

# GRADE-CERQual training worksheet

## Making a GRADE-CERQual assessment:

- Relevance
- Methodological limitations
- Coherence
- Adequacy
- Making an overall assessment (**PARTIALLY PRE-FILLED**)

## FASD example



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## Exercise: Making a GRADE-CERQual assessment

The example below is based on an existing qualitative evidence synthesis<sup>1</sup> but the data have been slightly altered or simplified for the purposes of this exercise.

**Scenario:** You are carrying out a qualitative evidence synthesis to explore parents' and other informal caregivers' views and experiences of caring for children with Foetal Alcohol Spectrum Disorders (FASD)<sup>2</sup>.

The review includes studies:

- from any country
- that explore parents' and other caregivers' experiences of raising children with FASD. These could include biological parents, relatives, adoptive parents, or foster parents
- that use qualitative methods for data collection (e.g. observation, open individual or group interviews, document analysis) and qualitative methods for data analysis

The review is produced and includes 14 qualitative studies. The review presents a number of findings, including the following:

**Summary of the review finding<sup>3</sup>:** Parents and other caregivers experience a lack of understanding and knowledge about FASD among different types of service providers, including healthcare providers, social workers, educators and members of the police force.

This review finding was based on data from six of the included studies. The remaining studies did not offer any data that was relevant for this finding.

Table 1 and 2 present information about these six studies and show the data on which this particular review finding was based. Using the information you find in Tables 1 and 2, follow the exercises below to assess the four CERQual components, before making an overall CERQual assessment of confidence in the evidence.

*In these exercises, assume that you are the author of the review on FASD.*

<sup>1</sup> The reference for the full synthesis is: Domeij H, Fahlström G, Bertilsson G, Hultcrantz M, Munthe-Kaas H, Gordh CN, Helgesson G. Experiences of living with fetal alcohol spectrum disorders: a systematic review and synthesis of qualitative data. *Dev Med Child Neurol.* 2018;60(8):741-752.

<sup>2</sup> Fetal Alcohol Spectrum Disorders (FASD) are a group of conditions that can occur in a person whose mother consumed alcohol during pregnancy. These effects can include physical problems and problems with behavior and learning. Often, a person with an FASD has a mix of these problems. (From: <http://fasdcenter.samhsa.gov/aboutUs/aboutFASD.aspx#1>)

<sup>3</sup> This is a summary of the full finding. You should be able to do the exercise using the summary. However, in the full qualitative evidence syntheses, the finding is also presented in more detail.

## Exercise 1: Assessing relevance

**Relevance:** The extent to which the body of data from the primary studies supporting a review finding is applicable to the context specified in the review question. By “context” we refer to a complex and interacting composite that includes, but is not restricted to, the perspective or population, the phenomenon of interest, and the setting.

We are less confident that the review finding reflects the phenomenon of interest when the contexts of the primary studies underlying a review finding are substantively different from the context of the review question.

Concerns about relevance fall into three groups:

- Indirect relevance – included studies do not directly reflect the review question
- Partial relevance – included studies only represent a subset of the review question
- Unclear relevance – the extent to which the included studies reflect the review question is unclear

### What to do

1. Assess the extent to which the studies presented in Table 1 are applicable to the context specified in the review question
2. Decide whether any concerns you have are serious enough to reduce your confidence in the review finding
3. Note your provisional assessment in Table 3, including notes about any concerns
4. If there is time, discuss how these concerns could be addressed in future research

### Tips

Is there anything about the studies that raises concerns about their relevance? For instance:

- Time (e.g., were the studies conducted too long ago to be relevant?)
- Setting (e.g., is the country or place of care relevant?)
- Phenomenon of interest (e.g., is the phenomenon of interest in the study different from the one specified in the review question?)
- Perspective (e.g., do we only have information about a subset of the population of interest?)

## Exercise 2: Assessing methodological limitations

**Methodological limitations:** The extent to which there are *concerns about the design or conduct of the primary studies* that contributed evidence to a review finding.

We are less confident that the review finding reflects the phenomenon of interest when the primary studies underlying a review finding are shown to have problems in the way they were designed or conducted.

The methodological limitations of contributing studies are assessed using an appropriate critical appraisal tool for qualitative studies.

