

Disability-Inclusive Research Co-Design Guide

Training & Best-Practice Resource | Accessible Adaptive VR | NeuroViu

Purpose. This guide helps research teams engage people with lived experience of disability as contributors to study design, accessibility planning, technology development, participant-facing materials, procedures, and interpretation safeguards. The goal is to move from one-time feedback toward a traceable process in which lived-experience input can influence research decisions.

Core principle. Meaningful engagement requires more than asking whether a finished study is accessible. Research teams should identify decisions that participants and lived-experience contributors can genuinely influence, make the engagement process accessible, document recommendations, and show what changed or why a recommendation could not be adopted.

1. Define the Decisions Open to Co-Design

Before engagement begins, identify which study decisions are still changeable. Examples include recruitment language, consent format, visit length, communication methods, sensory settings, physical setup, technology controls, pause/stop procedures, accommodation workflows, behavioral measures, staff instructions, and dissemination materials.

Avoid inviting contributors to 'co-design' a process when all substantive decisions have already been finalized.

2. Seek Relevant and Varied Perspectives

Disability is not a single experience. Seek perspectives relevant to the study's likely access demands and population. Depending on the research, this may include physical or mobility, sensory, cognitive, intellectual or developmental, communication or speech, chronic illness or energy-limiting, mental-health-related, and multiple or intersecting access perspectives.

Do not assume one contributor represents an entire disability community. Document the scope and limitations of the perspectives included.

3. Make the Engagement Process Accessible

Area	Questions for the research team
Communication	Can contributors participate using their preferred accessible communication method? Are materials available in usable formats and sufficiently in advance?
Scheduling / energy	Can timing, session length, breaks, pacing, or asynchronous participation be adjusted when feasible?
Physical / technology access	Can contributors access the meeting environment, platform, device, controls, or prototype being reviewed?
Sensory access	Can visual, auditory, motion, brightness, volume, or other sensory demands be adjusted when feasible?
Support	Can a support person, interpreter, communication aid, assistive technology, or other access support be used when appropriate?
Compensation	When feasible and appropriate, are lived-experience contributors compensated for their time and expertise?

4. Co-Design Session Workflow

Step 1 - Orient. Explain the study, technology, research question, known constraints, and which decisions contributors can influence.

Step 2 - Experience. When safe and appropriate, allow contributors to review or interact with the relevant materials, workflow, prototype, or research environment using needed accommodations.

Step 3 - Identify barriers. Ask what could make recruitment, consent, participation, communication, technology use, data collection, or follow-up inaccessible or unnecessarily difficult.

Step 4 - Generate options. Ask contributors what accommodations, alternatives, or design changes could reduce the identified barriers.

Step 5 - Prioritize. Discuss feasibility, safety, scientific requirements, participant burden, and which changes should be tested first.

Step 6 - Test and refine. Evaluate modifications with relevant users when feasible rather than assuming the proposed solution resolves the barrier.

Step 7 - Close the loop. Tell contributors what changed, what did not change, and why.

5. Co-Design Decision Log

Use a decision log so engagement can be traced to concrete research or technology changes.

Document	Record
Decision / component	What part of the study, technology, material, or procedure was reviewed?
Perspective engaged	Relevant lived-experience/access perspective; avoid unnecessary diagnostic detail.
Barrier / recommendation	What problem or recommendation did the contributor identify?
Research-team response	Accepted, adapted, deferred, or not adopted - with rationale.
Modification	What changed in the protocol, technology, material, environment, or training?
Follow-up	Was the modification reviewed or tested again, and what was the response?

6. Questions to Ask Contributors

Examples include: What part of this procedure would be hardest to access? What would make the instructions or consent easier to use? Is there anything about the physical or sensory environment that should be adjustable? Could the technology require a movement, communication method, or response that some participants cannot use? What could researchers misinterpret about participant behavior? What would make it easier to pause, request help, modify the procedure, or stop? How should participants be told what accommodations are available?

7. Indicators of Meaningful Engagement

Research teams can document the number and range of contributors engaged; study stages at which engagement occurred; barriers and recommendations identified; proportion of recommendations resulting in modifications; reasons recommendations were not adopted; accessibility of the engagement process itself; contributor feedback on whether their input was understood; and whether contributors were informed about resulting changes.

8. Integration With Accessible Adaptive VR

Co-design findings should feed directly into the **Barrier -> Accommodation -> Participant Response -> Design Modification** process. Relevant changes can then be reflected in the Accommodation Planning Form, Participant Pause/Stop/Modification Procedure, Behavioral Data Interpretation Safeguards, study protocol, participant materials, technology, and staff training.

Implementation note. The original eight-participant Skyward Sojourn study was not designed as a disability co-design study and disability status was not systematically documented. This guide supports the current pilot/refinement phase of the broader Accessible Adaptive VR framework and future ethically reviewed implementation. It should not be used to characterize the earlier study as evidence of disability engagement.

Scope note. This guide is intended for adaptation and does not replace community-specific expertise, institutional accessibility requirements, ethics review, or applicable law.