

“I’m not just a guinea pig”: Academic and community perceptions of participatory autism research

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Abstract

Despite calls for increased community engagement in autism research, the published evidence base suggests that participatory autism research remains rare. This study examined the extent and nature of community engagement in Australian research projects commissioned by the Autism CRC. Data were gathered using an online survey, comprising quantitative scale items and qualitative free-text responses, which was completed by 64 academic partners and 15 community partners. Quantitative findings indicated that autism research stakeholders in Australia are largely supportive of community engagement in research, and have had positive experiences of participatory research. These findings were not wholly corroborated by the qualitative findings, however, which suggested that participants lacked understanding of participatory research, and held attitudes that may hinder the conduct of successful participatory research. Systemic issues within research settings were also perceived to impede community engagement in research. Both academic and community partners would benefit from better understanding of participatory research approaches, paired with practical and epistemological shifts at the systemic level, to ensure that future community engagement in autism research is respectful, equitable, and beneficial to all stakeholders.

Keywords

Autism, participatory research, community engagement, co-production, patient and public involvement, stakeholders

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The importance of community engagement in research and practice has been recognised by scholars for at least half a century (Arnstein, 1969). With highly-respected academic publications, such as *The British Medical Journal*, advocating for greater community engagement in research and practice (Richards, Montori, Godlee, Lapsley, & Paul, 2013), participatory approaches have become increasingly common over the past two to three decades, particularly in health research and research with minority communities (Macaulay, 2017). As participatory approaches gain broader acceptance as effective and inclusive methods for conducting research, it is timely to examine whether, and how, community engagement has been employed in autism research.

Participatory research is an umbrella term that refers collectively to the many different research methods and methodologies that employ inclusive and community-engaged practices (Cargo & Mercer, 2008). In general, participatory research involves academic partners (research professionals and/or research students) working together with community partners (including, for example, autistic people; their families and supporters; service providers; and other stakeholders), with community partners actively contributing to a project at any - ideally, all – stage/s of the research process. Historically, community engagement in research has been depicted as existing in a hierarchy (see Figure 1; although see Tritter & McCallum, 2006, for critique). This hierarchy spans from (at the lowest levels) no community participation in research through to (at the highest levels) community-led research (Arnstein, 1969).

[insert Figure 1 about here]

Power dynamics are key in participatory research (Cornwall & Jewkes, 1995). In non-participatory research, it is typical for academics to hold power and control over all decision-making throughout the research process, with community members contributing only by providing data as participants. In contrast, in participatory research, the power is shared between academic and community partners to varying degrees. At lower levels of participation (see Figure 1), community partners may provide feedback or consultation that influences decision-making, with academics retaining final decision-making power. At higher levels of participation, academic and community partners work in collaboration, sharing power equally and making decisions jointly. At the highest levels of participation, community partners assume control of the research process, and academic partners provide consultation and guidance only (Cargo & Mercer, 2008; Ocloo & Matthews, 2016).

One of the factors most strongly associated with the success of participatory research is the quality of relationships between partners (Jagosh et al., 2015; Khodyakov et al., 2011). Within these relationships, which are developed over time and often with considerable effort, different partners will play different roles and contribute different expertise. The purpose of participatory research is not to integrate academic partners into the target community, or to train community partners in research (although these outcomes do sometimes occur), but to bring together the respective expertise of academic and community partners to produce research that is scientifically sound, while also relevant and beneficial to the target community (Cargo & Mercer, 2008).

Despite calls from autistic academics for increased community participation in autism research (Chown et al., 2017; den Houting, 2019; Milton, Mills, & Pellicano, 2014), the relevant evidence base is minimal to date (Jivraj, Sacrey, Newton, Nicholas, & Zwaigenbaum, 2014). Consistent with broader neurodivergent community involvement in research, attempts to implement stakeholder engagement in autism research most frequently

involve community stakeholders in consultative or advisory roles (Au-Yeung et al., 2019; Cassidy, Bradley, Shaw, & Baron-Cohen, 2018; Jivraj et al., 2014). Equitable approaches to research co-production remain rare within autism research, although examples do exist (Fletcher-Watson et al., 2018; Kourti & MacLeod, 2019; Pellicano et al., 2020). Worth noting is the Academic Autism Spectrum Partnership in Research and Education (AASPIRE), a collaborative research team that brings together people from the academic community, the autistic community, and the broader stakeholder community to conduct Community-Based Participatory Research (CBPR) projects designed to benefit autistic people (e.g., Nicolaidis & Raymaker, 2015; Nicolaidis et al., 2011; Nicolaidis et al., 2012). The AASPIRE team recently published their practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants (Nicolaidis et al., 2019).

Most frequently, published papers in the autism research literature do not mention community engagement in the research process (Jivraj et al., 2014). This suggests that one of two things is true: there was no community engagement during the process of these research projects; or, there was community engagement but authors did not mention this in publication/s. Both alternatives imply that academic stakeholders do not often value community input into the conduct of autism research. In addition, Hollin and Pearce (2019) recently found that autism scientists perceived engagement with autistic stakeholders as difficult, and largely interpreted autistic community partners as causing this difficulty.

There are some potential challenges associated with the conduct of participatory research, including the need to achieve a balance of scientific rigour and community acceptability; the additional complexity of managing interpersonal relationships and power dynamics across stakeholder groups; and greater financial and opportunity costs compared to non-participatory research (Blackburn et al., 2018; Brett et al., 2014). Nonetheless, available evidence suggests that the benefits of community involvement in health and social care research outweigh these

challenges, producing research outcomes that are more rigorous, more feasible, and more relevant and acceptable to the target community (Brett et al., 2014; Forsythe et al., 2019). Community engagement should, therefore, be considered especially important in the case of autism research, as reports have consistently demonstrated the mismatch between the landscape of autism research funding – which focuses predominantly on the causes and underlying biology of autism – and the stated priorities of community members (Autistica, 2016; den Houting & Pellicano, 2019; Frazier et al., 2018; Office of Autism Research Coordination, 2019; Pellicano, Dinsmore, & Charman, 2014). Pellicano, Dinsmore, and Charman (2013) put forward three recommendations for future autism research that may be useful in addressing this mismatch: 1) research funding must be distributed more evenly, with more funds invested in under-researched areas; 2) strategic partnerships must be developed between relevant stakeholder groups; and 3) there must be greater engagement between academic and community stakeholders throughout the research process.

In 2013, the Cooperative Research Centre for Living with Autism (Autism CRC) was established, under the Australian Government's Cooperative Research Centres (CRC) Program, as the world's first national, cooperative research effort focused on autism. The CRC Program is an initiative designed to support collaboration between industry, researchers, and the community, with each CRC established in order to address a specified industry challenge (Australian Government, 2019). Autism CRC comprises a collaborative team of more than 50 participant organisations, including universities, autism service providers, autistic and other advocacy organisations, industry entities, and government departments. Autism CRC invests in research projects spanning three key programs of research: 1) 'Early Years', with a focus on earlier and more accurate assessment and diagnosis; 2) 'School Years', aiming to optimise educational experiences and outcomes for autistic students; and 3) 'Adulthood', aiming to enhance opportunities and improve wellbeing for autistic adults.

Autism CRC state that they are “committed to inclusive research practices and co-production of outcomes with those on the spectrum, their families and supporters... to ensure our research provides practical and tangible outputs that benefit the community” (Cooperative Research Centre for Living with Autism, 2018, p. 2). Autism CRC investment in research appears to have contributed to a shift in the landscape of autism research funding in Australia, with funds distributed more evenly across topic areas since Autism CRC was founded (den Houting & Pellicano, 2019).

Since its establishment, Autism CRC has launched various initiatives to promote participatory autism research, with a specific focus on research partnerships or ‘co-production’. These initiatives include a research training program aimed at upskilling autistic adults to act as peer researchers (Autism CRC, 2020b); recognition of participant organisations with a sustainable commitment to research co-production as Research Co-Production Partners (Autism CRC, 2020a); and the publication of an Inclusive Research Practice Guide (Autism CRC, 2016). The Autism CRC encourages researchers to include strategies for meaningful community engagement in investment proposals, and the level of community engagement is taken into consideration in investment decisions.

