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Citation for published version (APA):

Le Cunff, A.-L., Ellis Logan, P., Ford, R., Martis, B.-L., Mousset, I., Sekibo, J., Dommett, E., & Giampietro, V. (2023). Co-Design for Participatory Neurodiversity Research: Collaborating with a Community Advisory Board to Design a Research Study. *Journal of Participatory Research Methods*.

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Co-Design for Participatory Neurodiversity Research: Collaborating with a Community Advisory Board to Design a Research Study

BRIEF REPORT

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Abstract: Inclusive research practice characterised by the involvement of neurodivergent people in meaningful roles has been described as “requirement of excellence” in neurodiversity research. This report describes a co-design process in partnership with a Community Advisory Board undertaken to develop a research study involving neurotypical and neurodivergent students as participants. From the formation of the partnership with seven Community Advisory Board members to the outcomes of the co-design process, this report details the methods associated with each step, as well as the benefits and challenges collated in collaboration with members of the Community Advisory Board. Opportunities for improvement in co-design for participatory neurodiversity research are suggested.

Tags: Participatory Research, Participatory Engagement, Participatory Design, Design Approach, Neurodiversity

Introduction

“Neurodiversity” is an umbrella term encompassing neurodevelopmental conditions such as autistic spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), dyslexia, dyscalculia, dyspraxia, and Tourette’s syndrome, among others (Clouder et al., 2020). The term “neurotypical” refers to individuals deemed to have standard brain functions, while “neurodivergent” relates to individuals whose neurodevelopmental functioning differs from what is considered standard (Jurgens, 2020). In addition to conceptualising neurodiversity based on differences between individuals, another definition of neurodiversity refers to the diversity within an individual’s cognitive ability: while a neurotypical individual’s cognitive scores tend to form a relatively “flat” profile, neurodivergent individuals tend to display large disparities between cognitive scores, forming a “spiky” profile (Doyle, 2020). Based on the prevalence, overlap, and under-diagnosis of neurodevelopmental conditions included under the umbrella term of neurodiversity, neurodivergent individuals are estimated to represent around 15–20% of the worldwide population (Doyle, 2020). As neurodivergent and neurotypical people think and experience the world differently, it is considered necessary to incorporate the perspectives of neurodivergent people to increase our understanding of neurodiversity, and for researchers to provide opportunities for neurodivergent people to share their views and to shape the development of research that can have a significant impact on their lives.

Inclusive research practice, characterised by the inclusion of neurodivergent people in meaningful roles, has been described as “requirement of excellence” in neurodiversity research (Fletcher-Watson et al., 2021). This may be of even greater importance when the constructs under study are likely to significantly differ between neurotypical and neurodivergent participants because they depend on the cognitive processes in which significant variation may occur in neurodivergent individuals. At the intersection of science and practice, participatory research methods are intended for planning and conducting research with the people whose lived experience is under study (Bergold & Thomas, 2012). Methods that emphasise participation are based on the premise that research must be done “with” and not “on” people, with the goal of instigating meaningful change through collective effort (Cornwall & Jewkes, 1995). Research involving community partners is

conducive to greater rigour, external validity and translatability compared to research conducted exclusively by researchers (Lasker & Weiss, 2003).

Recent neurodiversity research has implemented participatory methods with different levels of involvement. In this context, involvement refers to the level of participation of relevant stakeholders as partners in some or all phases of the research, and participation refers to the various ways stakeholders take part in the research (Tarpey, 2015). For instance, Pavlopoulou (2021) applied a novel approach where autistic adolescents were invited to collect and analyse their own data with the support of an academic researcher. While this level of involvement offered unique insights not usually captured by traditional methods used in sleep research, the researcher noted the need to further include participants in the co-production process (Pavlopoulou, 2021). At a higher level of involvement, Crane and colleagues (2019) used a community-based participatory research (CBPR) approach where a group of young autistic people selected the research topic and where the research itself was conducted by members of that group. Among the limitations mentioned by the researchers was that the people who took part in the project were cognitively and verbally able; people with additional intellectual disabilities may be unable to advocate for themselves verbally through such participatory research projects (Crane et al., 2019). Another way of involving community partners—which shares similar benefits and limitations—is the formation of a Community Advisory Board to provide feedback throughout the research process (Newman et al., 2011). Composed of members who share a common experience, interest, or identity, a Community Advisory Board provides a mechanism for community members to be represented in research activities (Newman et al., 2011). Community Advisory Board members can help ensure the data is interpreted correctly and that the results are representative of the experience under study, so that the research is translational and relevant to their lives (Vaughn et al., 2018). Each level of involvement comes with its own set of challenges and opportunities (Duea et al., 2022). For instance, a Community Advisory Board improves effectiveness of research and opportunities to translate the research into action, but is labour intensive and time consuming, and may not be representative of the wider community (Dias & Gama, 2014; Newman et al., 2011). In addition, consultative models can generate valuable feedback to refine research design but do not provide community members with the decision-making power of co-researchers (Joosten et al., 2021). Ultimately, the level of involvement should be determined based on the project's goals and available resources, ideally in conversation with community members (Duea et al., 2022).

