Developing an Evaluation Framework to Promote Meaningful Participation of Autistic People in Research: The Evaluating Levels of Participation in Autism Research Tool and Participatory Action Research Group Checklist

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Developing an evaluation framework to promote meaningful participation of autistic people in research: The Evaluating Levels of Participation in Autism Research Tool (ELPART) and Participatory Action Research (PAR) Group Checklist.

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Abstract

Despite growing recognition of the participation of autistic people as collaborators in research, this field continues to face several significant challenges. Key issues include a lack of guidance for researchers on how to implement participatory methods effectively and a shortage of evaluation tools to support best practice. Meaningful participation has the potential to redress power imbalances, reduce stigma, and ensure that research accurately reflects the lived experiences of autistic individuals, leading to more relevant and effective services and support.

To address these challenges, researchers codeveloped and refined a standardised evaluative framework to promote meaningful autistic participation across all research stages and evaluate good practice in establishing a Participatory Action Research (PAR) Group while enhancing transparency regarding the extent of involvement. Draft tools were developed by a neurodivergent lead researcher, with the development and refinement process led by autistic researchers who facilitated consultation with participatory researchers, ensuring that the tools reflected diverse perspectives and lived experiences.

The refined evaluation framework consists of the Evaluating Levels of Participation in Autism Research Tool (ELPART) which promotes participation of autistic people as collaborators across the stages of research and the Participatory Action Research (PAR) group checklist which evaluates inclusive and accessible interactions with autistic collaborators. Both tools support researchers in addressing power dynamics, provide specific guidance on how to operationalise participatory approaches and serve as frameworks for evaluating and enhancing the meaningful participation of autistic individuals in research. These tools can support equitable and impactful collaborations between researchers and the autistic community.

Introduction

In recent years, there has been increasing emphasis on the meaningful involvement of autistic people as collaborators in research, with participatory and co-produced approaches widely recognised as best practice.[1,2] Despite growing numbers of projects being led predominantly, and in some cases exclusively, by autistic academics,[3,4] they remain underrepresented.[5.] Furthermore, participatory practices with autistic community researchers as collaborators are often embedded within neuro-normative frameworks privileging neurotypical knowledge and ways of working.[6]

Participatory Research is a collaborative approach with researchers and participants working together to identify issues and generate knowledge, emphasising shared decision-making and valuing lived experience. Participatory Action Research (PAR) extends this approach by emphasizing action and the principle that those with lived experience are best placed to shape solutions.[7] Participatory research continues to face structural, cultural, and practical barriers with the autistic community. Tan et al[8] undertook a systematic evaluation of participation levels of autistic people in research using den Houting et al's[9] framework. Although autistic involvement in research has increased in recent years, they found it was often distal and limited to consultation during the design stage, rather than embedded throughout the research process. Neurotypical researchers continued to hold decision-making power, and there was a lack of transparency and clarity around levels of involvement. In some fields particularly, such as autism genetic research, autistic involvement remains minimal.[10] Definitions of participation also vary, leading to inconsistent implementation,[11,12] and participatory research is often understood superficially by academics.[9]

Participatory research spans a spectrum of practices, from shaping research questions to redistributing decision-making power as equal partners and co-authors.[13] Navigating this spectrum is challenging; it is an iterative process requiring ongoing reflexivity and a willingness to address entrenched power dynamics.[5] Challenges vary and interact depending on a researcher's neurotype, their relationship to the community being studied, and their position within the academic hierarchy. Early career researchers may face barriers such as limited institutional support or lack of understanding of meaningful participation from supervisors, while more established researchers may struggle to move away from hierarchical practices.[12] Neurotypical senior researchers may need to invest effort in building rapport and ensuring accessibility, whereas autistic early career researchers may lack the security or authority to challenge established norms.

Although enthusiasm for autistic involvement is growing, many researchers still lack the tools and support needed to implement participatory approaches effectively.[2]

Background to participatory research with the autistic community

In critical neurodiversity studies, “business as usual” refers to neurotypical researchers dominating the field which reproduce power imbalances, marginalise lived experience, and frame neurodivergence as a deficit to be studied “from outside.”[15] This is evident in autism research, where medical and psychiatric traditions have positioned autistic people as a problem to be solved[16,17] reinforcing misconceptions that they cannot equally participate in the research process.[12] Historically, research centres neurotypical perspectives, with little accommodation for autistic participation.[18]

Participatory research directly engages marginalised communities to redress power imbalances, whether through collaborative research teams including community members with lived experience or creative participatory methods such as photovoice.[9,19] Inspired by Freire’s social justice work, which advocates for dialogic, participatory learning enabling oppressed people to develop critical awareness and act to change inequitable systems, participatory research promotes equity in knowledge production.[20] When implemented meaningfully, it moves beyond tokenistic inclusion to redistribute power and redefine whose knowledge counts.[21,22]

Over the last decade, autistic-led and mixed neurotype collaborations have begun to challenge neurotypical framings of autism research[.4,23] These developments highlight that participatory approaches are not only about inviting autistic involvement into existing academic spaces, but also recognising the distinct knowledge, processing styles, communication preferences, and priorities that autistic researchers and communities bring.[24,25] Even within all-autistic research teams, attention to diversity remains crucial to avoid privileging certain academic voices and ensure outcomes represent the wider community.[4]

Challenges of participatory autism research

The current challenges of participatory autism research can be divided into the areas detailed below: Definitional ambiguity and shallow participation, misalignment between research and community priorities, inconsistencies in practice and power and epistemic injustice.

Definitional ambiguity and shallow participation

Researchers and autistic communities often differ in their understanding of what genuine participation entails. Pellicano, Dinsmore, and Charman[26] found researchers frequently described their work as participatory, though autistic community members disagreed. Similarly, Masterson et al.[27] noted inconsistent uses of coproduction in health and social care, often without genuine involvement. den Houting et al.[9] observed autistic participation was typically limited to advisory consultation, with professionals or carers more often engaged as partners.[27] Tan et al.[8] further highlighted ambiguity over who qualifies as a “community member,” with professionals sometimes included under this label. These findings highlight the need for clearer guidance to ensure meaningful and transparent participation.

Misalignment between research and community priorities

Autism research often fails to align with autistic community priorities. Studies consistently identify a gap between research being conducted and what autistic people prioritise.[12.26.28,29] For example, Kaljusto et al.[10] found 87% of 149 articles in autism and genetics journals did not align with community priorities. Involvement of autistic individuals in research priority-setting is needed to address this.

Inconsistencies in practice

Although some projects demonstrate best practice,[23] participation is often concentrated at the design stage rather than embedded across all stages, from funding applications to dissemination.[8,9] Pellicano et al.[26,30] found limited opportunities for autistic involvement beyond design and dialogue. Similarly, Jivraj et al.[31] identified only two studies in which community members were consistently engaged throughout, though their strict inclusion criteria excluded more recent developments. Without deeper involvement, there is a risk of reverting to tokenistic practices.

Power and epistemic injustice

Superficial or tokenistic involvement reinforces what Bertilsdotter Rosqvist and Jackson-Perry[15] call neurotypical epistemic privilege, where neurotypical perspectives dominate what is considered valid knowledge. This can perpetuate epistemic injustice for autistic people,[5] leading to feelings of exploitation and exclusion.[32] Such practices foster mistrust in the autistic community and sustain deficit-based discourses in research.[8,33] They also risk producing services and support misaligned to the diverse needs of autistic people.[34,35]

Existing good practice guidelines around participatory autism research

One of the main obstacles to adopting participatory autism research is the lack of clear, practical guidance on how to implement them effectively.[12,15]

Arnstein's ladder[36] has long been used to conceptualise levels of participation, from manipulation at the bottom to citizen power at the top. In autism research, participation is often tokenistic and sits in the lower levels.[2] den Houting et al.[9] adapted another model for the autistic community, reframing it as "doing to," "doing for," and "doing with." While useful, critics argue that Arnstein's ladder presents participation as linear and oversimplifies its complexities.[37] In autism research, power dynamics, accessibility needs, and communication preferences often shift across research stages, so participation is rarely linear.[37,9] Power sharing is necessary but insufficient if neurodivergent researchers or participants cannot engage meaningfully due to systemic barriers. The ladder does not account for the adjustments, pacing, and communication support needed for equitable autistic participation.[14,38] Furthermore, the ladder fails to capture the quality of participation and the reciprocity involved in participatory partnerships. For example, autistic individuals may be given formal roles (e.g., on advisory boards) without real influence, or their contributions may be valued in some stages but dismissed in others.[26,29] This broad framework does not specifiy how to implement participation throughout the research stages with autistic people.

Several frameworks have sought to provide more structured guidance on participation. The *Guidance for Reporting Involvement of Patients and the Public (GRIPP2)* framework[39] represents an important step toward improving transparency, consistency, and accountability in participatory work. While GRIPP2 offers a valuable foundation by encouraging researchers to document how involvement occurs, it was not designed specifically for autism research and focuses primarily on reporting rather than guiding practice. This highlights the need for autism-specific tools that support inclusive and equitable practices across research stages.

Valuable guidelines for meaningful participation specifically in autism research have been produced by Nicolaidis et al.,[13] Gowen et al.[40] and Dark.[41] Whilst some provide a broad framework for ethical and inclusive research practices,[41] they lack specific guidance on how to operationalise these principles in different research contexts. This makes it difficult for researchers, especially those unfamiliar with participatory approaches, to apply these principles meaningfully.

Building on the need for structured and actionable guidelines, the Cooperative Research Centre for Living with Autism (*Autism CRC*)[42] produced a range of *Inclusive Research Practice Guides.* These guidelines include a checklist for good practice in supporting participation in research for autistic individuals (Checklist 5), utilising a 3-point scale to assess the involvement of autistic participants in research. This useful checklist provides a broad overview of participation but lacks specific strategies for power sharing, accessibility, compensation and reflective practice.

These examples highlight progress in articulating participatory principles, but also the need for a practical, autism-specific framework that supports researchers in applying them consistently and meaningfully. Without such tools, participatory approaches risk remaining underutilised or superficial.[26] With this in mind, the aim of this project was to co-develop and refine tools with the autistic community to;

1. Evaluate and identify different levels of community participation in autistic research - Evaluating Levels of Participation in Autism Research Tool (ELPART).
2. Evaluate good practice in establishing a Participatory Action Research (PAR) Group with autistic people (PAR group checklist).

It is proposed these tools will aid researchers, in both neurotypical and autistic led teams, adopting PAR approaches and in promoting best practice in autism research. Specifically, it is envisaged that these tools will;

- Promote and provide specific guidance around the meaningful inclusion of autistic people throughout the research process, from conception of an idea through to dissemination of results (ELPART).

- Aid transparency in autistic involvement throughout the research process and in decision making,[31] promoting the fair acknowledgement of autistic people’s views (ELPART and PAR group checklist).

- Aid reflection and learning at all stages of the research process (ELPART).

- Address power dynamics and disrupt “business as usual”[15] by promoting autistic people as co-researchers or co-producers with real decision-making power and centering lived experience as epistemically valid and necessary (ELPART and PAR group checklist).

Methods

Positionality

Our neurotypes shape how we know and produce knowledge.[15] Transparency and reflection were particularly important given the historical misrepresentation of autistic people in research and the resulting epistemic injustices.[5]

The core research team comprised six autistic and ADHD people with intersecting experiential, researcher, and professional knowledge of neurodiversity and participatory approaches. The lead researcher identifies as an ADHD-er and as the mother of an autistic daughter, with career experience in participatory work as well as academic experience via university teaching and conducting doctoral research. Community researchers wore several hats; all brought experiential knowledge as autistic people, alongside academic and professional expertise as postgraduate students, with one having additional experience as an early-career academic.

Later, four additional mixed-neurotype (neurotypical and autistic) participatory researchers with relevant academic expertise were consulted. Perspectives were grounded in the neurodiversity paradigm[6] and the principle of “Nothing About Us Without Us.”

Participants and recruitment

Throughout this paper, we distinguish between *community researchers* and *participatory researchers.* This distinction is important because the researchers with community-based knowledge led the process and held final decision-making abilities.

Community researchers were part of a Participatory Action Research (PAR) advisory group established for over four years by the lead researcher during earlier PhD work on autistic students’ mental health.[35,43] All members of the group are autistic, with experience as students or recent graduates. Members were originally recruited through university networks, autism groups, and advertisements. As part of this ongoing work, the PAR group had already reflected on their participatory approach and developed creative strategies to promote meaningful involvement. This foundation provided a strong basis for tool development.

Following the award of Spotlight funding, four autistic PAR group members were recruited as community researchers to lead development and refinement over a four-month period. To broaden perspectives, four additional mixed-neurotype participatory researchers were invited, including two established academics, a doctoral researcher, and a charity employee. They were known to the lead author through conferences, professional networks, and previous collaborations. Recruitment aimed to balance career stages and recognise power differences between early career and senior researchers.[44] All participants co-authored this article.

Development and refinement process

The lead author drafted initial tool versions, drawing on 30 years of participatory experience. These were shared with autistic community researchers, who led iterative refinement in partnership with the lead author. Feedback focused on clarity, accessibility, and relevance, ensuring the tools resonated with lived experience. The process is described as co-development rather than full co-production, as community researchers shaped but did not initiate the drafts and the lead author held overall responsibility. This may have created a power imbalance. Reflecting on sources of power, whether from positionality or structural roles, is essential for creating inclusive research environments.

Building relationships and reflexivity

Throughout the process, the lead researcher engaged in open discussions around her positionality. Her status as a mother of an autistic daughter and as an ADHD-er, positioned her as an "insider" within the neurodivergent community, conveying a common stigmatised identity that can build trust, deepen relationships, and minimise the risk of bias or inaccurate assumptions.[25,45] Over time, effort was made to build trust, respect, and open and clear communication, leading to positive relationships, which are critical in participatory research.[12,9] In his Double Empathy Problem theory, Milton[46] refers to the mutual misunderstanding that can occur between autistic and neurotypical people, suggesting that communication difficulties arise not from a deficit within autistic individuals but from differences in social experience and perspective on both sides. To avoid this, the lead researcher engaged in continuous self-reflection and evaluation, to ensure that autistic communication or actions were not misinterpreted, to identify weaknesses and improve engagement strategies.[47]

Accommodations and accessibility

In participatory research, it is essential to provide appropriate accommodations to enable full involvement.[38] Recognising the diversity of autistic strengths, challenges, and needs, the project prioritised "bending towards the [community researchers'] skill set"[16](p380) rather than expecting them to adapt to neurotypical norms.

The online platform Microsoft Teams was the most practical and accessible option for hosting meetings, allowing community researchers to manage their sensory environments. From the outset, individual adjustments were discussed and implemented, including allowing extra time for processing, enabling captions, and recording sessions. Community researchers could switch off cameras or microphones if preferred. Contributions could be made via chat during or after meetings, or by email, resisting the assumption that spoken word is the optimal mode of communication.[15]

All requested adjustments were accommodated, as the short project built on years of prior collaboration and mutual understanding within the group.

The community researcher role was carved and customised to fit individual skills and capacities, rather than requiring conformity to a traditional research assistant role.

Initial meetings discussed preferred roles, which included chairing meetings, participating in tool review discussions, and conducting a literature review. Flexibility was provided in terms of hours worked.

Community researchers had existing postgraduate research experience sono immediate training was required, but ongoing support was provided through regular meetings with the lead researcher. These sessions identified support needs, and provided additional information. For example, one community researcher who had taken a lead on research activities had to step down due to personal circumstances. Another member subsequently assumed the chairing role, supported by pre and debrief meetings with the lead researcher to discuss agendas and raise concerns. This flexibility ensured continuity of leadership and support.

As a mixed neurotype core team of ADHD and autistic researchers working collaboratively, we occasionally encountered challenges arising from our cognitive styles. For example, the lead author found it difficult to attend to and implement discussed changes to the tools due to attentional differences and challenges with organisational tasks. A reflective exercise with the core research team at the end of the wider PhD research project plans to explore how our mixed neurotypes influenced the research process and to identify strategies for supporting diverse ways of working in future collaborations.

Activities Undertaken

The development and refinement process included multiple structured activities:

Literature Review: A community researcher conducted a review to confirm alignment with relevant themes and to ensure the tools addressed barriers to participation.

Community Researcher Focus Groups: Two, one hour focus groups were held to review the tools. Discussions were recorded and transcribed, and suggested amendments were collated. The lead researcher implemented changes and returned updated drafts for feedback.

Participatory Researcher Meetings: Two, one hour meetings were held with the participatory researchers, led and chaired by community researchers. These were recorded, transcribed, and analysed for suggested amendments. The lead researcher incorporated changes based on these discussions.

Final Review: A concluding meeting was held with community researchers to discuss the changes suggested by participatory researchers and resolve outstanding issues.

Outcomes

Through the development and refinement process, the tools underwent significant transformation (Table 1 and 2), with changes shaped by autistic community and participatory researchers. Their leadership ensured that the final tools were not only theoretically grounded but practical, accessible, applicable across a wide range of research contexts and reflective of autistic priorities and lived experience.

Key modifications included broadening scope so that items applied beyond questionnaires or interviews, for example changing “disseminating questionnaires” to “promoting research” and “carrying out interviews/focus groups” to “collecting data.” Questions were also rephrased to acknowledge diverse methods such as clinical trials.

Addressing disagreements and power

With four autistic community researchers holding a majority status and decision-making power, the community researchers ensured that autistic voices were not overruled by neurotypical researchers which contributed to a power shift, disrupting “business as usual”.[5] Disagreements were openly discussed, with consensus reached collectively, with members discussing and debating issues and justifying their views. For example, a proposal to include an overall score on the ELPART was debated and replaced with stage-based scoring to avoid superficial assessments.

The lead researcher practised deliberate self-disempowerment by stepping back where appropriate, resisting tokenism, and prioritising autistic-led leadership.[5] For instance, she did not attend the first community meeting so members could freely critique draft tools, only joining later at their request.

Introducing the tools

The ELPART and PAR Group Checklist were designed to encourage more meaningful participatory research by providing structured frameworks that promote best practice and address power imbalances.[9,12,14]

PAR Group Checklist

The PAR Group Checklist (see Figure 1) sets out good practice for establishing and supporting a PAR group with autistic people. A three-point traffic light scale (green = yes, amber = partly, red = no) was chosen for simplicity and actionability.[49] Items are organised across four domains: establishing the group, creating accessible interactions, redressing power dynamics, and reflective practice. A notes column provides space for researchers to record further actions.

1: Establishing the PAR group

The first stage of the Checklist focuses on establishing the PAR group. Ideally, this should occur during the planning stages of the research process to ensure meaningful engagement[9,50] and early involvement which is crucial in defining research aims and objectives aligned to autistic priorities.

Recruitment should be targeted to ensure group members possess relevant expertise and lived experience aligned with the research focus.[12,13] For instance, in our research exploring autistic university student mental health, we recruited recent graduates or current students.[35] In circumstances where neurotypical input is also required, i.e. in comparison studies, ensuring autistic voices are not overruled by neurotypical researchers,[5] and that inclusive and equitable practices enable full participation, address power imbalances and integrate autistic and neurotypical perspectives is crucial. For example, providing clarity around the decision-making process from the outset and ensuring neurotypical researchers practice deliberate self-disempowerment to redress power dynamics.[5]

As we increasingly move towards autistic academic led research teams, in some cases exclusively made up of autistic people, it is important to acknowledge the power and privilege that autistic academics have compared to autistic people without research experience. Thom-Jones and Lowe highlight the importance of autistic researchers recognising their own limitations in terms of knowledge and experience.[23] Gaining the views and experiences of a wider and diverse group of autistic people is therefore important.

Research often focuses on “easily researchable” autistic individuals, who are verbally fluent, sit still, and have moderate support needs, while excluding others with higher support needs or varied communication styles.[51] Research also highlights the underrepresentation of marginalised groups, including LGBTQ+ individuals and people from ethnically minoritised backgrounds[14,41,52] Utilising methods that broaden representation and avoid exclusionary biases is therefore important,[51] along with ensuring researchers are representative of marginalised communities[53] and develop trusting relationships. Pickard et al. suggest partnering with relevant organisations, such as charities, supports inclusive recruitment efforts and ensures diverse autistic voices are heard.[12]

Prospective group members should receive clear information about the group aims and their role in the research project Autistic individuals should have autonomy over their level of engagement, with expectations made explicit from the outset. A lack of clarity in how autistic perspectives shape decision-making has previously resulted in exclusion and frustration.[31] Clarity is also needed around compensation and reimbursement. Transparency in accountability and decision-making is crucial to address historical power imbalances, particularly where autistic ways of knowing are resisted or marginalised by neurotypical individuals in influential roles.[5] This dynamic is illustrated in a first-person account by Michael (2021), who described how their contributions were acknowledged only when aligned with neurotypical perspectives, leading them to question the meaningfulness of future participatory research contributions.[54] Such lack of transparency is typical in participatory research[14] and undermines trust, leading to disengagement and dissatisfaction among group members.[13] Establishing clear expectations from the start can prevent these issues, even if involvement is restricted to specific aspects of the project.

Ethical principles should be agreed collaboratively ensuring that research aligns with the values and priorities of the autistic community. This includes researchers sharing their positionality, acknowledging their biases and the inherent power dynamics in the research process. In neuromixed research teams, valuing experiential, professional, and scientific forms of knowledge is essential, while recognising their relevance varies by context and that arguments should be judged on their merit rather than the source.[5] This transparency fosters more open and honest environments, allowing for authentic collaboration between autistic and neurotypical researchers.

The language used to describe autistic people remains a contested issue, often signalling power imbalances between researchers and the autistic community. Autistic individuals have historically been subjected to stigmatising, deficit-based language imposed by others.[16,33] In a review of articles in genetic and autism journals, Kaljusto et al. rated 80% of 116 articles as using stigmatising or probably stigmatising language.[10] Research shows many autistic individuals prefer identity-first language (e.g., "autistic person" rather than "person with autism").[55] However, perspectives on terminology vary, and no universally accepted definition of autism exists.[55] Group members should collectively establish preferred language guidelines to ensure research terminology aligns with community preferences.[13,41]

Strong relationships between researchers and community members are critical in participatory research.[9,12] These require time and effort to build, emphasising trust, mutual respect, and clear communication. Effective strategies for collaboration include: encouraging open dialogue and active listening, providing opportunities for feedback and addressing concerns constructively, recognising and celebrating contributions and engaging in reflective practice to continuously improve research processes.[13]

Honest communication is foundational to successful participatory research[56] and directly impacts relationships between researchers and group members.[57] To avoid the bi-directional misunderstandings between autistic and neurotypical people, as outlined in Milton's Double

Empathy Problem,[46] researchers must be mindful of their communication styles, ensuring they are clear, concise, and adaptable to group members' needs. They should respect the communication preferences of each group member and accommodate their needs/preferences throughout the research process.

2: Creating Accessible Interactions

The second stage of the checklist is about accessible interactions, which is key to promoting participation of autistic people in research.[14,35,38] However, in a small sample of 15 autistic people, den Houting et al. found reasonable adjustments in participatory research were reported by less than half of autistic participants.[9] Given the underrepresentation of non-speaking autistic individuals,[14] adopting appropriate methods supporting diverse participation needs is crucial. Considering the heterogeneous nature of the autistic community, research processes should be tailored to individual strengths, challenges, and preferences[16] Key considerations include: Flexible modes of engagement (e.g., online meetings, email contributions, chat-based discussions), providing accessible materials in advance (e.g., agendas, meeting notes) and adapting communication formats to suit individual needs (e.g., written over spoken interactions). For example, in our PhD research PAR group, meetings were held online, but some participants preferred to engage via email or contribute through chat. Preferences were continually reassessed throughout the research process to accommodate changing needs.

3: Redressing Power Imbalances

To ensure equitable participation, group members should have the opportunity to lead interactions (e.g., facilitating meetings, shaping discussions) where appropriate. This may require additional support where there are many differing members' needs to ensure implementation of reasonable adjustments. Flexible engagement, allowing participants to adjust their involvement (e.g., choosing to contribute via written feedback rather than in meetings, taking breaks during discussions, or stepping back from activities temporarily without justification). During interactions, the group should crucially feel they can speak up, are listened to and that interactions feel safe and mutually supportive.[35] Neurotypical researchers should critically reflect on the power they hold as academics and neurotypical researchers, the power they hold as individuals working alongside community members. Actively examining power dynamics and practising self-disempowerment are essential to equitable collaboration. As outlined above, everyone should be equally involved in decision making. Strategies such as ‘Fist to Five’[58] where community researchers show their level of agreement via a hand signal ranging from a fist (strong objection) to five fingers (enthusiastic support) can support this.[58]

Although compensation is a crucial factor in addressing power imbalances, 42% of den Houting et al’s small sample of 15 community partners in autism research report not receiving payment.[9] Compensation should be equivalent to researcher or research assistant pay where possible, reinforcing the value of autistic contributions. Building costs into grant applications ensures that payment is fair and equitable. However, institutional restrictions and regulations governing how participants are paid and the rates permitted may still present challenges. In our case, the PhD researcher sought additional funding to employ autistic research assistants, ensuring fair compensation.

