BC Healthy Connections Project

Questionnaire Administration

Lessons from the BC Healthy Connections Project

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Caitlin Riebe, Rosemary Lever,
Kathleen Hjertaas, Ange Cullen, Nicole Catherine
for the BC Healthy Connections Project Scientific Team

Children's Health Policy Centre
SFU FACULTY OF HEALTH SCIENCES
McMaster University HEALTH SCIENCES

We celebrate the Indigenous Peoples on whose traditional territories we are all privileged to live and work.

Citing This Manual

Caitlin Riebe, Rosemary Lever, Kathleen Hjertaas, Ange Cullen, Nicole Catherine for the BC Healthy Connections Project Scientific Team.

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We are deeply grateful to our Study Team members, past and present, who contributed so much time and effort towards the development of this study.

BC Healthy Connections Project
Children's Health Policy Centre, Faculty of Health Sciences, Simon Fraser University
2435 – 515 West Hastings Street, Vancouver, BC V6B 5K3
778.782.7775 | childhealthpolicy.ca

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Glossary and Abbreviations

BC	British Columbia
BCHCP	British Columbia Healthy Connections Project
CHPC	Children's Health Policy Centre
NFP	Nurse-Family Partnership
OP	Operating Procedures
RCT	Randomized Controlled Trial
SFI	Scientific Field Interviewer
SFU	Simon Fraser University

Preamble

The British Columbia Healthy Connections Project

The BC Healthy Connections Project (BCHCP) is a randomized controlled trial (RCT) examining the effectiveness of the Nurse-Family Partnership (NFP) program. NFP involves nurses visiting young, disadvantaged mothers in their homes, providing intensive supports starting early in the first pregnancy and continuing until children reach their second birthday.[1] The aim of the BCHCP is to evaluate NFP's effectiveness compared with BC's existing health and social services in improving child and maternal outcomes. The project is led by a research team based at the Children's Health Policy Centre (CHPC) in the Faculty of Health Sciences at Simon Fraser University (SFU) in Vancouver, British Columbia (BC) — with collaborators at McMaster University, the University of British Columbia, the University of Victoria and the Public Health Agency of Canada. The first Canadian evaluation of NFP's effectiveness, this RCT is running from 2011 to 2022 with 739 mothers and 731 children enrolled. This trial is embedded within BC's public health and child health systems, involving close collaborations with the BC Ministries of Health, Children and Family Development and Mental Health and Addictions, and with four regional BC Health Authorities — Fraser, Interior, Island and Vancouver Coastal Health. The BCHCP also involves two adjunctive studies: a nursing process evaluation and an evaluation of NFP's impact on biological markers of maternal and child stress in a sub-sample of RCT families.[2,3] The trial was registered on August 24, 2012 with ClinicalTrials.gov (Identifier: NCT01672060) prior to study enrolment commencing; the trial also has research ethics approvals from 10 participating agencies and universities. For a full description of the trial, methods and procedures, see the published RCT study protocol.[4]

Scope of BCHCP RCT Data Collection

Eligible and consenting participants living in the four participating Health Authorities were recruited in early pregnancy (i.e., prior to 28 weeks gestation), between October 2013 and December 2016. Participants completed the baseline interview and were then randomly assigned to the intervention group (NFP plus existing services) or the comparison group (existing services only). Research interviews were conducted until late 2019 and involved multiple methods and sources including:

- maternal self-report questionnaires administered in the home or by telephone
- child and maternal observational and cognitive tests in the home

Administrative public health data collection is ongoing until late 2020 to inform findings on the RCT's primary outcome indicator — childhood injuries.