### What to do

1. Look at the assessments of methodological limitations in Table 2 (a simplified critical appraisal table)
2. Decide whether any concerns you have are serious enough to reduce your confidence in the review finding
3. Note your provisional assessment in Table 3, including notes about any concerns
4. If there is time, discuss how these concerns could be addressed in future research

### Tips

Where methodological limitations have been identified, think about the following issues:

- Is this particular limitation likely to have had a serious impact on the review finding? Some limitations may be more serious than others and other limitations may be serious for some review findings but not for others. For instance, the use of some methods of data collection may be particularly inappropriate for some review findings but not others
- Where some of the studies have serious limitations, what is the relative contribution of these studies to the review finding? If these studies are key studies, this is of more concern. If these studies contribute little to a finding, this may be less of a concern.

## Exercise 3: Assessing coherence

**Coherence:** How clear the fit is between the data from the primary studies and the review finding.

We are less confident that the finding reflects the phenomenon of interest when the fit between the data from the primary studies and the review finding that synthesizes these data is not completely clear. This may be because patterns in the data are not well explored or explained.

### What to do

1. Assess the extent to which there is a clear fit between the data in Table 1 and the review finding
2. Decide whether any concerns you have about coherence are serious enough to reduce your confidence in the review finding
3. Note your provisional assessment in Table 3, including notes about any concerns
4. If there is time, discuss how these concerns could be addressed in future research

### Tips

- Discuss whether the finding is more descriptive or more explanatory. You may have concerns regarding coherence where you have:
  - Contradictory data – Some of the data from included studies contradict the review finding.
  - Ambiguous data – It is not clear if some of the underlying data support the review finding because key aspects of the underlying body of evidence may be vaguely defined or described or defined in different ways.
  - Alternative explanations – For more explanatory findings, there may be plausible alternative descriptions, interpretations or explanations that could be used to synthesize the underlying data and these competing theories may not been explored or assessed by the review authors.
- Varied data or ambiguous data must either be reflected in the review finding or discussed and represented in the assessment of coherence.

## Assessing adequacy of data – completed in advance

**Adequacy of data:** The degree of *richness* and *quantity of data* supporting a review finding.

We are less confident that the finding reflects the phenomenon of interest when the data underlying a review finding are not sufficiently rich or only come from a small number of studies or participants.

### Tips

You may have concerns regarding the adequacy of the data if:

- these do not provide you with sufficient detail to gain an understanding of the phenomenon described in the review finding
- the review finding is supported by data from only one or very few studies, participants or observations

For review findings that are simple and primarily descriptive, relatively superficial data may be sufficient. Some review findings, however, are more complex or explanatory, for example when they suggest associations or relationships between different factors. For such findings,

you are more likely to have concerns regarding data adequacy if the finding is based on data that are too superficial to allow a sufficient exploration of the phenomenon.

## Exercise 4: Assessing your overall confidence in the finding

**CERQual level of confidence:** An assessment of the extent to which the review finding is a reasonable representation of the phenomenon of interest.

CERQual levels	Definition of level of confidence in a review finding
High confidence	It is highly likely that the review finding is a reasonable representation of the phenomenon of interest
Moderate confidence	It is moderately likely that the review finding is a reasonable representation of the phenomenon of interest
Low confidence	It is possible that the review finding is a reasonable representation of the phenomenon of interest
Very low confidence	It is not clear whether the review finding is a reasonable representation of the phenomenon of interest

### What to do

- Make an overall assessment at the bottom of Table 3 based on your assessment of the four components.
- We start with having “high confidence” in a review finding. Downgrade your confidence if you have serious concerns about one or more of the components.
- This assessment is a judgement. Be transparent and explain your assessment.
- If there is time, specify how any concerns could be addressed in future research

### Tips

While you may have concerns about a single component, you may be uncertain about whether these concerns are serious enough to lower your confidence. Where you have some (but not very serious) concerns about more than one component, one option is to downgrade once (i.e. from “high confidence” to “moderate confidence”) to reflect your concerns with several CERQual components.