In most participatory neurodiversity research studies, the participatory component is described as part of the overall methods. The lack of space limits the level of detail in

explaining their methodological development process and the ability for other researchers to fully understand the benefits and challenges of each approach. It is uncommon for neurodiversity researchers to publish separate reports focusing specifically on the development process of their participatory methods despite the value of this to others (Costley et al., 2022; French et al., 2020; Hussein, 2021; Ward et al., 2022). By facilitating knowledge exchange, for example, through detailed accounts of the characteristics, benefits, and challenges of their methodological development process, such reports greatly contribute to the critical appraisal of participatory methods in neurodiversity research.

This knowledge sharing is likely to be useful in all types of studies, but some methodologies create more specific challenges for participatory components. For example, using focus groups in community-based participatory research, as was the case in our study, comes with its own sets of challenges, such as overlapping recruitment pool of focus group participants and Community Advisory Board members, and sometimes requires additional training of Community Advisory Board members (Makosky et al., 2010). However, to the best of our knowledge, no report specifically describes the benefits and challenges of co-designing a focus group research study with a Community Advisory Board in the context of neurodiversity research. By documenting key lessons relevant to co-designing a focus group study with a Community Advisory Board, the aim of this report is to facilitate such a knowledge exchange in neurodiversity research.

As part of a research project exploring the relationship between cognitive load and neurodiversity in online education, we collaborated with a Community Advisory Board composed of neurodivergent students to co-design a focus groups study, iteratively implementing their feedback on all aspects of the research design, from research questions and ethical approval to topic guide and experimental setting. Focus groups are a form of group discussion that capitalises on interactive communication between research participants to generate qualitative data (Kitzinger, 1995). They have been defined as a “carefully planned series of discussions, designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment” (Krueger, 2014). Focus groups are particularly useful when complementing other methods of data collection for providing in-depth insights in a relatively short amount of time (Gundumogula, 2020). They are increasingly used in participatory research as a bridging strategy for scientific inquiry and community knowledge, and their popularity has grown across a wide range of disciplines including education and health research (Nyumba, Wilson, Derrick & Mukherjee, 2018). When conducting research with focus groups, members of the Community Advisory Board are most often included in recruiting participants, moderating the discussions, and disseminating the findings to the lay audience and to their community audience (Makosky

et al., 2010). However, throughout the partnership, a Community Advisory Board can be involved at any stage of the research process: design, data collection, analysis, dissemination, and action (Vaughn & Jacquez, 2020). This report shares the decisions made during the design phase of the focus group study and the lessons learned from collaborating with our Community Advisory Board composed of neurodivergent students.

Co-Design Process

The co-design process followed three main phases: partnership formation where Community Advisory Board members were recruited, and mutual expectations were defined; iterative development through collaboration where members shared feedback; outcome reporting where members received a detailed overview of how their feedback was implemented and the resulting decision from the ethics committee.

