
Checklist

for the realization of participation-oriented research with
people with profound and multiple disabilities (pimd)



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The present checklist for the realization of participation-oriented research with people with profound intellectual and multiple disabilities (PIMD) is based on the draft "Indisputable elements in the design of participation-oriented research with people with profound intellectual and multiple disabilities" (unpublished manuscript) and on the paper "Sensitive Interpretation of Communication (SeKD)" (<https://zenodo.org/record/6373109#.Yl02CdPP02w>), which were created by students in the context of the M.A. Rehabilitation Sciences under the supervision of Dr. Caren Keeley and with the collaboration of Timo Dins at the University of Cologne.

This checklist is currently under evaluation, and you are welcome to participate in this process. Feel free to send your feedback to ckeeley@uni-koeln.de.

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Overarching aspects

Realizing participation-oriented research means to carefully consider several overarching aspects throughout the research process. These are:

- Recognizing the possibilities and needs regarding the communication of the respondents, which includes a mindful and sensitive attention to signs of discomfort/communication signs.
- Empowering respondents to communicate their own preferences and needs in the research process (which also entails to ensure informed (ongoing) consent at all times)
- Developing, designing and realizing the research process in a multi-method way and considering multi-perspective approaches
- To be aware of and take into account all resources needed as well as available (including time, material or social/professional support)
- Recognizing (critical) reflection on the research process as a central and accompanying element.

Notice:

The sub-items of the checklist serve for your own reflection regarding the participation-oriented realization of your own research project(s). Each sub-item has been supplemented with space for own notes, so that possible particularities, limitations or challenges of the respective research process can be mentioned.

a. Preparation

- (How) Have I/have we dealt in advance with the reality of life of the people with whom I/we want to do research? How did I/ did we introduce ourselves and get to know each other?

- What biographical information should I/we take into account in the research?

- What should I/we consider about the environment of the person with whom I/we want to do research (e.g., important people, certain routines that the person enjoys, etc.)?

- What knowledge about communication opportunities and interaction patterns is relevant to the research? What communicative possibilities do I/we expect?

- How can I/we best organise joint communication (e.g. use of augmentative and alternative communication (AAC) or inclusion of important caregivers)?

- How can signs of discomfort be identified (e.g., facial expressions, gestures, or considering the interpretation of caregivers)?

- Which methodical approaches have I/we developed in advance (in order to prepare well for getting to know each other) and do we/I have alternative methods / multimodal ways of approaching the person at hand?

- (How) Have I/ have we prepared the project information in a way that is appropriate and accessible for the target group?

- [Did I/did we involve people with PIMD in the application process of the research project]?

- [To what extent) Have I/ have we considered professional and material resources as well as enough time for the different steps in the research process?

Additional comments:



b. Documentation of the process of getting to know each other and the consent process

- (To what extent) Did I/did we succeed in making the questions and goals of the research project understandable? What evidence is there to support or oppose this?

- If unclear/uncertain: What justifies continuing the research process even without clear signs of understanding the research questions and goals (e.g., involving the opinion of long-term social contacts like parents or caregivers)?

- (To what extent) Can I/we also assume trust and consent to future meetings in the further course of the research process? What evidence is there to support or oppose this?

- (How) Did I/ did we consider a "reflective validation" (evaluating one's interpretation) through proxy consent? [Applies to all participants and also to proxy consent itself, as well as to (informed) consent of those involved]

Note: In case of ambiguity/uncertainty, long-term social contacts would have to be consulted and, if necessary, future meetings should be cancelled.

Additional comments:



c. Research process

- (How) Have I/we succeeded in (repeatedly) specifying the research question and objectives in concrete terms so that the respective planning steps can be carried out as participatory as possible?

- (To what extent) Did I/we succeed in making the questions and goals of our research comprehensible again and again in the further course of the research process? What evidence is there to support or oppose this?

- In case of ambiguity/uncertainty: What justifies continuing the research process even without clear signs of understanding the research questions and goals (e.g., involving the opinion of long-term social contacts like parents or caregivers)?

- (To what extent) Can I/we continue to assume trust and consent to future meetings as the research process continues? What evidence is there to support or oppose this?

Note: In case of ambiguity/uncertainty, long-term social contacts would have to be consulted and, if necessary, future meetings should be cancelled.

- (How) Have I/we designed multi-method approaches that make it possible for me to approach the subjective views of the participants and their everyday reality as closely as possible?

- What methodological approaches have I/we developed in advance to make the research process participatory?

- (To what extent) Was it taken into account that different methodological approaches could be used (e.g., if a methodological approach proves to be unsuitable when meeting the person(s))?

- (How) Did I/ did we involve supporters and/or other long-term social contacts? (To what extent) Were different perspectives consulted in the research (e.g., by close people, professionals from other professions or institutions, etc.)?

- (To what extent) Was it possible to take into account the knowledge gained in advance about the reality of the life of the person with whom I/we want to do the research? Did these prove useful? What new information did I/we gain that I/we were not previously aware of?

Additional comments:



d. Communicative behavior¹

o (How) Did I offer AAC resources and include them in the conversation?

o (How) Did I listen actively?

E.g., by asking questions or giving brief feedback.

o (How) Did I give feedback on how I understood certain utterances?

Please also ask yourself: Is it appropriate to give this feedback in the given situation? And please be descriptive here, not interpretative.

o (How) Have I used circular questions?

Questions that focus on the impact of a behavior within the system.

o (How) Did I focus on what I saw/heard/etc.?

Include only what can be perceived in interpretation, strive for objectivity, knowing that it does not exist without limitations.

o (How) Did I consider the context/situation?

Is it quiet or rather noisy? Are we in familiar surroundings or are there many new impressions that need to be processed in parallel? Do I perceive the person as stressed, anxious, or agitated?

¹ Fleischmann, Madita; Lange, Charlotte; Schüssler, Ilay (2022): Wie Kommunikation von Menschen mit Komplexer Behinderung angemessen deuten? Handlungsideen für sensiblen Umgang mit Interpretationen individueller Ausdrucksmöglichkeiten - Eine Handreichung für Unterstützer*innenkreise. (<https://doi.org/10.5281/zenodo.6373109>) <https://zenodo.org/record/6373109#.YlO2CdPP02w>

o (How) Did I paraphrase/verbalize?

Repeat utterances in own words or put gestures, etc. into words to clarify what I understood. This can convey what I interpret and I can have my interpretation confirmed if necessary.

o (How) Did I endure pauses and give enough time to understand and respond?

o (How) Did I use reframing?

Reinterpreting the other person's remarks, giving them a new framework

o (How) Did I define goals (of the communication), if applicable?

Clarify the goal of the communication to make it clear what you are trying to achieve. Even if communication does not always have to be goal-oriented, it can be helpful to clarify intentions for oneself beforehand or, under certain circumstances, to communicate them as well

o Have I used "I" messages?

Communicate own feelings, needs, expectations and perceptions, be open / transparent / congruent / authentic.

o Did I reflect on my emotions and communicate them if necessary?

Did the communication trigger something in me (provocation, frustration, stress, approval, etc.)?
Did it influence my further actions?

o Did signs of discomfort appear?

Additional comments:



e. Data analysis and feedback of results

- (To what extent) Is participation in the evaluation conceivable and designable?

- (How) Have I/have we made the process conclusion recognizable and experienceable?

- (How) Did I/ did we design the presentation of results in a manner that is accessible to the person(s) involved (depending on their „cognitive /intellectual development“)?

- (How) Did I/ did we transfer the results back into practice?

Additional comments:
