Stages of the Research Cycle (Model Framework)

**Deciding what to research**
- Request from Commonwealth of Australia Department of Health and Ageing (DoHA) to undertake project to develop a diagnostic instrument for FASD in Australia (FASD Project)

**Deciding how to do it**
- Agreement with DoHA to undertake FASD Project
- Australian FASD Collaboration (Collaboration) established

**Doing it**
- Systematic literature review
- Community conversations
- Development of questions for Delphi survey
- Participants for Delphi survey identified
- Delphi survey with health professionals
- Data analysed
- Consensus development workshop to develop the diagnostic instrument
- Clinicians and consumer sub-groups to finalise instrument and accompanying guidelines

**Letting people know the results**
- Final report produced
- Papers published in journals
- Information on Alcohol, Pregnancy & FASD website
- Community Conversation participants provided with a report of the outcomes from the Community Conversations + uploaded to website
- All Collaboration members reviewed and approved final report and papers for publication
- All Collaboration members listed as authors on final report and published papers
- All Collaboration members disseminated information through their networks

**Knowing what to research next**
- Next steps
- Outcomes from Community Conversations and workshop will be used to inform next steps for diagnostic instrument and future policy and research
- Consumer representatives wish to continue involvement in FASD research

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FASD Project Flowchart

- Previous FASD research and recommendations in monograph + advocacy from NOFASARD & RFFADA over a long period of time
- Consumer and community involvement in project development
- Collaboration included 2 consumer and community representatives + 1 consumer advocate
- Collaboration members
- Community Conversations held in Western Australia and Queensland with 32 participants
- Statements from Community Conversations used to inform Delphi survey for health professionals
- All Collaboration members identified participants
- All Collaboration members reviewed and approved survey questions
- All Collaboration members considered the evidence from the literature review, Community Conversations and Delphi survey and used consensus to develop the content of the diagnostic instrument
- Consumer and community representatives developed: Information on FASD Assessment for Parents and Carers; Information for clinicians on the issues patients and their parents or carers may experience during the diagnostic process; and a Consent Form
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