Partnership Formation

Prior to recruitment of the Community Advisory Board, the participatory research agreement and the advert were reviewed by two members of the institutional Neurodiversity and Mental Health Society. Once agreed, the advert was posted on the institutional Neurodiversity and Mental Health Society's online forums, via the Student Mental Health Research Network (SMaRteN), and on our project website (neuronlined.org) with a link to the participatory research agreement detailing the purpose of the research, the role of the board, eligibility criteria, the possible risks and benefits, and compensation. To ensure a diversity of views and lived experiences, the application form included questions about the applicant's level of study, neurodevelopmental condition(s), age, and gender. Applicants were informed that the Community Advisory Board would communicate primarily via email, with possible in-person or online meetings if required, and that their contribution should take no more than one hour a month for the rest of the calendar year. All eligible applicants were offered the opportunity to join a one-to-one video call with the principal investigator to ask any questions before being invited to sign the participatory research agreement.

Iterative Development

Participatory research requires an openness on the part of board members to disclose their personal opinions and experiences. In an institutional setting, the facilitation of such open conversations necessitates the creation of a safe space, where board members can be confident that their views will be accepted, even if they contradict those of others (Wicks &

Reason, 2009). To create a safe space for Community Advisory Board members, we maintained anonymity between members by letting them communicate directly with the research team, who would in turn share back anonymised contributions with the group. We also established a mixed formal and informal participation policy, ensuring that participants could reach out at any time so that the gaps often left behind by formal participation were filled with informal exchanges with the research team (Townsend, Wilkinson & Burgess, 2013).

The following documents were shared with the Community Advisory Board for feedback: (1) focus group protocol, including objectives, draft research questions, methods, setting, target sample, inclusion and exclusion criteria, recruitment process, a detailed description of the intervention, and the planned analysis; (2) participant information sheet and (3) participant consent form from the ethics application. To give Community Advisory Board members an overview of the documents and reduce potential overwhelm, the principal investigator recorded a short video walkthrough explaining the content and aim of each document. Community Advisory Board members were given one week to share their initial feedback. Some feedback was iteratively clarified over email, until the documents were ready for submission to the university's ethics committee.

Outcome Reporting

Finally, to contribute to research that is democratic, reflexive, and respectful, we collated and anonymised all the feedback received from the Community Advisory Board during the iterative development process. We created a "transparency report" detailing what action(s) were or were not taken following the feedback, and why. The transparency report was shared with the Community Advisory Board after the final version of the documents was approved by the ethics committee, with an opportunity to share any final feedback before the start of the recruitment period. Community Advisory Board members were asked to share feedback on the iterative development process itself, via an anonymous form, to contribute to the discussion section of this report, including benefits of participating in the Community Advisory Board, any challenges they faced throughout the co-design process, and opportunities for improvement for future collaborations. Finally, Community Advisory Board members were involved in the preparation of this report by reviewing the content and providing suggestions.

Outcomes of the Co-Design Process

Out of eight applications, seven eligible board members were fully onboarded to the Community Advisory Board (Table 1). The one non-eligible applicant had already graduated from their PhD, and we required the Community Advisory Board to be students currently enrolled at a UK university given that the focus of the research project was student populations. One participant asked to join a one-to-one video conversation with the principal investigator, which improved accessibility during the recruitment process. Within the Community Advisory Board, four different conditions were represented: ADHD, ASD, dyslexia, and dyspraxia. There were five female (71.4%), one male (14.3%) and one non-binary (14.3%) students in the Community Advisory Board, with an average age of 29.3 years ($SD = 9.48$; range 19 – 45 years). As the intersection of gender diversity and neurodiversity is of considerable interest, the presence of a non-binary Community Advisory Board member to contribute their perspective is especially valuable (Van Schalkwyk, 2018). In terms of level of study, two members were studying for a bachelor’s degree at the undergraduate level (28.6%), two members were studying for a master’s degree at the taught postgraduate level (28.6%), and three members were studying for a PhD at the research postgraduate level (42.8%). The ethnicity of the Community Advisory Board was highly homogenous, with only one Black student and six students from a white background.

Table 1

Demographic data of the Community Advisory Board.