To date, it remains unclear whether Autism CRC’s initiatives have been successful in facilitating participatory autism research and fostering effective co-production relationships between academic and community partners. In this study, we examined the extent and nature of community partner engagement in research projects commissioned by Autism CRC. In so doing, we investigated (1) when, how, and how often community partners were involved in Autism CRC research projects, and (2) how academic and community partners perceived such engagement.

Method

Ethics

This study received ethical approval from the [blinded for review] University Human Research Ethics Committee (Project ID 3300). All participants provided informed consent within the online questionnaire.

Recruitment

Recruitment for this study was initiated by Autism CRC, who contacted all Autism CRC Project Leaders (N=31) with a request to nominate the current and previous members of their project team/s (including all academic and community partners) for participation in this study. This recruitment approach is common in studies evaluating community engagement in research (Jagosh et al., 2015; Oetzel, Villegas, et al., 2015; Oetzel, Zhou, et al., 2015; Spears Johnson, Kraemer Diaz, & Arcury, 2016). Nominations could be provided by completing a brief Qualtrics survey, or directly emailing the first author of this paper. Twenty-one (68%) Autism CRC Project Leaders responded to this request, providing names and email addresses for 127 project team members as potential participants. We then sent all Project Leaders and nominated project team members a link to the study's anonymous online questionnaire. Participants who were affiliated with more than one Autism CRC research project (n=48) were randomly assigned one specific research project to consider when responding.

Participants

Ninety-five participants accessed the anonymous online questionnaire. Of these 95 participants, 16 (17%) were excluded from analyses for failing to provide responses to any items (n=6) or responding only to consent items and/or demographic items (n=10). This resulted in a final sample of 79 participants, of whom 61 (77%) completed all survey items. The recruitment and participation process is outlined in Figure 2.

[Insert Figure 2 about here]

Participants ranged from 21 to 71 years of age ($M=44.30$, $SD=14.00$), and were predominantly women ($n=62$, 78%). Almost all participants had completed university qualifications ($n=73$, 92%). Specific data on race/ethnicity were not recorded. Demographic data are shown in Table 1.

[Insert Table 1 about here]

All participants were associated with Autism CRC as either current or previous Project Leaders and/or project team members. For the purpose of this project, all participants were asked to classify themselves as either an academic partner (defined as researchers, including research students; $n=64$, 81%) or a community partner (defined as all other autism community stakeholders, including autistic people, their families/carers, and service providers; $n=15$, 19%). Eleven (14%) participants self-reported being autistic, of whom seven identified as community partners and four identified as academic partners. The remaining eight participants who identified themselves as community partners included family members/carers of autistic people, researchers, service providers, and other community stakeholders.

Measures

Data were gathered using two online questionnaires – one for academic partners and one for community partners (see Supplementary materials) – that were identical in terms of content, with minor wording changes to some items for clarity. Each participant completed only one of the two questionnaires, hosted through the Qualtrics platform.

The online questionnaires included a combination of items created specifically for this study (*bespoke items*), and items adapted from a survey designed by Oetzel, Zhou, et al. (2015), which was later used by the same authors to test Wallerstein et al.'s (2008) CBPR Conceptual Model (Oetzel et al., 2018). The questionnaires began with bespoke items measuring

participants' attitudes towards participatory autism research, and their perceptions of the level of community engagement in Autism CRC research. These questions were rated on five-point scales, for consistency with later items.

Following Oetzel et al. (2018), our survey included an adapted version of the Community Engagement in Research Index (CERI, Khodyakov et al., 2013), a 12-item scale that measures the level of community engagement across different phases of a research project. The original version of the CERI is rated on a three-point scale, however Khodyakov et al. noted that this scale may not have adequately captured the variability in levels of participation, and recommended that the measure be rated on a five- or seven-point scale in future. We therefore adopted a five-point rating scale (*no engagement* [1] to *extensive engagement* [5]) for the CERI in this study.

Next, participants responded to a series of bespoke items assessing adjustments made to their research project to accommodate community partners' needs, as well as any compensation community partners received for their contributions to the project. Participants were presented with a list of potential forms of compensation that community partners may have received, and were asked to endorse all that applied to their project.

Our survey also included Oetzel, Zhou et al.'s (2015) questions on partnership structural values (i.e., the extent to which academic and community partners have shared experiences and values; 11 items), relationships between partners (i.e., how well different partners work together; 26 items), and partnership synergy (i.e., how partners' skills and knowledge strengthen the group's work; five items), with wording modified slightly to ensure applicability to the autism community. Items were rated on five-point scales with anchors adapted to suit individual items, for example *not at all* (1) to *a great deal* (5). Lastly, our survey included bespoke items assessing the level and type of impact that community

engagement had on project processes and project outcomes. These items were also rated on five-point scales with anchors adapted to suit individual items, for example *very negative* (1) to *very positive* (5). The majority of quantitative items in the questionnaire also included “I don’t know” and “Not applicable” as response options.

In addition, we asked participants to provide free-text responses detailing their understanding of the phrase “participatory research”, any benefits or challenges they had encountered in previous experiences of participatory research, and their suggestions for improving community engagement in research.

Data analyses

Quantitative data from the scale questions were analysed through descriptive statistics, using IBM SPSS Statistics Version 25. Inferential statistics are not reported due to (i) the small cohort of community partners ($n < 10$ for many items) and uneven sampling distribution, and (ii) the diversity of roles within each (academic, community) group, which meant that the two participant groups may not represent genuinely independent populations. Therefore, academic and community partner data are primarily reported in aggregate, and also reported separately where different patterns of responding are evident, based on eyeball estimation. Mean (M) and standard deviation (SD) are reported for all quantitative scale data. For additional detail, data regarding the level and nature of community engagement are also reported as n (%). Data regarding adjustments to accommodate community partners’ needs (gathered using “select all that apply” items) are reported as n (%). Missing data for each item were excluded pairwise (i.e., excluded only from analyses for which relevant data were missing). Based on feedback from our Autistic Advisory Group (see below), most items included “I don’t know” (DK) and “not applicable” (NA) as response options. When these

options were endorsed, these were reported as a separate category and/or excluded from analyses.

Qualitative data from the free-text questions were analysed using a realist, inductive thematic analysis. In this form of analysis, data are assumed to reflect participants' experiences and reality, and themes are derived from the data rather than from any pre-existing theory or coding framework. We identified themes at both the semantic level, based on the explicit meanings of the data, and at the latent level, based on the ideas, patterns, and assumptions that appear to underlie the data (Braun & Clarke, 2006). The first author read all free-text responses, then re-read all responses and assigned codes to the data using NVivo 12. Both authors then reviewed the coded transcripts and collaboratively identified the themes reported in the Results section. The first author then examined the text assigned to codes within each theme, and selected illustrative quotes to describe the themes. The first author approached the qualitative data analysis from the perspective of an Autistic researcher and advocate, while the second author approached the analysis from the perspective of an autism researcher who does not identify as autistic. Both authors are advocates for increased community engagement in autism research. We were mindful of this philosophical standpoint during qualitative analyses and acknowledge that – as with all thematic analyses (see Braun & Clarke, 2006, 2019) – our particular values and assumptions will be reflected to some extent in our findings.

Community engagement in this study

This study was conducted with considerable engagement from the autistic community. The last author, an experienced non-autistic researcher, secured the funding and therefore developed the initial project plan for this study. The project plan was further developed by the first author, an autistic researcher, when they joined the project as a Postdoctoral Fellow.

Although we acknowledge that an inherent power imbalance existed given our respective status as non-autistic and autistic, to the best of our ability the researchers worked in partnership on this research project, with shared power and responsibility for decision-making.

In addition, an Autistic Advisory Group was established during the early stages of the project. This group consisted of five autistic adults with experience as both peer researchers and research participants, who acted as consultants for this study. The researchers and advisory group met regularly through web conferencing, with additional consultation via email as required. The advisory group provided feedback on draft versions of the recruitment procedures, ethics documentation (including Participant Information and Consent Forms [PICFs]) and online questionnaires prior to commencement of data collection. In response to this consultation, substantial changes were made to the questionnaires, and minor changes were made to PICFs. Prior to data analysis, a summary of the dataset was discussed with the advisory group, and the group identified data of interest. This input guided final data analysis and reporting of findings. Members of the advisory group also contributed to this manuscript and are credited as authors, where appropriate. Advisory group members were paid for the time they spent consulting on this project.

