assistants, were involved and updated throughout the project on its progress, and were acknowledged as co-authors on publications. This conveys a level of professional respect for the contributions of autistic people to the project which places their expertise on the same level as academic expertise, which is important for genuine participatory work. We strongly recommend that these practices are adopted more widely by academics carrying out participatory work, to emphasise publicly the esteem in which they hold their partners.

Limitations

While we endeavoured to make the research environment as accessible as possible for our collaborators, a power imbalance still remained. The academics included teaching staff from the participating universities, some of whom had previously taught or supervised some of the students. This is likely to have created a more obvious “leadership” role within the partnership

where the academics were viewed as experts to be deferred to by those students, even if staff did not intend to create this dynamic (Areljung et al., 2021; Vincent et al., 2017). Future participatory research projects working with any students in higher education, but especially those working with neurodivergent students who may feel disempowered in these interactions (Scott & Sedgewick, 2021; Vincent et al., 2017), should endeavour to find ways to equalise the relationships within the group. This could be done by actively seeking out students who have not worked with the academics previously, or who are in different departments and courses. This was another situation where having a Research Associate running the project who was not a member of teaching staff was helpful, as this individual had no direct power relationship with the students, and as they were also autistic, students felt comfortable sharing requests for reasonable adjustments with them.

While an entirely representative group of collaborators would not be possible or necessary for work of this nature (Fletcher-Watson et al., 2019; Nind, 2011), it is still important to recognise that some groups of autistic people are less represented within research, including in participatory research, such as those who do not use spoken communication, who have co-occurring intellectual disabilities, non-white autistic people, and those outside the Global North (den Houting et al., 2021; Nair et al., 2024). Our students were all white and communicated verbally, placing them among the more privileged voices within autism research (Nind, 2011). Intersectionality across race, gender and co-occurring needs, as well as different means of communication were included in the training, but it is possible that a more diverse group of student partners would have resulted in different recommendations for staff practice, and different suggestions of what to emphasise within the training itself.

Similarly, the group of students recruited for this project were largely from Social Sciences backgrounds, many studying for degrees in Psychology, which may also have impacted the advice given to trainees. Again, we included topics such as difficult laboratory environments in the course, but without the input of lived experience. As discussed in the previous section, these students had prior experience in qualitative data analysis through their studies and did not require additional training, which is an advantage that similar projects are unlikely to have. For future studies, we recommend finding ways to advertise the opportunity to participate more broadly, as students do not always respond to email approaches – practical strategies such as physical posters up in student spaces are likely to reach a wider and more representative population.

This work had the benefit of funding for a dedicated full-time Research Assistant, which meant that an autistic researcher could be hired, increasing the amount of lived experience brought to the project. While clearly not always possible to recruit a candidate from the community being worked with, the PI made the conscious decision to include a statement welcoming neurodivergent candidates for the post in the hope of attracting strong

applications from those with relevant lived experience. This simple practice did indeed result in more declarations of neurodivergence than often seen in job applications, and is an easily applicable recommendation for a wide variety of projects seeking to embed participatory practices in their work. In cases where funding is limited, or a suitable autistic candidate cannot be recruited, we strongly recommend seeking experienced researchers already working within the field as potential collaborators or advisors.

Benefits

The PAG members in the current work provided reflective statements about their involvement, several of which mentioned the personal benefits of the project. Firstly, a key benefit was in the ability to effect change and add to the support available at universities, which may not have been possible to the same degree outside of a funded project such as this. Participatory work is often focused on practical outcomes, rather than traditional scholarship, allowing collaborators to generate positive changes for their communities (Brown, 2022; Rodriguez Espinosa & Verney, 2021).

“Being autistic means we often experience difficulties that could have been avoidable if the people around us had a better understanding, particularly in higher education. Often it can leave you with a feeling of wanting to make change, but it can be hard to know how to go about this by yourself.” (Sarah)

“It felt really valuable to use [my previous negative experiences at university] to improve the provision for future autistic students, and know that I was contributing to tangible change.” (Freya)

“I felt enjoyment from participating, as well as a sense of achievement of helping the autism community.” (Robert)

Many of the student PAG members were aiming for postgraduate study and careers in research, so support for these goals was embedded into the funding plan. Collaborators were extensively involved in the research process, from funding to dissemination, including attendance at conferences to provide as much experience as possible.