Neurodiversity	Level of Study	Gender	Ethnicity
Dyslexia	Taught Postgraduate	Female	Black
ADHD, Dyspraxia	Research Postgraduate	Female	White (British)
ASD	Undergraduate	Female	Any other white background
ADHD	Taught Postgraduate	Female	White (British)
ASD	Undergraduate	Male	White (British)
ADHD, Dyslexia	Research Postgraduate	Female	White (British)
ADHD	Research Postgraduate	Non-Binary	White (British)

Collaborating with a Community Advisory Board of neurodivergent students to co-design the focus groups study as co-researchers led to several improvements to the research design (Table 2). The diversity of perspectives and lived experience of

neurodiversity allowed for the identification of blind spots and strengthened the generalisability of the findings. For instance, the research team did not notice the formatting issues in the documents, which were identified by the two dyslexic members of the Community Advisory Board. The feedback we received from neurodivergent students prior to recruitment helped improve the accessibility of the documents and the focus group discussions themselves. We also provided additional clarifications to ensure the psychological comfort of participants, such as definitions of key concepts to be discussed, different formats for the materials, and pronouns to address members of the research team.

Table 2

Suggestions and outcomes for the feedback provided by the Community Advisory Board.

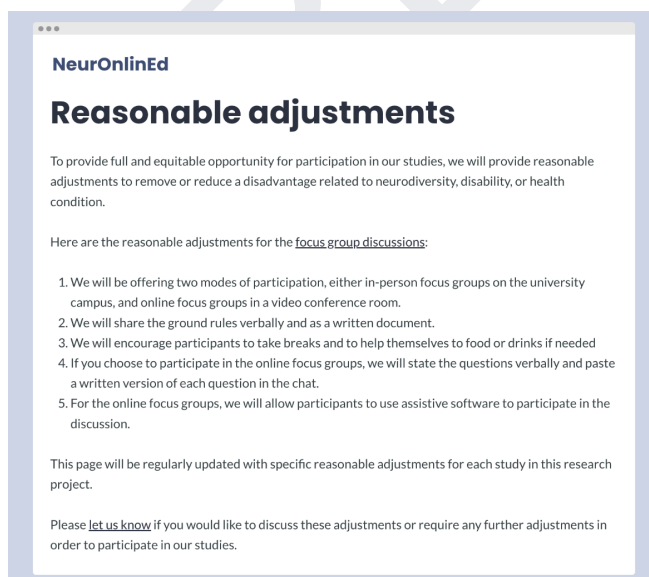
Suggestion	Outcome
Shorten and reformulate some of the content of the information sheet to make it easier to digest	The content was reformatted and shortened, and some sections were broken down into bullet points.
Provide clarifications for definitions, inclusion/exclusion criteria, and risks of taking part	The definition of cognitive load was clarified, we gave more details about the inclusion/exclusion criteria especially regarding co-occurring conditions, and we expanded on the risks of taking part.
Provide additional material or different formats to support neurodivergent participants	We will record a short introductory video, but for the purpose of following ethical guidelines, we will still need the participants to read and consent to the content of the information sheet.
Fix formatting issues	We ensured we are using the same font throughout, and the information sheet has been converted to an online webpage so the font and line spacing can be adjusted by potential participants.
Provide pronouns to address members of the research team	We provided pronouns for all research team members mentioned in participant-facing documents.
Add a section detailing reasonable adjustments to make the focus groups accessible	To keep the information sheet to a reasonable length, reasonable adjustments will be included in the introduction of the focus groups. For instance, to ensure the online and face-to-face groups provide a similar experience, we will encourage participants to turn their camera on for online focus groups, though this will not be enforced.

Following the iterative development of the research design through collaboration with the Community Advisory Board, ethical approval was granted immediately with only minor

suggested revisions. The suggested revisions from the Ethics Committee were as follows: (1) Please note if you will be recruiting via any private social media groups you will need gatekeeper permission from the administrator of the group; (2) Please ensure participants are aware it may not be possible to withdraw focus group data. This should also be clear in the information sheet; (3) Please ensure it is clear in the information sheet that participants will be split into neurodivergent and neurotypical groups. While all of these were already mentioned in the documentation, we further clarified each element to address the Ethics Committee's suggestions. Once the revisions suggested by the Ethics Committee were implemented, the research team created a transparency report collating the feedback received from the Community Advisory Board, how it was implemented, and detailing the changes made in response to the feedback received from the Ethics Committee. The transparency report offered an opportunity for the Community Advisory Board to share any final suggestions. This last round of feedback resulted in the creation of a page on our website stating which reasonable adjustments would be made available during the focus groups to remove or reduce any disadvantage related to the participant's neurodivergence, to provide opportunities for full and equitable participation regardless of personal circumstances or health status, and to account for the logistical challenges some may face because of the COVID-19 pandemic. While reasonable adjustments were implicitly mentioned in the protocol and information sheet, the page on our website offered a central place for potential participants to consider reasonable adjustments as part of their decision to participate (Figure 1).