**Table 1: Study description and extracted data**

*(Remember that some of the data presented here have also been used by the review authors to support other findings in the review)*

REVIEW FINDING: Parents and other caregivers experience a lack of understanding and knowledge about FASD among different types of service providers, including healthcare providers, social workers, educators and members of the police force.				
STUDY #	QUESTION / OBJECTIVE	STUDY SETTING	STUDY PARTICIPANTS	EXTRACTED DATA
Study 1 - 2013	The struggle to bring up a child with FASD.	UK	30 (?) adoptive-, foster- or birth parents.	“Many of the families reported difficulties in getting appropriate and sufficient support from professionals they met. This included doctors, social workers and educators. This led to greater perceived difficulties and the impression that they had nowhere to turn to obtain answers about how to best support their children”- <u>theme Lack of knowledge among professionals</u> . “Often families reported that as a result of this lack of knowledge about FASD, they were blamed for poor parenting rather than supported by professionals”. - <u>theme Feeling misunderstood and blamed</u> .
Study 2 – 2006	Understand the perspectives of the families who received these services. Diagnostic process and experiences of families.	FAS-diagnostic clinics, rural and urban settings across Alaska, USA	Parents of 5 FASD students (aged 3-19 years, 4 boys; one with FAS, others alcohol exposed). Foster parents of three, biological parent of two, adopted parent of one, grandmother of one.	“Many of the parents felt that they did not receive the help they needed from the social service agencies.”- <u>theme Limited or No Support</u> .
Study 3 - 2008	Describe the lived experiences of New Zealand-birth mothers, from pregnancy onwards, of a child diagnosed with FASD. Experiences of birth mothers of children	FASD-agency, probably urban, Hamilton, New Zealand	8 birth mothers (29-64 years) of 9 FASD children (FAS, FAE, pFAE <sup>4</sup> )	“During pregnancy, labour, delivery and the postpartum period, the women found themselves in the midst of many different medical and health professionals. The women expected that these professionals would show empathy and support as well as knowledge. However, the women said that they did not experience this, being left to cope the best way they could with their ‘different’ child.”- <u>Theme Medical and Health Professionals Abandon the Mothers</u> “It was also common for the professionals to confuse FAS with Down syndrome (because of the similar facial characteristics) or ADHD <sup>5</sup> .”- <u>theme Theme Medical and Health Professionals Abandon the Mothers (Mothers want a diagnosis for their child)</u>

<sup>4</sup> FAE: foetal alcohol effect; pFAE: possible foetal alcohol effect.

<sup>5</sup> ADHD: Attention deficit hyperactivity disorder.



	diagnosed with FASD.			<p>“Since the women and their disabled children were seen as a burden on the educational system, they were generally viewed negatively and without empathy by school teachers. The teachers took no interest in the child and could not be bothered to listen to the birth mothers.”-<i>theme Birth Mothers and their Children are Unsupported in the Educational System (Mothers not listened to by teachers)</i></p> <p>“The women said that since the teachers had little or no knowledge of FASD, the disabled child was labelled as lazy, naughty, spoilt, dumb. They appeared unable to comprehend that the child’s behaviour was not of his or her own making”- theme <i>Birth Mothers and their Children are Unsupported in the Educational System (Child’s behaviour not understood by teachers)</i></p> <p>“It is not uncommon for the child with FASD to participate in petty crime, for which the mother is blamed. The eldest mother, who was working full-time, recalled her encounter with the police: “I’m trying to work and he was pinching my car and pinching my little scooter...Taking off at nine and of course, they said “Why aren’t you watching him?” and I said “You have to sleep sometimes”. <i>Theme- Birth Mothers are the Cause of Criminal Behaviour (Police blame the mothers for the child’s behaviour)</i></p>
<b>Study 4 - 2001</b>	Parents experiences raising a child with FASD	Community agencies, Alberta city and environs, Canada	11 parents (7 adoptive, 3 birth and 1 foster). Age: 32-59 years (mean 45,8) Raising 14 children, aged 5-21.	Some parents encountered barriers as they were seeking answers to their children’s apparent deficits. Several participants indicated that prenatal alcohol exposure was “not on (the doctor’s) radar screen”, and that aberrations in behaviour and development were dismissed as “nothing to worry about.” Frances expressed frustration with the lack of awareness of FASD exhibited by some mental health professionals: <i>theme- Something’s not right (Not on the radar)</i>
<b>Study 5 - 2001</b>	To compare the experiences of parenting stress in families with a child diagnosed with FASD	Disability support organisations across northern Ontario, Canada	31 parents of all sorts of children with FASD (age 1-36 years; mean: 16,51 years)	Parents stressed the need for knowledge in order to advocate appropriately for their children. Parents of children with FASD, in particular, also discussed having to educate doctors. (...) Therefore, parents unmistakably needed to be the expert on their children and needed to express their issues and concerns to make sure that their children received the most appropriate and necessary services and support. <i>Theme: I do it all: the multiple roles that parents play.</i>
<b>Study 6 - 2011</b>	Explore the experiences of raising a child with FASD.	UK	One birth mother and 3 adoptive mothers with 1 or several children with FASD or ARND <sup>6</sup> . Children: 6 FASD, 1 ARND Male 8, 9 and 24 years old Female 4, 5, 9, 13 years old	“All parents experienced the disability in terms of the lack of provision from professionals and services that understood the diagnosis and could support the needs of the families and their children.”- <i>theme Experiencing disability</i>