Results

Quantitative findings

Level and nature of community engagement. Three bespoke questions assessed overall attitudes towards, and perceived level of, community partner engagement in Autism CRC research (Figures 3-5). Eighty two percent (n=64 out of 78) of respondents indicated a preference for either extensive or moderate community engagement in autism research (M=4.23, SD=0.74). While 35% (n=24 out of 68) of respondents reported that there is

moderate or extensive engagement currently in Autism CRC research, 59% (n=40 out of 68) reported that there is only some engagement with community partners (M=3.40, SD=0.81). Most participants (72%; n=47 out of 65 respondents), however, indicated that the ideal level of community engagement is higher than the current level, while the remaining participants (n=18, 28%) reported that the current level was ideal (M=3.97, SD=0.73). No participants reported that a reduction in community engagement was required. Academic and community partners provided similar patterns of responses (see Figures 3-5).

[Insert Figures 3-5 about here]

Examination of community partner engagement at specific stages of the research process, measured using the adapted CERI (Khodyakov et al., 2013; see Figure 6), showed that engagement was highest during the middle stages of the research process. Seventy three percent (n=40 out of 55) of respondents reported at least some community partner engagement in participant recruitment (M=3.38, SD=1.51), and 68% (n=34 out of 50) reported at least some engagement in designing or modifying interview and/or survey questions (M=3.30, SD=1.59). Less community engagement was reported during the early stages of the research process, including in grant proposal writing (M=1.86, SD=1.30) and background research (M=1.96, SD=1.38), and later stages of the research process, including in data analysis (M=2.23, SD=1.57) and dissemination (e.g., giving presentations at meetings and conferences [M=1.91, SD=1.41]). Academic and community partners provided similar patterns of responses to these items, although community partners tended to report “no engagement” more frequently (see Supplementary Figures 1 and 2).

[Insert Figure 6 about here]

Regarding adjustments to accommodate community partners' needs, 39% (n=24 out of 61) of academic and 69% (n=9 out of 13) of community partners reported that adjustments had been

made. The remaining academic partners (18%, n=11) (and no community partners) reported that adjustments had not been made.

Figure 7 depicts community partner compensation reported by the 57 participants (45 academic and 12 community partners) who endorsed at least one option. Community partners were commonly credited as authors or contributors on research outputs. One third of both academic (n=15, 33%) and community partners (n=4, 33%) indicated that community partners were paid for engagement as part of their usual employment, while 14 (31%) academic partners and two (17%) community partners reported that community partners were paid directly for their engagement. Other forms of compensation were less common. Notably, 10 (22%) academic partners and five (42%) community partners indicated that at least some community partners engaged in their project did not receive any form of compensation for their engagement.

[Insert Figure 7 about here]

Partnership dynamics. Participants reported good structural values within partnerships, with similar ratings by academic and community partners (see Supplementary Table 1). The highest-rated item measured academic partners' commitment to community engagement as a long-term process (M=4.44, SD=0.93), while the lowest-rated item measured academic partners' personal experience with autism (M=3.54, SD=1.24). Participants also reported good relationships between partners (see Supplementary Table 2). The highest-rated item indicated that partners showed positive attitudes towards one another (M=4.65, SD=0.59), while the lowest-rated item assessed whether disrespectful comments were made in communications between partners (M=1.32, SD=0.58).

Outcomes of community engagement. Participants reported high levels of synergy within project teams (see Supplementary Table 3). The highest-rated item indicated that teams were

able to develop goals that were understood and supported by all partners (M=4.49, SD=0.62), while the lowest-rated item measured the team's ability to develop strategies that are likely to work for the autism community (M=4.35, SD=0.73). Again, academic and community partners' mean scores were similar.

Overall, participants reported that community partner engagement had a moderate level of impact on their research process (M=3.68, SD=1.17, n=53) *and* outcomes (M=4.16, SD=0.91, n=50), and reported that the type of impact was positive (research process: M=4.29, SD=0.76, n=49; research outcomes: M=4.40, SD=0.73, n=50).

Summary. Overall, the quantitative results indicated that participants were supportive of community engagement in autism research. They also believed that community partners were engaged throughout various stages of Autism CRC research projects, with highest engagement during the middle stages of research. Participants reported good partnership characteristics and perceived that community engagement had impacted positively on the research processes and outcomes. Next, we report analyses on the qualitative responses, which served to enrich our interpretation of the quantitative findings and provide greater insight into participants' perceptions of participatory autism research.

Qualitative findings

We identified four interrelated but distinct themes, and a number of associated sub-themes, which are described in turn below. Quotes are attributed according to the type of partner (academic partner: AP; community partner: CP) and participant identification number.

1. Participatory research as aspirational

a. Participatory research is valuable

Participatory research was overwhelmingly perceived as a positive approach to autism research. At a semantic level, participants almost universally expressed support for

community engagement in autism research: *“I think community partners should be involved to the fullest extent that is possible and appropriate”* (AP14); and *“It is vital to involve community members in research so that relevant research which improves people’s lives can be undertaken”* (CP12). Participants’ perceptions of the benefits of community engagement were generally consistent with the broader evidence base, with participants particularly noting that community engagement leads to better quality and more relevant research: *“Through my experience, the more involvement of autistic people the better quality autism research”* (AP29); and *“Instead of research where I just answer the questions put to me, I can have input on the questions themselves. That’s important because I think the wrong questions have often led research (and subsequently understanding of autistic people) astray to our detriment”* (CP3).

b. Participatory research is not a panacea

Despite such broad support for participatory research, there were latent indications that academic partners tended to perceive high-level community engagement as an aspirational goal. Participants identified various practical barriers that were perceived to make participatory research impractical and difficult to achieve: *“In my project, there was difficulty meeting timelines and the intended outcomes were not met to the extent they could/should have been as a result of such participatory autism research”* (AP24). There was also a perception that participatory research is necessary or appropriate only for some autism research projects: *“I think that it is important for participatory autism research to be conducted, however it depends on the aims of the project and the outcomes”* (AP24). Specifically, academic partners indicated that participatory research may only be appropriate for projects that involve certain demographic groups within the autistic community: *“Having strict adherence to ‘participation’ at all stages of research can bias autism research towards studies able to engage particular demographics of the autistic community and discriminate*

against vulnerable members of the autistic community and lead to lack of funding for valuable projects” (AP27).

2. Superficial understanding of participatory research

Semantic definitions of participatory research, and descriptions of typical practices involved in conducting participatory research, varied considerably across participants. Considering these data at a latent level, some participants demonstrated no meaningful understanding of the term “participatory research”: *“Research that is done by recruiting participants as opposed to working with a pre-existing data set?” (AP25); and “Any participation, directly or indirectly, relating to the autism research” (AP5).* More commonly, participants demonstrated some understanding of participatory research, but tended to describe processes of consultation as opposed to high-level co-production: *“The population of interest for a study are directly consulted and involved in the design of the study, and are given ample opportunity to feed back to the researchers” (AP6); and “being involved in an advisory capacity” (CP5).* A minority of participants showed greater understanding of the processes involved in higher-level participatory research, describing active engagement in research partnerships: *“Autistic and neurotypical researchers work side by side, with the same rights to authorship, income, and recognition as any member of the team” (AP41); and “I’m not just a guinea pig or a single data point, I am part of the machinery that helps move research forward... I have a voice” (CP3).*

Few participants demonstrated deeper consideration of the nature of participatory research. Only a small number of comments discussed relationships between partners: *“organic progression [is] vital as the rapport between researcher and autistic advisor is crucial... success depends upon both parties being passionate, [and] truly committed to the subject of study as equals” (CP6).* Others highlighted a lack of relationship-building: *“the time and*

space needed to build high quality relationships with community partners wasn't there – and that's a real shame” (AP1). Only one participant commented on power dynamics: *“there is a shift in power base with a shared power structure”* (CP6).