Figure 1

List of reasonable adjustments on the project website.



Based on guidelines for conducting inclusive and accessible focus groups (Nind, 2008; Wattenberg, 2005), these reasonable adjustments included: (1) Offering two modes of participation, either in-person focus groups on the university campus, and online focus groups in a video conference room; (2) Sharing the ground rules verbally and as a written document; (3) Allowing participants to take breaks from the conversation, for example to help themselves to food or drinks if needed; (4) For the online focus groups, stating the questions verbally and pasting a written version of each question in the chat; (5) For the online focus groups, allowing participants to use assistive software to participate in the discussion. As these adjustments were either implicitly or explicitly included in the protocol, collating them in one central place for the participants' convenience did not require applying again for ethical approval.

Lessons Learned

Implementing a participatory neurodiversity research design resulted in added constraints. Developing the study protocol and supporting documents in partnership with the Community Advisory Board required more planning and longer timelines compared to traditional approaches where a smaller team needs to reach consensus before submission for ethical approval. A higher number of stakeholders also required an increased level of communication to ensure that all voices were heard and that conflicting opinions found a satisfying resolution. To ensure an equitable opportunity for participation to all Community Advisory Board members, the research team produced additional material such as the explanation video, which necessitated additional work. These constraints were in line with common challenges reported in participatory research studies (Duea, 2022). They were managed by allowing for more time for each step of the design process, and by clearly communicating expectations and milestones with all stakeholders.

In addition to being entirely manageable, these constraints were rewarded by positive outcomes, such as more accessible materials and increased psychological safety for participants in the focus group study. We can also speculate that implementing these suggestions from the Community Advisory Board led to a faster obtention of ethical approval as well as to an improved recruitment rate. The positive impact of such a collaborative approach to research design and the fact that specific issues were spotted by members with specific profiles highlights the importance of diversity in a Community Advisory Board (Newman et al., 2011). However, a limitation of our co-design process was the lack of ethnic diversity and the absence of members representing several conditions

commonly included under the neurodiversity umbrella, such as dyspraxia, dyscalculia, and Tourette’s syndrome. Ongoing recruitment will aim to address this limitation.

Besides the impact the co-design process had on the way the research team managed the research project, being part of the Community Advisory Board presented both benefits and challenges to the board members themselves. To enhance the usefulness of this report and draw practical lessons from this project, we asked Community Advisory Board members to share those benefits, challenges, as well as opportunities to improve the co-design process (Table 3).

Table 3

Benefits and challenges of joining Community Advisory Board in Participatory Neurodiversity Research

Benefits	Challenges	Opportunities
<ul style="list-style-type: none"> • Personal feeling of better representation and inclusion (x4) • Greater understanding of research process (x3) • Getting involved in research outside of own area of expertise (x1) • Better understanding of neurodiversity in general (x3) • Better understanding of own neurodiversity (x1) • Helping expand awareness of neurodiversity (x2) • Contributing to research that could lead to changes in policy (x2) • Increasing collaboration and discussion (x1) • Helping improve accessibility of research documents (x1) 	<ul style="list-style-type: none"> • Learning how to articulate certain aspects of own neurodiversity (x2) • Distinguishing between aspects of own neurodiversity and other’s neurodiversity (x1) • Lack of initial clarity as to roles and expectations, which was later clarified (x1) • Lack of clarity as to when the research team would need support (x1) • Anonymous nature limits interaction with other board members (x1) • Keeping up with email communication (x1) • Finding time to read and understand the material (x1) • Feeling of not contributing enough (x1) 	<ul style="list-style-type: none"> • Hosting group sessions for members who are comfortable breaking anonymity (x3) • Planning mock research experiments for members to identify the most stressful aspects of participation (x1) • Keeping on producing explanatory videos for each phase of the project (x1) • Recruiting more members to increase diversity of the board (x1) • Increasing compensation for board members (x1)