<sup>6</sup> ARND: alcohol-Related Neurodevelopmental Disorder



**Table 2: Simplified critical appraisal (quality appraisal) table**

REVIEW FINDING: Parents and other caregivers experience a lack of understanding and knowledge about FASD among different types of service providers, including healthcare providers, social workers, educators and members of the police force.							
STUDY #	METHODS OF DATA COLLECTION	METHODS OF DATA ANALYSIS	METHODOLOGICAL APPRAISAL (BASED ON A STANDARD TOOL FOR QUALITATIVE STUDIES)				
			Was ethics approval granted?	Is there an appropriate description of researcher reflexivity <sup>7</sup> ?	Is the sampling method appropriate?	Is the method of data collection appropriate?	Is the method of data analysis appropriate?
Study 1	Focus groups, semi-structured interviews	Thematic approach	Yes	Not described	Yes (but limited information about advertisement procedure)	Yes	Yes (but limited information)
Study 2	Semi-structured individual interviews. Observations of classrooms, meetings, home visits etc.	Categorical coding	Unclear (Not reported, but part of bigger project)	Not described	Yes	Yes	Yes
Study 3	Individual interviews, unstructured open-ended questions.	Content analysis	Yes	Not described, but study funded by the National FASD Advocacy Association of New Zealand	Yes	Yes	Yes
Study 4	Unstructured interviews, individual interviews	Phenomenological-hermeneutic analysis	Unclear (Not reported)	Not described, but study commissioned by the Canadian Foster Parents Association	Unclear (Not clearly described)	Yes	Yes (but only one author seemed to be active in the analysis)
Study 5	Individual or couple interviews, with follow up questions by email or telephone	Interpretative phenomenological analysis	Yes	Not described	Yes	Yes	Yes
Study 6	Interviews	Interpretative phenomenological analysis	Unclear (Not reported)	Not described, but study conducted by health professionals involved in the care of people with FASD	Unclear (Not clearly described)	Unclear (Not clearly described)	Unclear (Not clearly described)

<sup>7</sup> By reflexivity, we mean whether the reader gains an understanding of the researchers' role in the qualitative study (for example, past historical, social, cultural experiences, personal connections to sites and people, steps in gaining entry, and sensitive ethical issues) and how the researchers' roles may shape the interpretations made in the study? (Creswell JW: *Qualitative Procedures. Research design: qualitative, quantitative, and mixed method approaches* (2nd ed.). Thousand Oaks, CA: Sage Publications; 2003.)

**Table 3: Your assessment for each CERQual component and overall assessment**

In the table below describe any concerns you have about each component. Choose if these concerns are **minor**, **moderate** or **serious** (including why), or if you have **no or very minor** concerns.

When you have assessed each component make an overall GRADE-CERQual assessment of confidence in the finding (**high**, **moderate**, **low** or **very low**), and explain this assessment. Your explanation should include reference to each of the components.

#	Summarised review finding	Relevance	Methodological limitations	Adequacy	Coherence	GRADE-CERQual assessment of confidence	Explanation of GRADE-CERQual overall assessment
	Parents and other caregivers experience a lack of understanding and knowledge about FASD among different types of service providers, including healthcare providers, social workers, educators and members of the police force.			<b>No or very minor concerns</b>			