3. *Problems with power*

a. *Entrenched power dynamics*

As noted above, only one participant explicitly commented on power dynamics. However, when data were considered at a latent level, it appeared that traditional power dynamics remained entrenched in many participants' experiences of research. Both autistic and non-autistic community partners reported experiences of being engaged by academic partners to contribute to a research project, but subsequently facing limited opportunities for involvement: *“we have been asked by university personnel to co-lead projects in order to comply with [Autism] CRC guidelines, but then we have not always been invited to meetings to plan the research”* (CP14); and *“I have not been privy to how things have been run and only know the few things that I have been asked to participate in”* (CP3). Community partners also indicated a lack of power and control in the research process, reporting that academic partners tended to retain responsibility for decision making: *“university partners made decisions about substantial changes in the direction of the research, and then informed us of the change”* (CP14).

Interestingly, when asked about challenges within participatory research processes, community partners tended to report on challenges that they faced personally: *“Being able to articulate my opinions and input clearly because I was doing it through emails”* (CP8). In contrast, there was a tendency for academic partners to report challenges that they attributed to community partners. For example, one academic partner reported: *“Sometimes the community partners had difficulty understanding the merits of the research project”* (AP17),

while another stated that they found it challenging “*managing suggestions from autistic advisors that are beyond scope or not feasible within [the] specific research context/question*” (AP38). These comments imply that, although community partners were engaged in these research processes, the projects were based on the goals and priorities of the academic partners rather than those of the community partners. When community partners’ contributions did not facilitate the pursuit of these goals, the contributions were perceived as “challenging”.

b. Autistic people as passive participants

There was a lack of recognition, mostly evident in academic partners’ responses, that autistic people can have a role in research that goes beyond the role of being passive participants. At the semantic level, academic partners generally stated a willingness to work together with autistic people; but patterns observed within the data indicated a contrasting latent theme. Academic partners often referred to community partners (and autistic people in particular) as “participants”, “consumers”, or even “subjects”, but rarely as “partners”, “colleagues”, or other terms implying an equal power dynamic. For example: “*Involving the groups of individuals who are the subject of the research to be involved in the research process...*” (AP15); and “*meaningful collaborations with participants, or stakeholders*” (AP44). Similarly, some comments indicated that academic partners perceived community partners as a resource to be accessed when needed, rather than as a peer or colleague: “*If there was... a directory that could be accessed so that we could find community partners that would really help*” (AP46). When describing participatory research processes, academic partners tended to frame community engagement as an opportunity given to community partners by academic partners, as opposed to an equitable and reciprocal exchange. This was illustrated in comments like: “*People that meet the relevant participatory requirements of a project are*

given the opportunity to be involved” (AP35); and “allowing people on the autism spectrum to be active participants...” (AP17).

Academic partners also commented that community partners (particularly autistic community partners) should be representative of the broader autistic and autism communities, as illustrated in the following two quotes:

It is good to involve people on the spectrum in research, however, most of the people involved are high functioning. They are the minority but tend to speak on behalf of all people on the spectrum. Because autism sits on the premise of deficits in social communication, it will be difficult to ask the participant with ASD to imagine or report on behalf of others (AP18); and

I think there is a greater need for inclusion of those who are minimally verbal or have an intellectual disability in this space. Much [sic] of the research partnerships are with self-advocates who are typically female, high IQ, and well educated and do not adequately represent (nor can they) the diversity of individuals on the spectrum (AP30).

These comments imply that academic partners tend to measure autistic people against the standards expected of research participants (such as representativeness), even when they are acting as members of a research team. In contrast, some academic partners perceived diversity amongst community partners as challenging: *“there is a risk of multiple community representatives who have dramatically different views” (AP13); and “[it’s challenging] managing differing opinions across autistic advisors” (AP38).*

4. Systemic issues are perceived to constrain participation

a. Practical constraints

Systemic issues were perceived to play a considerable role in constraining academic partners' ability to adopt participatory research methods. At the semantic level, practical constraints – most notably, time and money – were identified by both academic and community partners as impacting on the implementation of participatory research methods. Some participants reported that project timelines were adjusted to accommodate community engagement: *“there have been times when I've asked for extension of time to the deadline”* (CP6). In contrast, other participants reported that short timeframes had limited community engagement: *“Project timeframe was short – would have found it less challenging with more time”* (AP45); *“everything was so rushed”* (AP1). Relatedly, some academic partners felt that community engagement had impacted on their ability to meet project timelines: *“Delayed responses meant the timeframe for each phase took longer than anticipated”* (AP36); and *“Program milestones were not always on time as the autistic researchers needed high levels of support from academic researchers on occasions”* (AP48). Funding was also identified as a practical systemic constraint to participatory research. Although one community partner noted that they were *“not... paid for my time”* (CP12), many academic partners recognised the importance of compensating community partners for time spent engaged in research. A number of comments highlighted the need for increased funding to support community partner engagement: *“Perhaps allocating more funding for community partners' time could help to facilitate further engagement”* (AP44).

b. Epistemological constraints

At the latent level, epistemological constraints were evident primarily in academic partners' comments. These comments, at times, reflected a perception that research systems are inflexible and immutable: *“Sometimes research has to be very rigid for certain reasons, with deviations from the norm not usually accepted. Community partners might not understand why at first”* (AP22). This perception suggests that it is not possible to change research

systems to accommodate community engagement, but that community partners must instead conform to existing systemic structures. Encouragingly, some academic partners identified this epistemological stance as problematic: “[*In future, we could*] challenge some researchers’ opinions on what research questions can benefit from engaging community partners” (AP38). One early career researcher noted that this may be a particular challenge when partnering with senior researchers, who may have considerable experience working within specific processes that they are reluctant to change: “*Sometimes it is difficult to change this rigid approach as an early career researcher. But I will keep trying!*” (AP29).

Discussion

This study investigated the extent and nature of community involvement in autism research projects commissioned by Australia’s Autism CRC. Autism CRC stakeholders reported overall support for community engagement in autism research, but closer examination of qualitative responses revealed more complex attitudes than suggested by quantitative findings.

Quantitative results indicated high levels of support for community engagement, and high levels of perceived community engagement in autism research amongst Autism CRC academic and community partners. Scores on the CERI were remarkably similar to those reported by Khodyakov et al. (2013), who found rates of active community engagement ranging from 23% to 70% across different phases of research. Consistent with Khodyakov et al., we found lower levels of community engagement during early stages of research, and higher levels of community engagement during the middle stages of research. Our finding of relatively limited engagement in dissemination of research findings was in contrast with Khodyakov et al., who found 61% engagement in this stage of research. These results suggest that work is needed to increase community engagement during specific stages of the autism

research process, particularly during early and late stages of research including grant proposal writing, background research, and dissemination of findings.

Less than half of participants reported that adjustments had been made in their research project to accommodate the engagement of community partners, and a substantial minority of participants reported that at least some community partners engaged in their research project did not receive compensation. This is a significant concern, and highlights the need for academic partners and research investors to allocate funds for the payment of community partners when proposing project budgets. Appropriate compensation can contribute to addressing power imbalances in partner relationships, particularly when community partners are members of a marginalised or financially disadvantaged community (Bell & Pahl, 2017; Filipe, Renedo, & Marston, 2017).

Taken together, there is a clear disconnect between the quantitative and qualitative findings reported here. Although the quantitative results indicate overall support for community engagement, the wide variation in understanding of participatory research demonstrated through qualitative findings raises questions regarding how meaningful that support is. In particular, the lack of representation of key participatory research concepts in the qualitative data suggests that, regardless of the degree to which participants may understand other aspects of participatory research, collectively there remain a number of particularly important gaps in knowledge that are likely to limit participants' ability to effectively co-produce research. This contrasts with findings regarding community engagement (typically referred to as *patient and public involvement*) in broader health sciences research, where both academic and community partners tend to demonstrate better understanding of key concepts relevant to participatory research (Baines & Regan de Bere, 2018; Snape et al., 2014).