The most mentioned benefit was a personal feeling of better representation and inclusion. A board member wrote: “Personal feeling of better representation and a sense that neurodivergent needs were being met with care and attention right from the start with study design and continued consideration throughout.” Another member wrote: “Feeling heard when expressing difficulties encountered during studies.” Members also mentioned a greater understanding of the research process, a better understanding of neurodiversity, and a better understanding of their own neurodiversity as benefits of joining the Community Advisory Board. Two members said a benefit was to contribute to research that could lead to changes in policy to better support neurodiversity. However, Community Advisory Board members faced some challenges, including difficulties in learning how to articulate certain aspects of their own diversity and distinguishing between aspects of their own diversity versus others’ neurodiversity. While expectations were later clarified, some elements of the collaboration process could have been better communicated by the research team, including roles and timelines. As the research team reached out to the Community Advisory Board members on an ad hoc basis, it has been difficult for some members to keep up with communication.

Several opportunities for improvement were suggested by the Community Advisory Board for the next phases of the research. By far, the most popular idea is to allow members who are comfortable breaking anonymity to interact between themselves, for example by organising group sessions to discuss the research. While the initial decision to maintain anonymity was motivated by the desire to foster psychological safety, recent research suggests that anonymity impedes active contribution and shared ownership in participatory research (Godfrey-Faussett, 2022). In addition, psychological safety can be achieved through creating a cohesive bond based on strong interpersonal relationships and can help maintain trust and collective action (Armstrong et al., 2022; Christens & Speer, 2015). The mismatch between the research team’s intention and the perception of the Community Advisory Board members highlights the importance of collecting feedback on the participatory research process itself, which is an important tool to foster reflexivity and encourage a constant re-evaluation of known and unknown assumptions (Olmos-Vega, Stalmeijer, Varpio & Kahlke, 2022). Community Advisory Board members also suggested to plan mock research experiments which would allow them to point out any potential stressors or sources of discomfort for participants; to keep on producing explanatory videos for each stage of the research collaboration; and to recruit more members to increase the diversity of the board. Finally, one board member suggested a higher compensation for their contribution, which was addressed thanks to additional funding.

In terms of next steps, we will implement all other recommendations in the next stages of the research collaboration, and in future co-design projects. In particular, we will host regular online meetings with members of the Community Advisory Board members to foster a belonging and shared experience, we will plan mock research experiments with Community Advisory Board members, and we will recruit more members to increase the diversity of the board. This last step will be crucial as community-based participatory research is viewed as a way to engage under-served groups, but only if they have the opportunity to participate with equitable involvement in all phases of the research process (Rochester & Carroll, 2022).

While this report focuses on the co-design process, partnering with a Community Advisory Board should not stop after ethical approval has been obtained and recruitment has started. As co-researchers, Community Advisory Board members can contribute a range of insights at all following stages of the research process, from data analysis, reporting, and dissemination. As both participatory research and neurodiversity research are in their infancy, our hope for this participatory neurodiversity research report is to inspire the systematic inclusion of neurodivergent co-researchers, with the aim of fostering long-term relationships that can inform the entirety of the research process and improve the chances that research findings turn into actionable change.

Conclusion

The aim of this report was to document the methods, outcomes, challenges, and benefits of co-designing a focus groups study with a Community Advisory Board. While participatory neurodiversity research creates additional constraints for the research team, it also results in increased quality and potential impact of the research through democratic, reflective, and inclusive practices. Notably, the Community Advisory Board members themselves experienced a range of benefits such as a better feeling of representation and inclusion, a greater understanding of the research process, and a better understanding of neurodiversity. They also experienced challenges such as learning how to articulate certain aspects of their own neurodiversity, keeping up with email communication, and finding the time to read and understand the material. To further improve the co-design process in future participatory neurodiversity research studies, the Community Advisory Board made several suggestions such as host group sessions for members who are comfortable breaking anonymity, planning mock research experiments, and recruiting more members to increase the diversity of the board. These suggestions will be implemented in the next stages of the research collaboration, and in future co-design projects.

Acknowledgements

We would like to thank the members of our Community Advisory Board, including those who could not contribute to this report as a co-author, for their continuous support and feedback throughout the research process.

Funding

This project received funding from the UK Research & Innovation (UKRI) Participatory Research Fund to produce a report detailing the process of co-designing a research study with a Community Advisory Board.

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