Beyond financial remuneration, involvement in participatory research should provide tangible benefits, such as: capacity building, career development opportunities and co-authorship on publications, should community researchers want to be included.[13] It should also be respected that not all community members will want to be named as authors on publications and the difficult position that this can place on autistic people as outlined by Fletcher Watson.[59] While some autistic individuals may not have an interest in academic careers, their participation offers an opportunity to develop transferable skills.[13]

4: Ongoing Reflection and Evaluation

Participatory research should be viewed as an ongoing effort, rather than a fixed goal. As Milton et al. argue:

> “Striving for participation and co-production can never be perceived as a given or a fully accomplished outcome” (p. 87).[60]

The first item in this section relates to regular reflection and discussion of group members' suggestions. Both neurotypical and neurodivergent researchers should engage in continuous self-reflection to ensure they are not cherry picking the autistic contributions only aligned to their own[54] or misinterpreting autistic communication or actions.[46] Overcoming this challenge is essential to avoid epistemic injustices by asking how we can facilitate mutual understanding.[5] Self-reflection on positionality and continuous evaluation are essential for identifying weaknesses and improving engagement strategies.[47] Neurotypical researchers should be acutely aware of their neurotypical frame of analysis, a dominant norm in research. Researchers can use tools such as reflective journals to capture how autistic collaborators contributed to a project, what decisions they influenced, and how power was shared. The second item in this section relates to community members evaluating their participation to inform adjustments enhancing participatory experiences.[13] Building in regular feedback loops provides community members with opportunities to give feedback on inclusivity, barriers and enable team reflection.

By maintaining reflective, adaptable, and inclusive practices, the PAR Group Checklist ensures participatory autism research is meaningful, ethical, and impactful.

ELPART

The ELPART tool (see Figure 2) evaluates autistic participation across five stages of the research process: deciding the research topic, selecting methods and tools, conducting research, analysing findings and disseminating results.

Scale

Each research stage in ELPART is assessed using a five-point scale, allowing researchers to evaluate the extent of autistic involvement using the following criteria:

- 0 = No involvement
- 1 = Minimal involvement
- 2 = Equal involvement
- 3 = Mostly autistic-led
- 4 = Completely autistic-led

Community researchers recommended a five-point scale to better capture decision-making power, allowing for more nuanced responses than a binary (Yes/No), This is particularly helpful for the ELPART, where involvement exists on a continuum from consultation to co-production to leadership. Scores can be mapped to existing participation levels outlined by Tan et al.[8] (Table 3). However, community researchers chose the terminology in the scoring system above to promote accessibility and clarity, particularly given the varying definitions of co-production and participation[11,12] and often superficial understanding of participatory research among academics.[9]

An overall score was avoided to prevent reducing participation to a checklist exercise. Moreover, ELPART is intended to support reflection on participation, and a single overall score would undermine that focus.

Stage 1: Deciding the Research Topic

Autistic people should be involved as early as possible, ideally in deciding the research focus. This stage includes two evaluation criteria:

1. Whether the initial research idea aligns with autistic community priorities.
2. Whether autistic individuals are involved in applying for research funding.

This addresses a long-standing issue in autism research - the gap between research priorities identified by the autistic community and the research actually conducted.[12,26,29] As Thom-Jones & Lowe state;

> “research topics deemed worthy of investigation should and can only be identified by members of the autistic and autism communities” (p. 164-165).[23]

Autistic academics could be advantaged in providing their lived experience,[23] but for neurotypical researchers, gaps remain in involving autistic people in grant applications due to academic barriers.[14] For example, autistic contributors are often only compensated after a project is funded, meaning they are often invited to “endorse” pre-written proposals rather than being equitably involved in shaping proposals. To address this, researchers could engage with autistic communities through social media or look at previous community priority setting research (e.g., Roche et al.[61]). One author described using social media polls to determine autistic community research priorities, demonstrating a practical engagement strategy. To promote the inclusion of people without social media access, researchers could develop links with community organisations and autism advocacy groups.[23]

Stage 2: Selecting Research Methods and Tools

Involving autistic people in methodological decisions improves research quality and inclusivity.[14] Methods should promote empowerment and social justice rather than reinforce barriers.[62, 63]

At this stage, the ELPART emphasises the importance of grounding decisions in collaborative and inclusive practices. Co-defining research questions and aims ensures that the work reflects autistic priorities rather than being shaped solely by academic interests. Carefully considering data collection methods helps minimise barriers to participation, promoting a wider range of autistic voices. Ensuring that questions and instructions are clear and understandable enables participants to share their perspectives fully and confidently. Using language aligned to autistic community preferences helps build trust and avoid reinforcing stigma. Finally, inclusive sampling methods capture diverse autistic experiences, minimising narrow or stereotypical representations. Together, these practices demonstrate how open dialogue between autistic people and researchers can generate research strategies that are creative and genuinely co-produced.

Stages 3 & 4: Conducting and Analysing Research

These stages ensure research promotes inclusivity and that autistic insights shape data analysis. Evaluation criteria includes;

1. Promoting research (including recruiting participants).
2. Collecting data.

Including autistic people as collaborators during these stages ensures research reaches under-represented communities. Autistic involvement in data collection (e.g., conducting interviews), canincrease research relevance and impact and enhance validity by ensuring accurate interpretations of autistic communication styles.[64] For example, autistic participants in Pellicano's study reported it was easier to tell their story when interviewed by autistic researchers and reported feeling heard, understood and safe.[3] In some research contexts (such as wet labs or neuroscience studies), it may not be practical for community members to participate in data collection. However, involving them in the analysis phase ensures that interpretations are informed by lived experience. A collaborative, participatory approach to coding qualitative data can promote inclusion, lead to improved data analysis and positively impact future data collection.[65]

Stage 4 evaluation criteria includes;

1. Choosing method of analysis
2. Analysis of results
3. Implications/interpretations of results
4. Deciding how results are presented.

Within this stage, autistic strengths such as hyperfocus, creativity, and monotropic attention can be advantageous in research, particularly in data coding and analysis[66] and community members can advise on creative and accessible ways to present results.

Stage 5: Dissemination of Results

Aligning to Participatory Action Research principles, involving autistic individuals in dissemination maximises community impact and drives change.[20,35,43] The ELPART evaluates:

1. Deciding how to disseminate results.
2. Opportunity to present research findings in public forums.
3. Opportunity to co-author research articles.

Offering autistic co-authorship promotes equitable recognition and skill development, enhancing employability and ensuring autistic people directly benefit from research participation.[13] Findings should be disseminated in ways that minimise stigma and align with community priorities[13] and community researchers could have creative ideas about disseminating results in non-academic settings.

Discussion

The ELPART and PAR Group Checklist were co-developed with autistic community researchers and participatory experts to provide practical frameworks for implementing participatory approaches in research. Both tools prioritise accessibility, usability and reflection, enabling researchers to evaluate participation systematically and address the historical power imbalances shaping the field.[9,13]

These tools respond to consistent calls for clearer guidance in participatory autism research.[12, 14] Unlike broad models such as Arnstein's ladder[13] which conceptualise power but lack practical steps, the ELPART and PAR Group Checklist operationalise participatory principles into concrete, stage-specific actions.

The ELPART is the first known tool to systematically assess autistic involvement across all stages of the research process, using a five-point scale to capture the continuum from consultation to leadership. By explicitly reflecting on decision making power, it provides transparency and accountability, which may assist funders and institutions in evaluating participatory quality.

The PAR Group Checklist complements this by outlining best practice for establishing and supporting participatory groups, with a simple traffic-light rating system making it easy to identify gaps and implement changes. Its emphasis on reflective practice encourages researchers to view participation as ongoing rather than a one-off achievement.