In a further disparity, our quantitative results indicate high rates of community engagement in Autism CRC research, while qualitative findings suggest that this community engagement was largely limited to consultation (see Figure 1), with a lack of true partnership in research processes. In particular, two of the qualitative themes – *superficial understanding of participatory research* and *problems with power* – highlight the limited understanding of participatory approaches amongst Autism CRC researchers, with academic partners retaining significant power and control within research partnerships, and an apparent failure to recognise community partners as equal partners in the research process. Nicolaidis (2019) recently raised the concern that an increased emphasis on participatory autism research may also lead to an increase in tokenism and exploitation of autistic people and other community partners. The combination of quantitative and qualitative findings presented here suggest that this is a valid concern.

Our findings suggest that Autism CRC academic partners have responded to the organisation's call for an increase in participatory research by attempting to engage with community partners, but a lack of familiarity with basic participatory research concepts has resulted in community engagement efforts that appear to sit primarily in the lower half of the participatory research hierarchy (see Figure 1). This outcome is consistent with previous findings regarding autism scientists' perspectives on community engagement (Hollin & Pearce, 2019), and also with the state of autism research more broadly (Fletcher-Watson et al., 2018). Given the paucity of published participatory autism research (Jivraj et al., 2014), it is not surprising to find that researchers working in this field lack familiarity with participatory research approaches. Indeed, this is also consistent with the nature of patient and public involvement in health research more broadly, with recent evidence suggesting that community engagement is often missing or of poor quality (Blackburn et al., 2018), and the majority of research continuing to be led and controlled by academic partners (Green, 2016;

Ocloo & Matthews, 2016). It is important to note that different levels of community engagement are often appropriate across different research contexts. For academic partners who are new to participatory research, for example, informing or consulting with community partners may be a simple and valuable step towards increasing community engagement in research. As partners' knowledge of, attitudes towards, and skills in participatory research grow more nuanced and as relationships between partners mature, equitable co-production and greater community control of research will become more feasible.

Interestingly, a number of academic partners in this sample raised concerns regarding a lack of "representativeness" amongst community partners (particularly autistic adults) engaged in Autism CRC research. It is worth noting that the academic members of a research team are rarely selected due to representativeness, but instead are chosen due to particular attributes and skills, and often because of established working relationships with other team members (Bozeman & Gaughan, 2011). Given that an element of a community partner's role is to contribute experiential (lived) expertise, it is certainly important that the community partners engaged in a given research project have experiential expertise relevant to that project; however, arguably, it is neither possible nor desirable to engage a group of community partners representative of the entire autism community in every research project. As Pellicano and Stears (2019) point out, decisions about which community partners to engage in any given research project should be made by all relevant stakeholder groups, and not left to researchers alone. That said, there are many groups within the autistic community – for example, non-speaking people and those with co-occurring intellectual disability – who have been underserved by both traditional and participatory research to date (Jack & Pelphrey, 2017; Russell et al., 2019; Stedman, Taylor, Erard, Peura, & Siegel, 2019). As Ocloo and Matthews (2016) note, systemic barriers can mean that "those with most to gain are most excluded" (p. 629). By establishing relationships with these underserved groups (and those

who support them) and co-designing relevant, accessible research projects, academic partners can use their power to work towards correcting this imbalance in autism research.

Consistent with previous work by Fletcher-Watson et al. (2018), our findings highlight the need for a systemic shift within the autism research establishment to facilitate more frequent and more equitable engagement with community partners. Effective participatory research often takes more time and is more expensive than traditional research (Blackburn et al., 2018; Hoeft et al., 2014). This should be taken into consideration by all stakeholders, particularly the funders of autism research, when developing and assessing grant proposals. But the shift must go deeper than this. An epistemological shift is needed before research co-production at the level of partnership or community control can become a mainstay of autism research (Pellicano, 2020). Importantly, these findings reveal a clear need for greater education and training of autism research stakeholders in the fundamentals of participatory research, as neither academic nor community partners will be able to contribute effectively to a research partnership if they are not cognisant of the theoretical and practical underpinnings of participation.

Limitations

This study had a number of limitations. First, our sample of community partners was small and precluded the use of inferential statistics, limiting the conclusions that can be drawn from the quantitative data. As participants were required to self-identify as either an academic or community partner, it is possible that some participants (e.g., autistic researchers) self-identified as academic partners when they could have also been classified as community partners, or vice-versa. The small sample of community partner participants may have been due to our recruitment process. Similar processes have previously produced samples, recruited within CBPR partnerships, comprising relatively even proportions of community

and academic partners (Jagosh et al., 2015; Oetzel, Zhou, et al., 2015; Spears Johnson et al., 2016). It is possible that, within Autism CRC research, Project Leaders did not consider community partners to be members of their project teams, and subsequently did not nominate these partners as potential participants.

Second, the quantitative measures used in this project were based on a survey by Oetzel, Zhou, et al. (2015), designed to assess community engagement within CBPR projects. The CBPR framework assumes a considerable level of community engagement in research, which was not true of many Autism CRC projects, therefore these measures may not have been fit for the purpose of this study. Although we excluded measures designed to assess specific CBPR research elements, endorsement of “I don’t know” and “Not applicable” responses was common, suggesting that participants had difficulty responding to items.

Finally, both quantitative and qualitative data were gathered and analysed collectively – that is, we considered data across all Autism CRC research projects, rather than reporting on each research project individually. We also used a broad definition of “community partner” (including autistic adults, family members of autistic people, service providers, and other stakeholders) and reported data from this group collectively. This approach was adopted to preserve participants’ anonymity. Nevertheless, this means that we are unable to reflect on any individual variability between research projects or specific stakeholder groups in terms of the nature and extent of community engagement. In future, it may be beneficial to conduct more detailed evaluations of individual research projects, to serve as exemplars for academics new to participatory research.

Conclusions

Findings from this study indicate that stakeholders within the Australian autism community are largely supportive of community engagement in research but may lack the depth of

understanding of participatory research that is essential for high-quality research co-production. By revealing the relatively limited knowledge of participatory research methods within this community, our study underlines the need for increased training and investment in this field. Greater investment is also necessary to counter commonly identified systemic barriers to participatory research, notably a perceived lack of time and money. Importantly, the quantitative and qualitative findings from this study each provide very different insights into participants' perceptions of participatory research, highlighting the need for further research on this topic using a range of methodologies and participant groups. Future work will need to consider the most effective ways for both academic and community partners to enhance their understanding of participatory research approaches, to ensure that community engagement in autism research is respectful, equitable, and beneficial to all stakeholders.

Table 1. *Participants' demographic data*

	Community partners (n = 15)	Academic partners (n = 64)	Total sample (n = 79)
Age			
Range	21–71	23–69	21–71
Mean (SD)	48.67 (16.68)	43.17 (13.14)	44.30 (14.00)
Gender			
Woman (including trans)	12 (80%)	50 (78%)	62 (78%)
Man (including trans)	2 (13%)	14 (22%)	16 (20%)
Other	1 (7%)	0 (0%)	1 (1%)
Education (highest completed)			
Grade 12 or below	1 (7%)	1 (2%)	2 (3%)
VET ^a certificate, Diploma, or Associate degree	4 (27%)	0 (0%)	4 (5%)
Bachelor degree (including honours)	5 (33%)	21 (33%)	26 (33%)
Masters degree	2 (13%)	7 (11%)	9 (11%)
PhD or Doctorate	3 (20%)	35 (55%)	38 (48%)
Connection to autism^b			
Researcher studying autism	2 (13%)	56 (88%)	58 (73%)
Student studying autism	0 (0%)	3 (5%)	3 (4%)
Autistic person	7 (47%)	4 (6%)	11 (14%)
Family/carer	3 (20%)	13 (20%)	16 (20%)
Service provider (autism-specific)	3 (20%)	6 (9%)	9 (11%)
Service provider (non-autism-specific)	2 (13%)	9 (14%)	11 (14%)
Other ^c	3 (20%)	4 (6%)	7 (9%)
Autism CRC Program/s^d			
Program 1 – Early Years	4 (27%)	19 (30%)	23 (29%)
Program 2 – School Years	2 (13%)	29 (45%)	31 (39%)
Program 3 – Adulthood	9 (60%)	29 (45%)	38 (48%)
Other	2 (13%)	1 (2%)	3 (4%)
Unsure	4 (27%)	3 (5%)	7 (9%)

Notes. ^a Vocational Education and Training

^b Given that people have multiple roles (e.g., a researcher who is also a parent of an autistic child), participants were able to select all options that applied to them; therefore, percentages do not add to 100

^c 'Other' connections to autism included research assistant, research manager, peer researcher, lecturer in autism studies, volunteer worker, and friend to autistic people.

