2024

Considerations When Planning Collaborative Research in FASD

Information for Research Teams

CanFASD
CANADA FASD RESEARCH NETWORK

Increasingly, people with lived experience of FASD, including caregivers and individuals with FASD, are calling for involvement in the development, implementation, and knowledge translation components of FASD research.

Although *nothing about us* without us has been a mantra in the disability field for decades, much of the research in FASD has occurred independent of those most affected by prenatal alcohol exposure.

At the 8th International Research Conference on Adolescents and Adults with FASD, we conducted a workshop discussing the issues which may impact our ability to conduct collaborative research in the field of FASD. The following document provides a list of issues you may wish to consider if you choose to do collaborative research in the field of FASD from the lens of individuals with FASD and their caregivers. There are a number of different research approaches that have emerged from different disciplinary traditions, and all are on a spectrum with regard to community participation. This document is not specific to any specific approach but more generally aligns with community-based participatory action research.

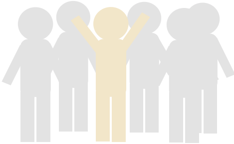
The following list of considerations will be explained further:

1. **Benefits**
2. **Unique Needs**
3. **Informed Participation**
4. **Reaching Potential Collaborators**
5. **Shared Leadership**
6. **Intellectual Property Ownership**
7. **Time/Support**
8. **Financial Supports**
9. **Common Language**
10. **Unconscious Bias**
11. **Support to Participants During and Following Research**
12. **Safeguarding**

1 Benefits

- Have you considered any potential benefits for the collaborators?
- Can you describe the potential benefits (and risks) in an understandable way?
- Are the benefits of participation worth it? For example, will the outcome support the advocacy for more services or supports?
- Have you conversed with collaborators about what would make research participation worth it for them? For example, collaborators may wish to build their research capacity in some way(s).

2 Unique Needs



Have you considered the unique needs of your collaborators?
For example:

- The lack of opportunity in smaller communities.
  - *Can you take the research planning out to them or use online platforms for research team meetings?*
- Rural and Indigenous populations are currently underserved.
  - *Is it possible to include the voice of those groups of individuals?*
  - *Are you examining the needs for support and services for those groups?*

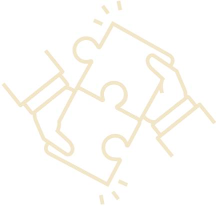
3 Informed Participation

Prospective participants need to know who is doing research and what the research is about. This information needs to be explained in a manner that will be easily understood with written versions to aid memory.

- What are the processes you use to ensure that individuals with FASD and/or caregivers fully understand the requirements of collaborating in research?
- How is this information shared?
- Have you provided a diversity of formats including written and visual formats to accommodate different strengths and processing of information?

4 Reaching Potential Collaborators

- What information are you providing to potential collaborators about what the research is about or what opportunities are available?
- Are you using all possible avenues to inform potential collaborators?
- Are you providing space for collaborators to contribute their ideas regarding methods for reaching out to other potential collaborators?



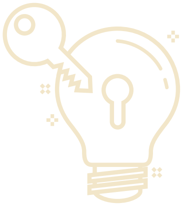
5 Shared Leadership

Collaboration requires shared leadership through all the stages of the research.

- How are you fully incorporating the voice of individuals with lived experience in your research plan? Keep in mind that fully incorporating collaborators' voices means addressing collaborator priorities in your research questions/objectives.
- Are there opportunities for people with lived experience to help shape your research question, methods, and/or knowledge translation?
- Have you had conversations with collaborators to understand their expectations with respect to shared leadership?
- How are you providing space for collaborators to share their knowledge and expertise throughout the research process?

6 Intellectual Property Ownership

- To what extent are collaborators being treated as owners of the intellectual property of the research?
- Have you and your collaborators discussed expectations and needs regarding intellectual property in a way that is safe for collaborators to assert their perspectives?



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Time/Support

- What kind of support are you able to provide collaborators?
- Are you providing support to collaborators? Is this support online or in person?
- How can you make allowances for collaborators to manage their personal lives while participating as a collaborator?
- Are you making accommodations to have flexible meeting times?
- Are you sharing materials with your collaborators in advance?
- Are these materials in a diversity of formats to support diverse needs and preferences for understanding information?
- Can you provide funding for travel or respite? Can you provide child minding services during research team meetings?
- Is there the flexibility to build and maintain connections with varied people, such as family, people with FASD, service providers, and researchers in your research plan/proposal?
- What resources are you including in your grant application to facilitate inclusion of individuals with lived experience?

8

Financial Supports

Participants need financial support including support for transportation, respite, honoraria, meals, their support person, etc. The financial cost of participating in or collaborating in research cannot be born by individuals with lived experience (i.e., caregivers, support people, or individuals with FASD).

- What kind of financial support can you offer individuals with FASD or caregivers who wish to participate in your research?

9

Common Language

- Are you able to communicate the research question, methods, etc., in a language that will be understood by all participants and research collaborators with lived experience?

- Current knowledge translation typically does not meet the needs of all parties.
  - How will you ensure that diverse needs are met through knowledge translation?
  - Do you have a mechanism in place for collaborators to contribute their ideas regarding knowledge translation?

- Are you planning to provide plain language summaries of your results?

- What other kinds of resources might be helpful for participants and research collaborators with lived experience?

- How are you planning to make those resources available to your participants and to individuals with lived experience more broadly?

10

Unconscious Bias

Current research commonly does not recognize strengths but rather focuses on deficits.

- To what extent can your research adopt a strength-based lens?

- Are the questions you are asking leading or asked in a way that may bias the responses?

- Is there an unconscious bias in the research you are interested in conducting?

11 Support to Participants During and Following Research

How are you supporting collaborators and participants following their involvement in your research.

- Are you considering the after-effects your research protocol may have on participants and are you providing support following their involvement in the research?

12 Safeguarding

People with challenges around comprehension can easily misinterpret communication. Sometimes people will take questions as facts, especially regarding personal history. The ‘memories’ can become confused with those presently in their lives leading to false allegations.

- Consider how you might put safeguarding measures in place to protect caregivers and yourselves against allegations of inappropriate conduct.
- How will you make sure the people can understand your questions?

This document is not an exhaustive list of the considerations that a researcher may need consider when planning a collaborative research project but is based on the collective wisdom of a large (80) group of caregivers, service providers and policy makers in the field of FASD. It is designed as a planning, discussion tool to assist you in considering factors which may impact the success of your collaborations.