Both tools should be applied at the outset of a project and revisited throughout to support ongoing reflection, rather than treated as a checklist completed at the project's end. The tools have the potential to strengthen participatory research by promoting autistic leadership, ensuring accessibility and embedding continuous reflection. Their adaptability means they can be applied across different methodologies and career stages, supporting researchers, including autistic-led teams, who are new to participatory work and experienced teams seeking greater accountability.

Limitations

Institutional change is needed alongside the ELPART and the PAR Group Checklist to address systemic barriers to participatory research such as limited time, resources and institutional structures that undervalue autistic involvement. [12,14] These tools can highlight gaps and prompt funders and universities to embed participatory standards, but cultural and attitudinal shifts remain essential.[56]

Not all projects will achieve full participation across all stages. Context, resources, and project scope shape what is possible, and even partial involvement can provide a starting point for reflection and deeper engagement in future work.[67] However, transparency about the extent and nature of autistic involvement is crucial[68] and these tools support researchers in assessing and reporting this.

The researchers co-developing these tools were primarily from Psychology and Education backgrounds, so requirements in other disciplines may differ. Community researchers were mostly white, female, and academically experienced, meaning that perspectives of autistic people from ethnically diverse groups, those with higher support needs, intellectual disabilities, or non-speaking individuals were underrepresented.

Next steps

Recent efforts to disseminate the tools, with community researchers and the lead researcher presenting the tools at paid guest lectures and at a webinar paid in vouchers. A website, hosting the tools, will be updated on an ongoing basis.

We acknowledge the tools as being at an early stage of development, with further community led validation needed. Rigorous external validation across diverse autistic communities (including non-speaking individuals and those with intellectual disabilities) and within diverse research contexts is needed to ensure these tools capture the full spectrum of autistic experiences.

Conclusion

This study addressed gaps in participatory autism research by developing and refining two tools: the ELPART and the PAR Group Checklist. Both were co-created with autistic researchers and participatory experts to provide structured, practical guidance for embedding autistic voices across all stages of research.

The tools aim to promote transparency, accountability, and equity, helping researchers reflect on their practices, avoid tokenism, and recognise autistic expertise as epistemically valid. By operationalising participatory principles, they move beyond broad frameworks to offer actionable steps that can be adapted across research contexts.

We hope these tools will support researchers at all career stages in centering autistic perspectives and advancing meaningful participatory research.

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Reference List

1. Le Cunff AL, Ellis Logan P, Martic BL, Mousset I, Sekibo J, Dommett E, Giampietro V. Co-Design for Participatory Neurodiversity Research: Collaborating with a Community Advisory Board to Design a Research Study. *J Particip Res Methods.* 2023;4(1). doi:10.35844/001c.66184

2. Fletcher-Watson S, Bölte S, Crompton CJ, Jones D, Lai MC, Mandy W, et al. Publishing standards for promoting excellence in autism research. *Autism.* 2021;25(6):1501-1504. doi: 10.1177/13623613211019830

3. Pellicano E, Lawson W, Hall G, Mahony J, Lilley R, Heyworth M, et al. “I knew she’d get it, and get me”: Participants’ perspectives of a participatory autism research project. *Autism Adulthood.* 2022;4(2):120-129. doi: 10.1089/aut.2021.0039

4. Williams GL, Ellis R, Holloway W, Caemawr S, Craine M, Williams K, Grant A. “Building our own house” as an insider-only Community-Partnered Participatory Research Council: Co-creating a safe space for Autistic knowledge production. *Autism.* 2024;29(9):2205-2215. doi:10.1177/13623613241253014

5. Désormeaux-Moreau M, Courcy I. Neuromixed Participatory Action Research: A Dialogical Method. In: Bertilsdotter Rosqvist H, Jackson-Perry D, eds. *The Palgrave Handbook of Research Methods and Ethics in Neurodiversity Studies.* Cham: Palgrave Macmillan; 2024:141-159. doi:10.1007/978-3-031-66127-3_9

6. Botha M, Cage E. “Autism research is in crisis”: A mixed method study of researchers’ constructions of autistic people and autism research. *Front Psychol.* 2022;13:7397. doi:10.3389/fpsyg.2022.1050897

7. Nind M. *What is Inclusive Research?* London: Bloomsbury Academic; 2014. doi: 10.5040/9781849668149

8. Tan DW, Crane L, Haar T, Heyworth M, Poulsen R, Pellicano E. Reporting community involvement in autism research: Findings from the journal *Autism. Autism.* 2024;29(2).

doi:10.1177/13623613241275263

9. den Houting J, Higgins J, Isaacs K, Mahony J, Pellicano E. “I’m not just a Guinea pig”: Academic and community perceptions of participatory autism research. *Autism.* 2021;25(1):148–163. doi:10.1177/1362361320951696

10. Kaljusto HK, Wilson E, Fletcher-Watson S. Do influential articles on the genetics of autism show evidence of engagement with the autistic community? *Am J Med Genet B Neuropsychiatr Genet.* 2025;e33030. doi: 10.1002/ajmg.b.33030

11. Masterson D, Areskoug Josefsson K, Robert G, Nylander E, Kjellström S. Mapping definitions of co-production and co-design in health and social care: A systematic scoping review providing lessons for the future. *Health Expect.* 2022;25(3):902-913. doi:10.1111/hex.13470

12. Pickard H, Pellicano E, den Houting J, Crane L. Participatory autism research: Early career and established researchers’ views and experiences. *Autism.* 2022;26(1):75-87. doi: 10.1177/13623613211019594

13. Nicolaidis C, Raymaker D, Kapp SK, Baggs A, Ashkenazy E, McDonald K, et al. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism.* 2019;23(8):2007–2019. doi:10.1177/1362361319830523

14. Fletcher-Watson S, Adams J, Brook K, Charman T, Crane L, Cusack J, et al. Making the future together: Shaping autism research through meaningful participation. *Autism.* 2019;23(4):943–953. doi:10.1177/1362361318786721

15. Bertilsdotter Rosqvist H, Jackson-Perry D, eds. *The Palgrave Handbook of Research Methods and Ethics in Neurodiversity Studies.* Cham: Palgrave Macmillan; 2024. doi:10.1007/978-3-031-66127-3

16. Rauchberg JS. Imagining a neuroqueer technoscience. *Stud Soc Justice.* 2022;16(2):370–388. doi:10.26522/ssj.v16i2.3415

17. Williams RM, Gilbert JE. Perseverations of the academy: A survey of wearable technologies applied to autism intervention. *Int J Hum Comput Stud.* 2020;143:102485. doi:10.1016/j.ijhcs.2020.102485

18. McDermott, C. (2022). Theorising the neurotypical gaze: Autistic love and relationships in The Bridge (Bron/Broen 2011–2018). Medical Humanities, 48(1), 51–62. doi.org/10.1136/medhum-2020-011906

19. Rose D. Participatory research: real or imagined. *Soc Psychiatry Psychiatr Epidemiol.* 2018;53(8):765–771. doi:10.1007/s00127-018-1549-3

20. May E. Critical pedagogy and disability in participatory research: A review. *Inf Learn Sci.* 2024;125(7–8):437–455. doi:10.1108/ILS-02-2023-0021

21. Milton DEM, Bracher M. Autistics speak but are they heard? *Med Sociol Online.* 2013;7(2):61–69.

22. Orsini M. Who needs to (un)know? On the generative possibilities of ignorance for autistic futures. *Int J Qual Stud Educ.* 2022;1–18.

23. Thom-Jones S, Lowe J. Innovative and neuroaffirming autistic approaches to autism research. In: Bertilsdotter Rosqvist H, Jackson-Perry D, eds. *The Palgrave Handbook of Research Methods and Ethics in Neurodiversity Studies.* Cham: Palgrave Macmillan; 2024:161–182. doi.org/10.1007/978-3-031-66127-3_10

24. Haar T, Brownlow C, Hall G, Heyworth M, Lawson W, Poulsen R, et al. “We have so much to offer”: Community members’ perspectives on autism research. *Autism.* 2025;29(9):2254–2267. doi: 10.1177/13623613241248713

25. Hume R. An inclusive methodology for research with multiply neurodivergent participants. In: The Palgrave Handbook of Research Methods and Ethics in Neurodiversity Studies.