^d Some participants were involved in research across more than one Autism CRC Program, therefore percentages do not add to 100

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Figure 1. A depiction of the hierarchy of participatory research (based on [Arnstein, 1969](#)).

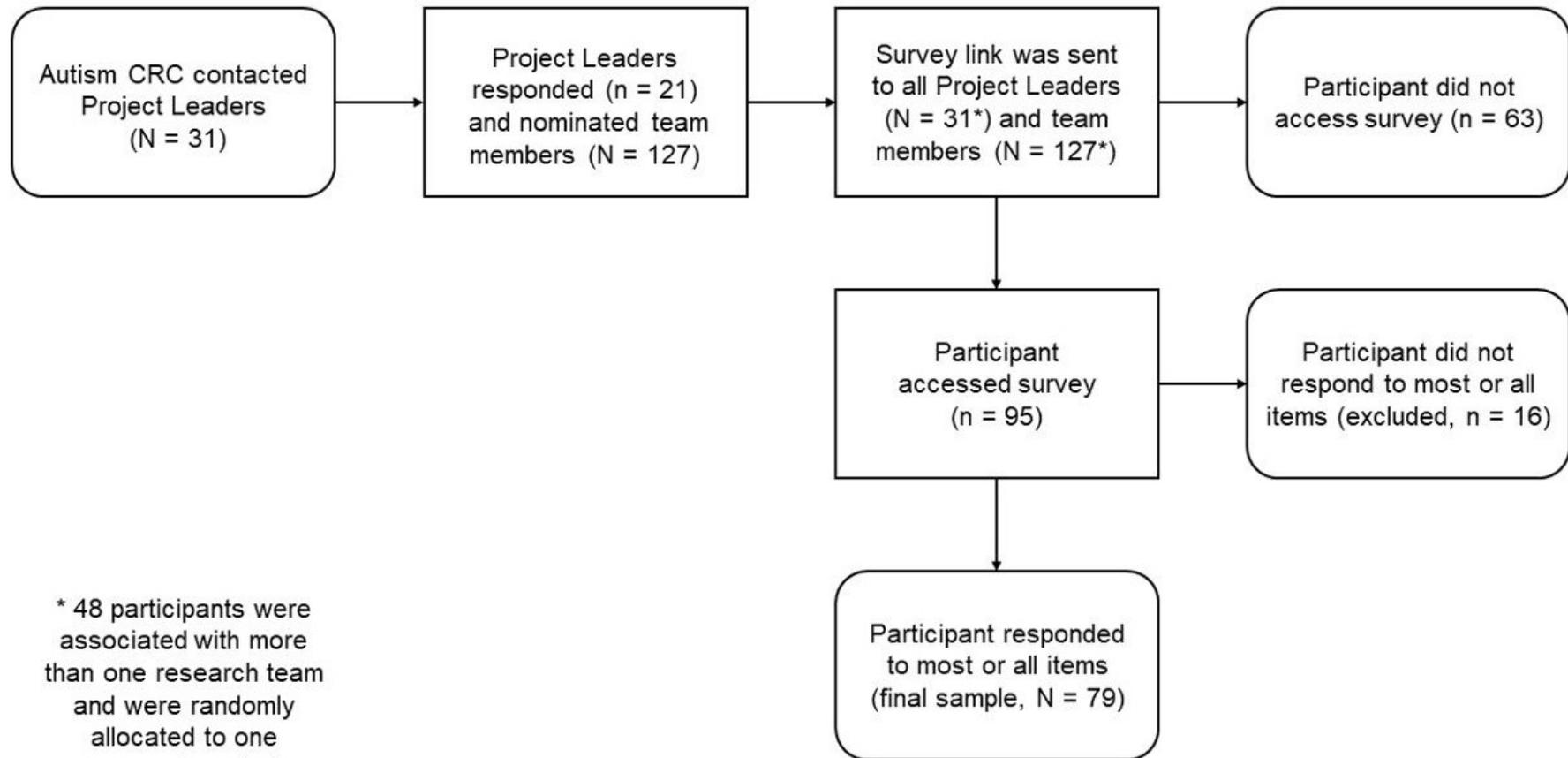


Figure 2. Participant recruitment process

Perceptions of participatory autism research

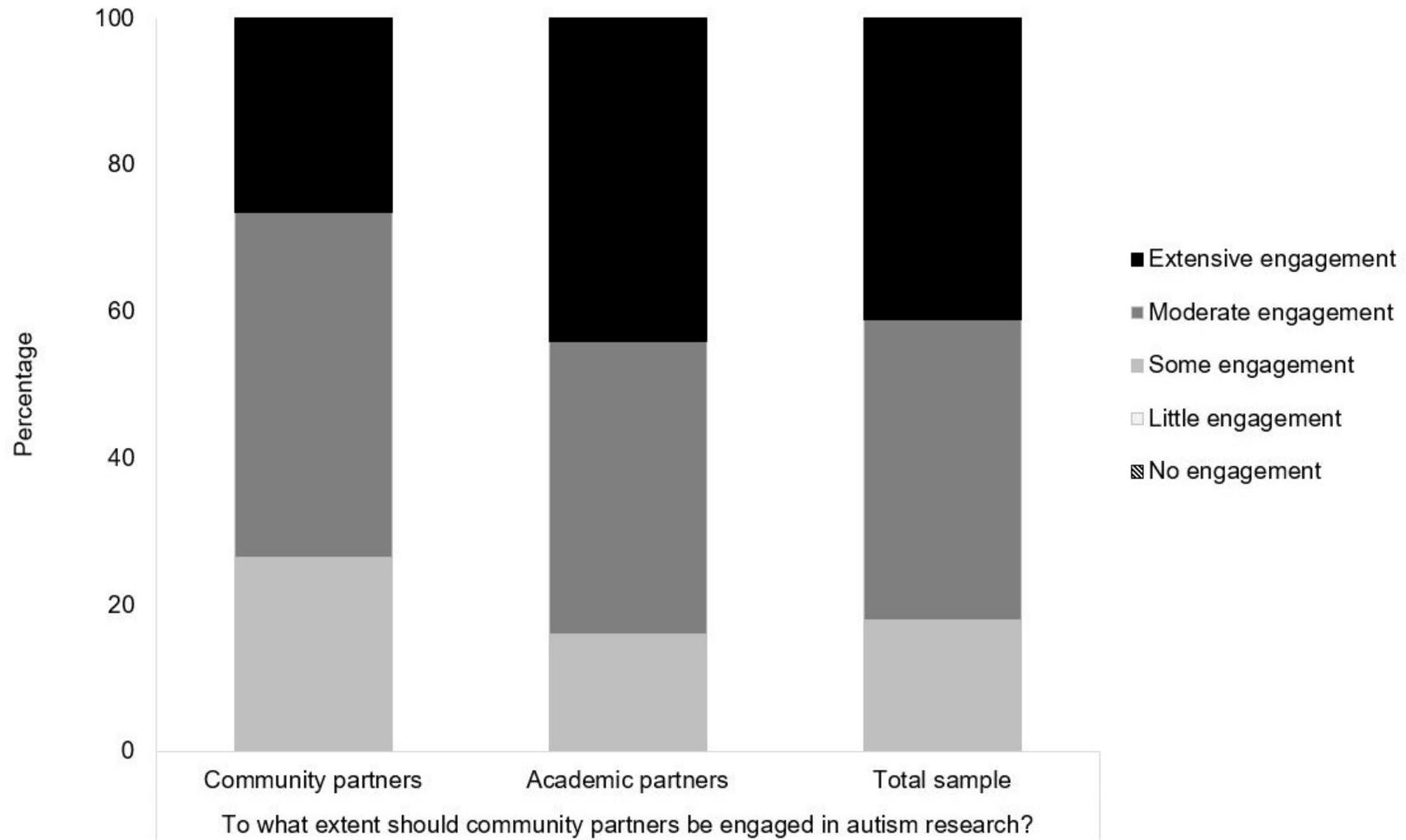


Figure 3. Attitudes towards community partner engagement in autism research

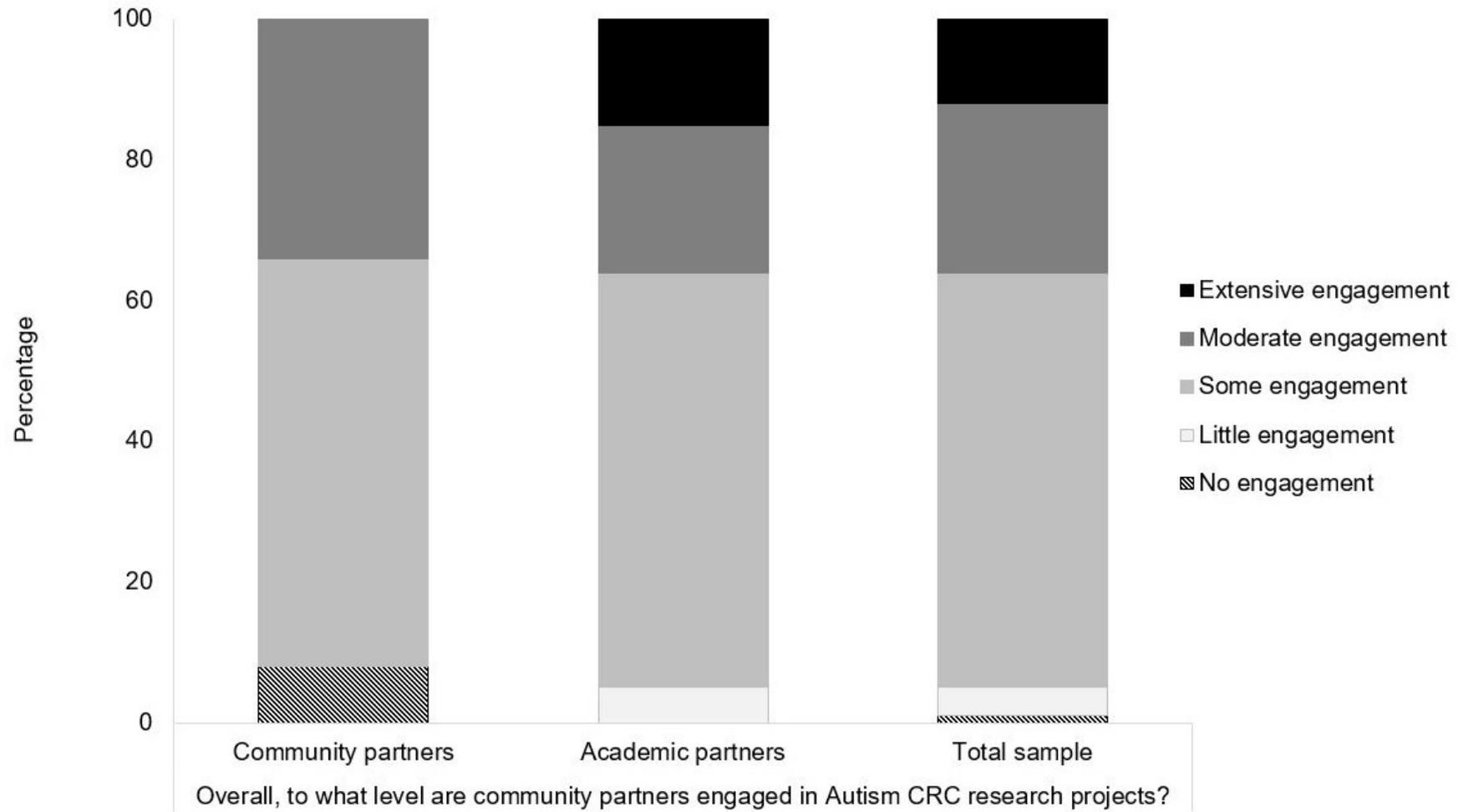


Figure 4. Perceptions of current community engagement in Autism CRC research

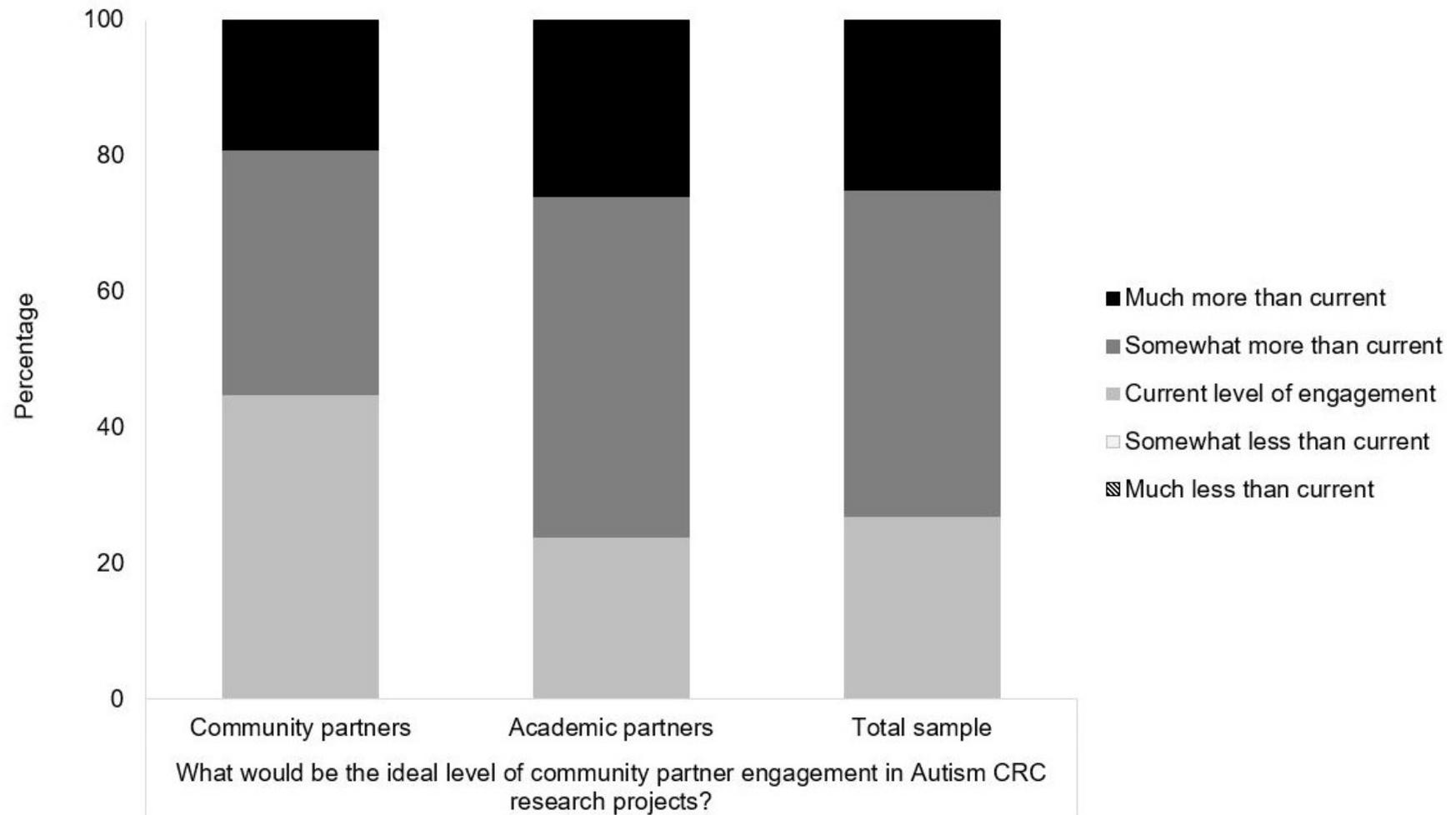