“I found a passion for research which has led to me now doing a PhD, and I made some wonderful connections and mentors who have been incredibly supportive of me as I have continued my education.” (Freya)

“I found the flexibility, range of experiences, and the opportunity to expand my knowledge invaluable,” (Freya)

From another perspective, the project itself benefitted from student involvement in a number of ways. For example, the training materials created by the PAG were regularly described by trainees as the highlight and most valuable aspect of the training. During the qualitative analysis, collaborators were able to identify a theme within the data that reflected their lived experience of trying to navigate complicated support systems and barriers, which had not been apparent to the research team. Aside from these measurable differences, the project has also fostered mutually beneficial collaborations and potential for future work.

The positive impact that participatory approaches have on research outcomes have been demonstrated on a number of occasions in prior work. For example, in work by Pellicano et al. (2022) examining the oral histories of older autistic adults, the participatory approach made participants feel comfortable enough to share more detailed information about their life experiences, enhancing the quality and depth of the research. A study by Aabe et al. (2019) involving co-production of autism knowledge in a UK Somali community also demonstrated impact at different levels. At a microlevel, the project helped amplify the voices of collaborators, increased the skills of the research team, and provided future collaboration opportunities for those involved. On a wider scale, the project's organisation has been able to grow and collaborate with other groups in the health, social care and education sectors to support Somali community members, professionals and policymakers.

The current work has focused on the applications of participatory work with autistic people in research. Elsewhere, similar approaches have been taken for more practical projects, such as co-creating supports for autistic people (Coney, 2023; Fabri et al., 2016). One example of ongoing work in this area is a collective activism and education group based in Scotland, run by autistic adults and working alongside the Scottish government and other organisations to improve services for autistic people (Autism Rights Group Highland, n.d.; Fletcher-Watson et al., 2019). The core concepts from the current work, such as a commitment to treating autistic people as equals and respecting their expertise, fair compensation and credit, and making involvement in the project accessible, could each be applied to work in other domains.

Conclusion

Previous work has shown that community members can benefit personally from collaborating in research projects, feeling more empowered, connected and that they are able to make a difference to the causes they care about (Brown, 2022; Nind, 2011; Pellicano et al., 2022). Our project showed that this was also the case for autistic students in higher education, particularly embedding employability skills which are crucial for this group, as well as proving the feasibility of working in a participatory manner with this group.

Participatory work is valuable because it brings together expertise from both sides, academic and lived experience: knowledge of research methodologies from academics, and knowledge of what is needed most to support individuals from within a community (Crane et al., 2023; den Houting et al., 2021). This is in addition to involving autistic academics, who have interlinking academic and lived experience. In the case of the current work, the participatory approach allowed us to create a practical training course that reflected the needs and priorities of existing autistic students, ensuring that their voices were heard throughout. We were also able to show that this approach is practicable and manageable in academic research, with minimal adaptations to usual academic working practices. It is hoped that

this demonstration of, and the recommendations for, autistic participatory work in higher education will encourage the use of this approach in future research focused on this group of students.

Submitted: December 12, 2024 EST. Accepted: March 10, 2025 EST. Published: August 21, 2025 EST.



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Appendices

Appendix A. Table summarising the responsibilities of team members throughout the project

Task	Autistic students	Partners from autistic-led organisations	Academic team members	Autistic research associate
Initial funding application	✓		✓	
Hiring research assistant	✓	✓	✓	
Reviewing ethics application	✓	✓	✓	✓
Submission of ethics application			✓	✓
Discussion of session topics and planning materials for the course	✓	✓	✓	
Preparation of materials (e.g. writing out slides, resource lists)			✓	✓
Creation of lived-experience videos for the course	✓		✓	✓
Final approval of course materials	✓	✓	✓	
Delivering the course			✓	✓
Quantitative analysis of trainee knowledge scores				✓
Qualitative analysis of trainee feedback	✓		✓	✓
Attending conferences	✓	✓	✓	✓
Presenting conference posters				✓
Co-authoring papers	✓		✓	✓