Cham, Switzerland: Palgrave Macmillan; 2024:215-231.doi:10.1007/978-3-031-66127-3_13

26. Pellicano E, Dinsmore A, Charman T. Views on researcher-community engagement in autism research in the United Kingdom: a mixed-methods study. *PLoS One.* 2014;9(10):e109946. doi:10.1371/journal.pone.0109946

27. Masterson D, Areskoug Josefsson K, Robert G, Nylander E, Kjellström S. Mapping definitions of co-production and co-design in health and social care: a systematic scoping review providing lessons for the future. *Health Expect.* 2022;25(3):902-913. doi:10.1111/hex.13470

28. Tang ES, Griffiths A, Welch GF. The impact of three key paradigm shifts on disability, inclusion, and autism in higher education in England: an integrative review. *Trends High Educ.* 2024;3(1):122-141. doi:10.3390/higheredu3010007

29. den Houting J, Pellicano E. A portfolio analysis of autism research funding in Australia, 2008–2017. *J Autism Dev Disord.* 2019;49:4400-4408. doi:10.1007/s10803-019-04155-1

30. Pellicano L. A future made together: new directions in the ethics of autism research. *J Res*

31. *Spec Educ Needs.* 2014;14(3):200-204. doi:10.1111/1471-3802.12070_5

32. Jivraj J, Sacrey L, Newton A, Nicholas D, Zwaigenbaum L. Assessing the influence of researcher–partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: a scoping review. *Autism.* 2014;18(7):782–793. doi:10.1177/1362361314539858

33. Powell L. We’re not your empathy exercise: Reclaiming co-production in neurodivergent research and practice. *Neurodiversity.* 2025;3. doi:10.1177/27546330251363393

34. Bottema-Beutel K, Kapp SK, Sasson N, Gernsbacher MA, Natri H, Botha M. Anti-ableism and scientific accuracy in autism research: a false dichotomy. *Front Psychiatry.* 2023;14:1244451. doi:10.3389/fpsyt.2023.1244451

35. Rudd, D., & Hwang, S. K. (2021). Participatory research in a pandemic: The impact of COVID-19 on co-designing research with autistic people. *Qualitative Social Work*. doi:10.1177/14733250211040102

36. Horton E, Goldschmied AZ, Knops MJJ, Brownhill LA, Bycroft A, Lloyd A, et al. Empowering voices: fostering reflective dialogue and redefining research dynamics in participatory approaches with the autistic community. *J Particip Res Methods.* 2024;5. doi:10.35844/001c.122455

37. Arnstein SR. A ladder of citizen participation. *J Am Inst Planners.* 1969;35(4):216–224. doi:10.1080/01944366908977225

38. Cornwall, A. (2008). "Unpacking ‘Participation’: Models, meanings, and practices." *Community Development Journal*, 43(3), 269-283. doi:10.1093/cdj/bsn010

39. Schwartz AE, Kramer JM, Cohn ES, McDonald KE. “That felt like real engagement”: fostering and maintaining inclusive research collaborations with individuals with intellectual disability. *Qual Health Res.* 2020;30(2):236-249. doi:10.1177/1049732319869620

40. Staniszewska S, Brett J, Simera I, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ.* 2017;358:j3453. doi:10.1136/bmj.j3453

41. Gowen E, Taylor R, Bleazard T, Greenstein A, Baimbridge P, Poole D. Guidelines for conducting research with the autism community. *Autism Policy Pract.* 2019;2(1):29-45.

42. Dark J. Eight principles of neuro-inclusion: an autistic perspective on innovating inclusive research methods. *Front Psychol.* 2024;15:1326536. doi:10.3389/fpsyg.2024.1326536

43. Cooperative Research Centre for Living with Autism. Inclusive research practice guides and checklists for autism research. Version 2. Brisbane, Queensland: Autism CRC Ltd; 2016.

44. Horton E, Brownhill L, Bycroft A, Goldschmied AZ, Knops MJ, Lloyd A, et al. In our own words: using participatory dialogue to reflect on the mental health experiences of autistic students in university. *Neurodiversity.* 2025;3. doi:10.1177/27546330241310372

45. Muhammad M, Wallerstein N, Sussman AL, Avila M, Belone L, Duran B. Reflections on researcher identity and power: the impact of positionality on community-based participatory research (CBPR) processes and outcomes. *Crit Sociol.* 2015;41(7-8):1045-1063. doi:10.1177/0896920513516025

46. Raymaker DM, McDonald KE, Ashkenazy E, Gerrity M, Baggs AM, Kripke C, et al. Barriers to healthcare: instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism.* 2017;21(8):972-984. doi:10.1177/1362361316661261

47. Milton DEM. On the ontological status of autism: The “double empathy problem.” *Disabil Soc.* 2012;27(6):883–887. doi:10.1080/09687599.2012.710008

48. Kindon S, Pain R, Kesby M. *Participatory Action Research Approaches and Methods: Connecting People, Participation and Place.* London: Routledge; 2007. doi:10.4324/9780203933671

49. Graff RB. Job carving. In: Volkmar FR, ed. *Encyclopedia of Autism Spectrum Disorders.* Cham: Springer International Publishing; 2021:2590–2591. doi:10.1007/978-3-319-91280-6_183

50. DeVon HA, Block ME, Moyle-Wright P, Ernst DM, Hayden SJ, Lazzara DJ, et al. Psychometric toolbox for testing validity and reliability. *J Nurs Scholarsh.* 2007;39(2):155–164. doi:10.1111/j.1547-5069.2007.00161.x

51. Garfield T, Yudell M. Participatory justice and ethics in autism research. *J Empir Res Hum Res Ethics.* 2019;14(5):455–457. doi:10.1177/1556264619858524

52. Srinivasan H. Who autism research leaves out. *Time.* July 31, 2023. https://time.com/6299599/autism-research-limited-essay/

53. NHS England. *Autism: A National Strategy 2021 to 2026.* NHS England; 2023.

54. Sierra-Mercado D, Lázaro-Muñoz G. Enhance diversity among researchers to promote participant trust in precision medicine research. *Am J Bioeth.* 2018;18(4):44–46. doi:10.1080/15265161.2018.1431323

55. Michael C. Is being othered a co-occurring condition of autism? *Autism in Adulthood: Challenges and Management.* 2021;3(2):118. doi:10.1089/aut.2021.0019

56. Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism.* 2016;20(4):442–462. doi:10.1177/1362361315588200

57. Redman S, Greenhalgh T, Adedokun L, Staniszewska S, Denegri S, Co-production of Knowledge Collection Steering Committee. Co-production of knowledge: the future. *BMJ.* 2021;372:n434. doi:10.1136/bmj.n434

58. Hollin G, Pearce W. Autism scientists' reflections on the opportunities and challenges of public engagement: A qualitative analysis. *J Autism Dev Disord.* 2019;49(3):809–818. doi:10.1007/s10803-018-3783-7

59. International Association of Facilitators. Method of the Month: Fist to Five. IAF. Published July 31, 2016. https://www.iaf-world.org/site/es/articles/2016-07-31/method-month-fist-five

60. Fletcher-Watson S. Reporting participatory methods and author positionality in autism. *Autism.* 2024;28(8):1869-1871. doi:10.1177/13623613241266950

61. Milton DEM, Ridout S, Kourti M, Loomes G, Martin N. A critical reflection on the development of the Participatory Autism Research Collective (PARC). *Tizard Learn*

Disabil Rev. 2019;24(2):82–89. doi:10.1108/TLDR-09-2018-0029

62. Roche L, Adams D, Clark M. Research priorities of the autism community: A systematic review of key stakeholder perspectives. *Autism.* 2021;25(2):336-348. doi:10.1177/1362361320967790

63. Rappaport J. Research methods and the empowerment social agenda. In: Tolan P, Keys C, Chertok F, Jason LA, eds. *Researching Community Psychology: Issues of Theory and Methods.* Washington, DC: American Psychological Association; 1990:51–63. doi:10.1037/10073-005

64. Foster-Fishman P, Nowell B, Deacon Z, Nievar MA, McCann P. Using methods that matter: The impact of reflection, dialogue, and voice. *American Journal of Community Psychology.* 2005;36:275-291. doi:10.1007/s10464-005-8626-y

65. Kaplan-Kahn EA, Caplan R. Combating stigma in autism research through centering autistic voices: a co-interview guide for qualitative research. *Front Psychiatry.* 2023;14:1248247. doi:10.3389/fpsyt.2023.1248247