Figure 5. Perceptions of ideal community engagement in Autism CRC research

Perceptions of participatory autism research

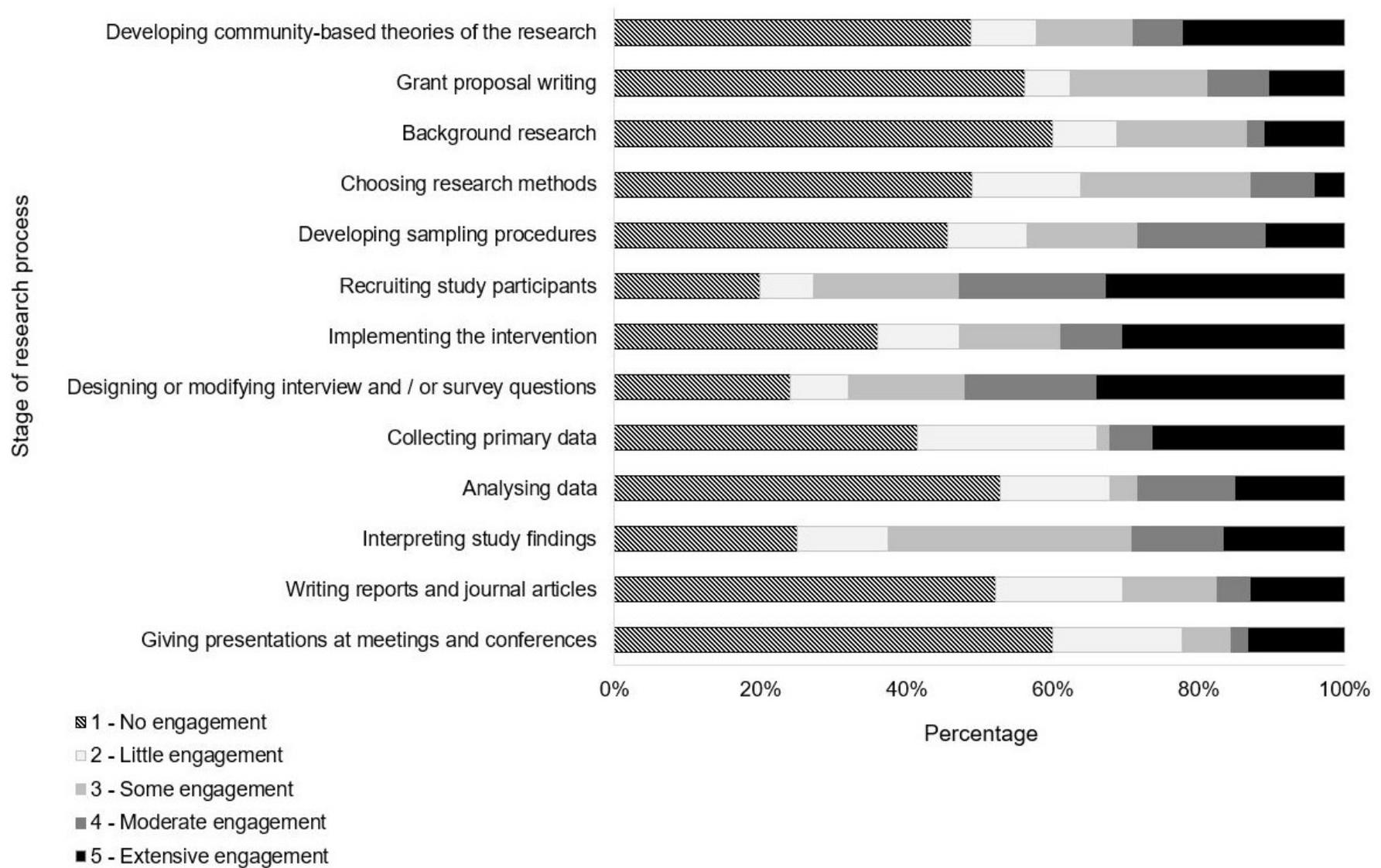


Figure 6. Levels of community engagement at specific stages of the research process

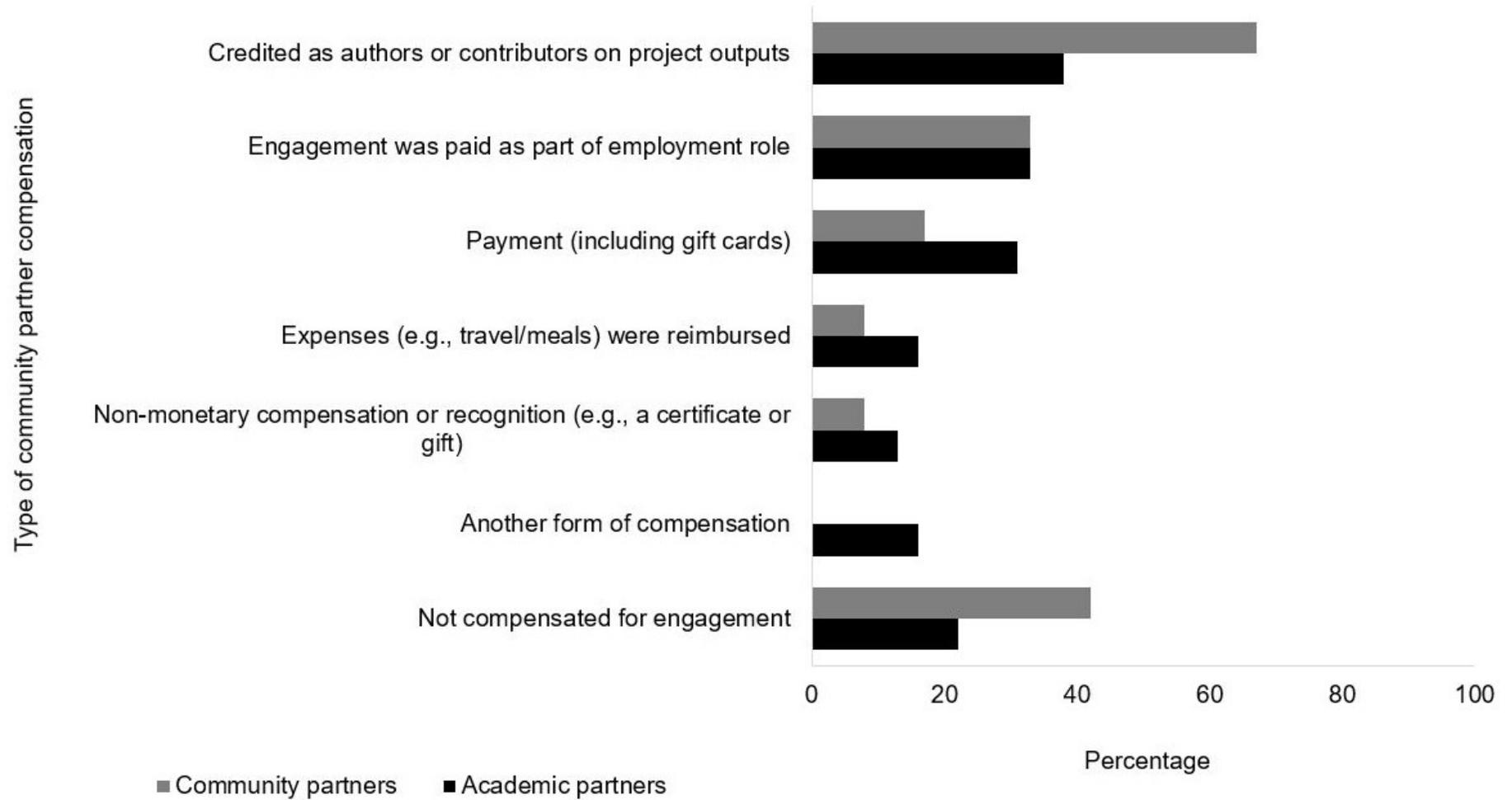


Figure 7. Types of compensation provided to community partners