66. Zreik T, El Masri R, Chaar S, Ali R, Meksassi B, Elias J, Lokot M. Collaborative coding in multi-national teams: benefits, challenges and experiences promoting equitable research. *Int J Qual Methods.* 2022;21. doi:10.1177/16094069221139474

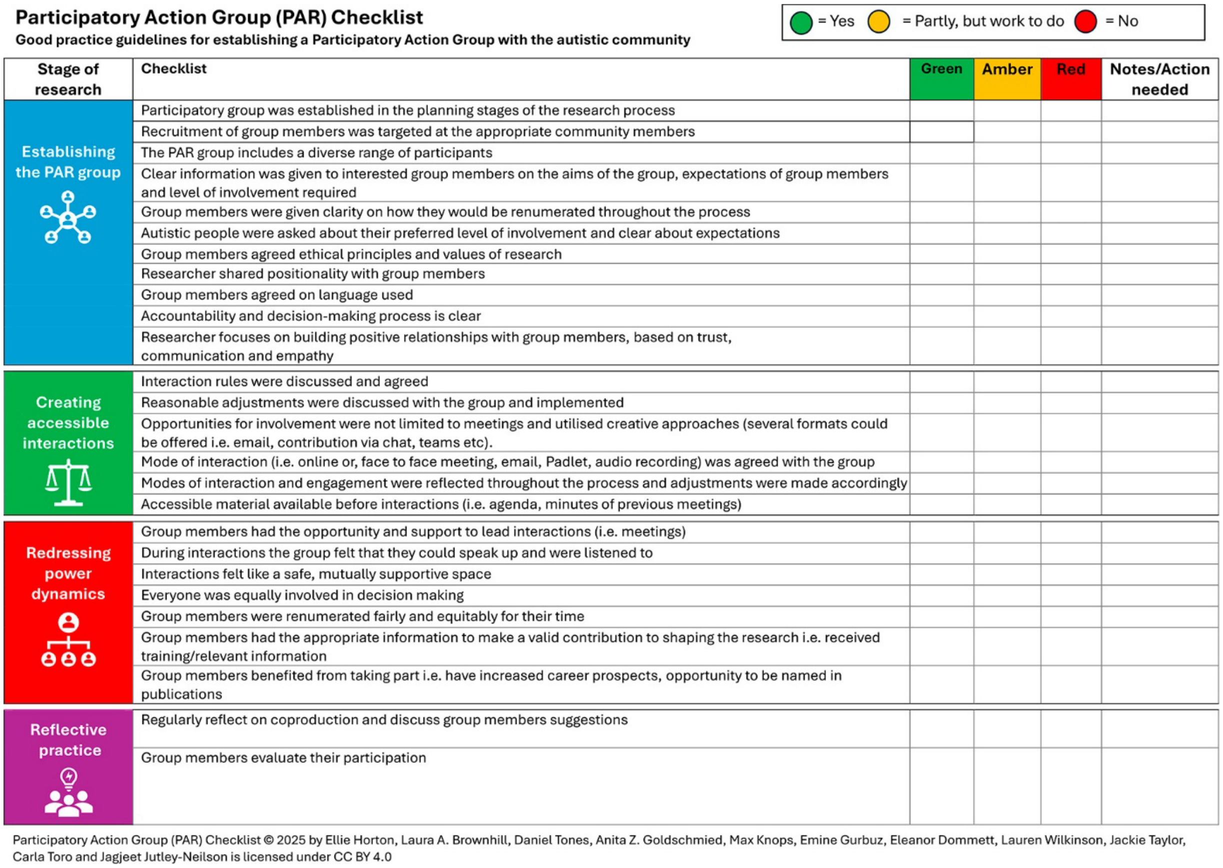
67. Grant A, Kara H. Considering the autistic advantage in qualitative research: the strengths of autistic researchers. *Contemp Soc Sci.* 2021;16(5):589–603. doi:10.1080/21582041.2021.1998589

68. Bellingham B, Elder E, Foxlewin B, Gale N, Rose G, Sam K, et al. ‘Co-design Kickstarter’: Community mental health drug and alcohol research network. *Community Mental Health Drug Alcohol Res Netw.* 2023. Available at: https://cmhdaresearchnetwork.com.au/resource/co-design-kickstarter/

69. Jackson-Perry D, Bertilsdotter Rosqvist H. An introduction to research methods and ethics in neurodiversity studies. In: Bertilsdotter Rosqvist H, Jackson-Perry D, eds. *The*

Palgrave Handbook of Research Methods and Ethics in Neurodiversity Studies. Cham: Palgrave Macmillan; 2024:3–23. doi:10.1007/978-3-031-66127-3_1

Figures



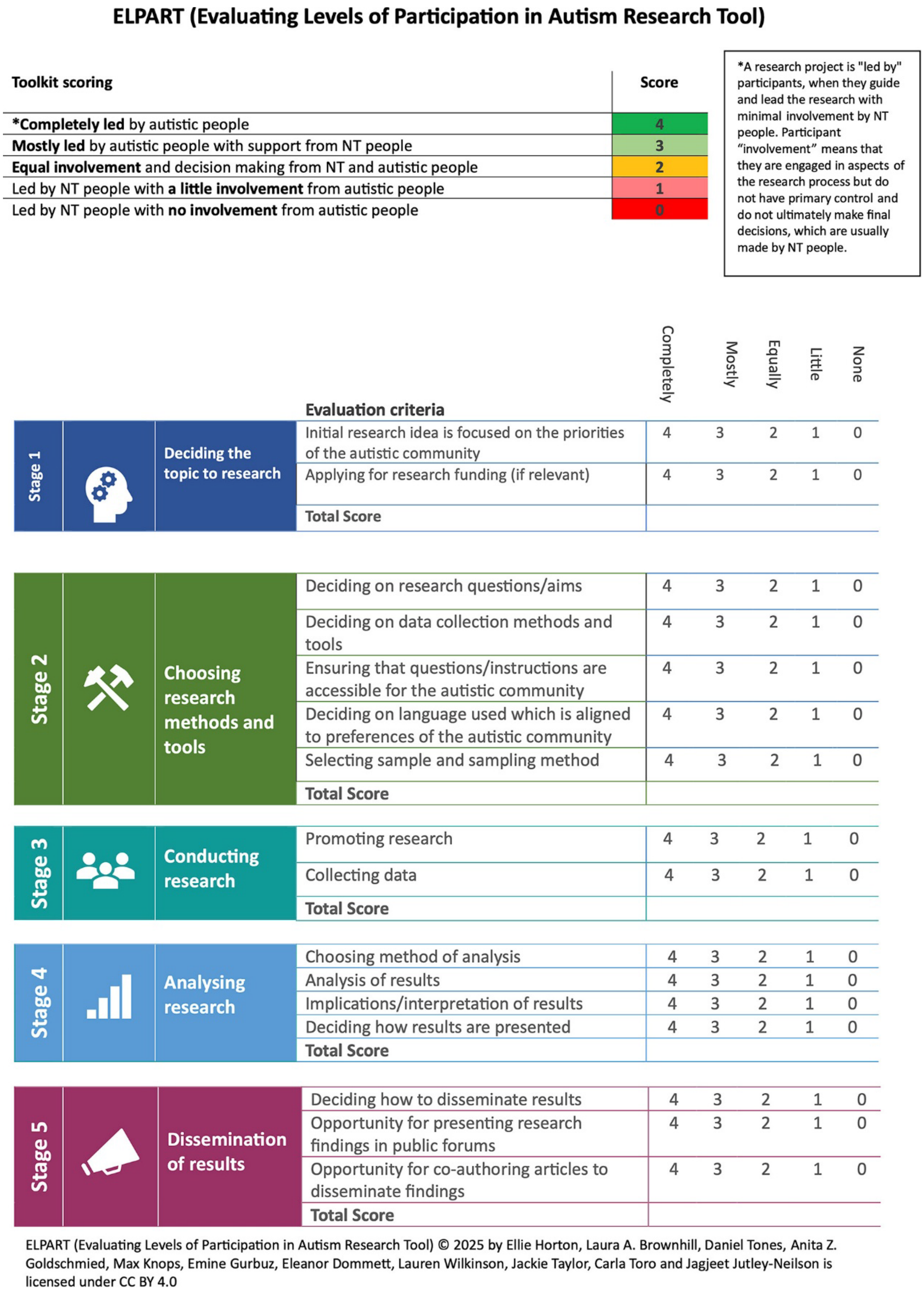
Participatory Action Group (PAR) Checklist

Good practice guidelines for establishing a Participatory Action Group with the autistic community

🟢 = Yes 🟡 = Partly, but work to do 🔴 = No

Stage of research	Checklist	Green	Amber	Red	Notes/Action needed
Establishing the PAR group	Participatory group was established in the planning stages of the research process				
	Recruitment of group members was targeted at the appropriate community members				
	The PAR group includes a diverse range of participants				
	Clear information was given to interested group members on the aims of the group, expectations of group members and level of involvement required				
	Group members were given clarity on how they would be renumerated throughout the process				
	Autistic people were asked about their preferred level of involvement and clear about expectations				
	Group members agreed ethical principles and values of research				
	Researcher shared positionality with group members				
	Group members agreed on language used				
	Accountability and decision-making process is clear				
	Researcher focuses on building positive relationships with group members, based on trust, communication and empathy				
Creating accessible interactions	Interaction rules were discussed and agreed				
	Reasonable adjustments were discussed with the group and implemented				
	Opportunities for involvement were not limited to meetings and utilised creative approaches (several formats could be offered i.e. email, contribution via chat, teams etc).				
	Mode of interaction (i.e. online or, face to face meeting, email, Padlet, audio recording) was agreed with the group				
	Modes of interaction and engagement were reflected throughout the process and adjustments were made accordingly				
	Accessible material available before interactions (i.e. agenda, minutes of previous meetings)				
Redressing power dynamics	Group members had the opportunity and support to lead interactions (i.e. meetings)				
	During interactions the group felt that they could speak up and were listened to				
	Interactions felt like a safe, mutually supportive space				
	Everyone was equally involved in decision making				
	Group members were renumerated fairly and equitably for their time				
	Group members had the appropriate information to make a valid contribution to shaping the research i.e. received training/relevant information				
	Group members benefited from taking part i.e. have increased career prospects, opportunity to be named in publications				
Reflective practice	Regularly reflect on coproduction and discuss group members suggestions				
	Group members evaluate their participation				

FIG. 1. The PAR Group Checklist. A guide for developing and sustaining Participatory Action Research groups, structured around four domains: establishing the group, creating accessible interactions, and redressing power dynamics and reflective practice. PAR, participatory action research.



ELPART (Evaluating Levels of Participation in Autism Research Tool)

Toolkit scoring	Score
***Completely led** by autistic people	4
Mostly led by autistic people with support from NT people	3
Equal involvement and decision making from NT and autistic people	2
Led by NT people with **a little involvement** from autistic people	1
Led by NT people with **no involvement** from autistic people	0

*A research project is "led by" participants, when they guide and lead the research with minimal involvement by NT people. Participant "involvement" means that they are engaged in aspects of the research process but do not have primary control and do not ultimately make final decisions, which are usually made by NT people.

Stage		Evaluation criteria	Completely	Mostly	Equally	Little	None
Stage 1	**Deciding the topic to research**	Initial research idea is focused on the priorities of the autistic community	4	3	2	1	0
		Applying for research funding (if relevant)	4	3	2	1	0
		Total Score					
Stage 2	**Choosing research methods and tools**	Deciding on research questions/aims	4	3	2	1	0
		Deciding on data collection methods and tools	4	3	2	1	0
		Ensuring that questions/instructions are accessible for the autistic community	4	3	2	1	0
		Deciding on language used which is aligned to preferences of the autistic community	4	3	2	1	0
		Selecting sample and sampling method	4	3	2	1	0
		Total Score					
Stage 3	**Conducting research**	Promoting research	4	3	2	1	0
		Collecting data	4	3	2	1	0
		Total Score					
Stage 4	**Analysing research**	Choosing method of analysis	4	3	2	1	0
		Analysis of results	4	3	2	1	0
		Implications/interpretation of results	4	3	2	1	0
		Deciding how results are presented	4	3	2	1	0
		Total Score					
Stage 5	**Dissemination of results**	Deciding how to disseminate results	4	3	2	1	0
		Opportunity for presenting research findings in public forums	4	3	2	1	0
		Opportunity for co-authoring articles to disseminate findings	4	3	2	1	0
		Total Score					

FIG. 2. The ELPART Framework. A process-based tool for assessing autistic involvement in research, spanning five stages from topic selection to dissemination. ELPART, Evaluating Levels of Participation in Autism Research Tool.

Tables

Table 1 – Development and refinement activity – PAR Group Checklist

Stage	**Actions**
General	
Important for tool to be applicable and relevant in a wide range of interactions rather than being restricted to meetings to promote inclusivity and ensure that members could participate according to their preferences.	Amended wording throughout from ‘meetings’ to ‘mode of interactions’.
Establishing the PAR group	
Item ‘Participatory group was established early in the research process’ could create confusion around what ‘early in the process’ means and to promote good practice in establishing the PAR group in the planning stages.	Amended wording to 'Participatory group was established in the planning stages of the research process’.
Importance of transparency and clarity around members' responsibilities and expectations.	Added item ‘Autistic people were asked about their preferred level of involvement and clear about expectations’.
Importance of agreeing on language used to describe autism.	Added item ‘Group members agreed on language used’.
Importance of transparency around the decision making process and accountability when establishing the group.	Added item ‘Accountability and decision making process is clear’.
Creating accessible interactions	
Important to reflect on inclusion throughout the research process in order to meet any changing needs.	Added item ‘Modes of interaction and engagement were reflected throughout the

	process and adjustments were made accordingly’.
Redressing power dynamics	
Item ‘Group members were paid for their time’. This is an important issue to redress power dynamics. Community members considered how they were paid to be an individual choice and outlined the need for flexibility. Ideally we need to pay people and ensure fair remuneration but also offer a range of options. The researchers discussed how this is often difficult due to bureaucracy in university and wider settings. We agreed that we should be explicit about how group members are remunerated from the start and where possible, ask for their preferences.	Amended wording to ‘Group members were remunerated fairly and equitably for their time’ with further guidance in accompanying materials.
Need to add examples for item ‘Group members had the appropriate information to make a valid contribution to shaping the research’.	Added example ‘i.e. received training/relevant information’.
Need to add an example for the item ‘Group members benefited from taking part’. Additionally, some members may not want to be named in publications.	Amended wording and added example to ‘Group members benefited from taking part i.e. have increased career prospects, opportunity to be named in publications’.
Important to reflect on decision making.	Added item ‘Everyone was equally involved in decision making’. We discussed adding good practice examples to the accompanying guidance.

Table 2. Development and refinement activity – ELPART

Stage	**Actions**
Scoring key Need for clarity around what is meant by 'led by' or 'involvement'.	Footnote with explanation was added.
Scoring key Terminology used in scoring key described autistic community members as 'researchers'. PAR group members should be considered researchers but researchers may also be neurodivergent, where do they fit in? Also, tool may be used within non academic settings such as in the voluntary sector, where they may not view themselves as traditional researchers so some flexibility is needed.	Amended wording from 'researcher' to 'people'.
Stage 1 (Deciding the Research Topic) Separate items 'Proposing initial research idea' and 'focused on the priorities of the autistic community' when they could be combined.	Items amalgamated into 'Initial research idea is focused on the priorities of the autistic community'
Stage 1 (Deciding the Research Topic) and 2 (Selecting Research Methods and Tools) Item 'Developing initial research idea' was duplicated across stage 1 and 2.	Amended wording in stage 1 to 'Initial research idea is focused on the priorities of the autistic community' and amended

	wording in stage 2 to ‘Deciding on research questions and aims’.
Stage 4 (Analysing Research) Autistic people should be involved in interpreting results and deciding how they are presented.	Added items ‘Implications/interpretations of results’ and ‘Deciding how results are presented’.

Table 3 - Mapping ELPART to Tan et al[8] participation levels.

Scoring	**ELPART**	**Tan et al.[8]**
0	Led by NT people with no involvement from autistic people	Informing
1	Led by NT people with a little involvement from autistic people	Consultation or engagement
2	Equal involvement and decision making from NT and autistic people	Co-production
3	Mostly led by autistic people with support from NT people	Community-led
4	Completely led by autistic people	Community-controlled