BCHCP Primary Outcome Indicator

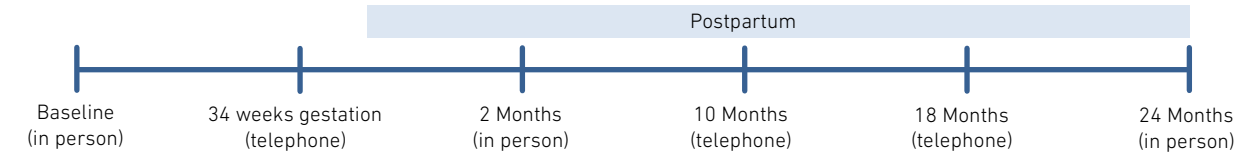
- Childhood injuries by age two years

BCHCP Secondary Outcome Indicators

- Prenatal substance use
- Child mental health at age two years
- Cognitive and language development at age two years
- Maternal subsequent pregnancies at 24-months postpartum

The SFU Study Team (or Study Team) includes Scientific Team members (Nominated Principal Investigator, BCHCP Scientific Director), onsite Study Team members and Scientific Field Interviewers (SFIs). The onsite Study Team continues to collect administrative and participant-tracking data, while SFIs have collected all interview data. (NFP home visits were separate and were the responsibility of the Health Authorities.) SFIs were located in the four Health Authorities and were masked to treatment group allocation. NFP nurses and participants were not masked. Participants were invited to participate in six interviews during pregnancy and postpartum (see Table 1 below):

Table 1. BC Healthy Connections Project Timeline



Between 2013–2019, the SFU Study Team tracked 739 participants to schedule in-person and telephone data collection interviews. Almost 4,000 interviews were completed across wide geographical areas and with participants who were experiencing extremes of socioeconomic disadvantage. For example, the data collected during the baseline interview confirm that we reached a cohort experiencing low income (84% reporting less than $20,000/annum), as well as associated adversities including: unstable housing (52%), intimate partner violence (50%) and severe anxiety or depression (47%), with many (70%) experiencing cumulative disadvantage (i.e., four or more indicators of adversity).[5]

1. Basic Questionnaire Administration

1.1 Introduction

This section provides details on the best practices for questionnaire administration. This includes directions on topics such as administration order, using response cards, and skip logic. There are also instructions for administering standardized measures, including directions on how and when to prompt participants to balance accurate data collection with standardized administration.

1.2 Administration Order

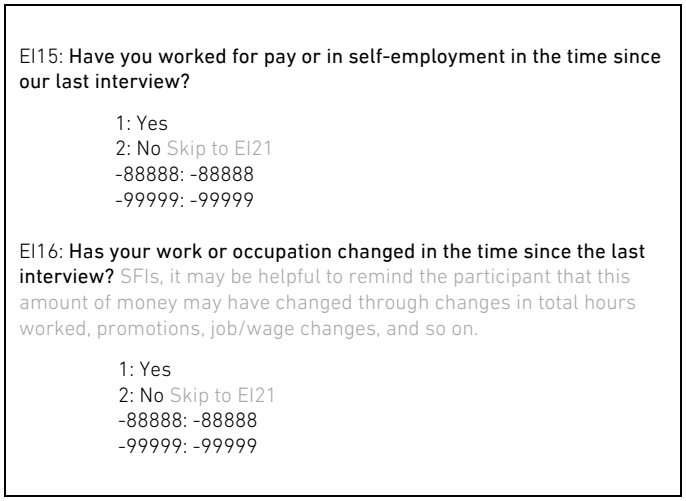
To ensure standardization, questions and sections are to be administered in the order presented within the questionnaire. The ordering in the BCHCP questionnaires is carefully planned. Questions are ordered to prioritize certain sections, correctly position sensitive questions, and hold the participant's interest. Sections that are administered differently have a "placeholder" in the questionnaires, in the form of their section titles.

Avoid deviating from standardized administration unless you have a clear rationale for why the change is necessary and how it will benefit the data. Such changes should be discussed with the Research Coordinator beforehand. If an immediate decision is required, pause the interview and consult the Research Coordinator by telephone.

1.3 Section Instructions

All instructions, questions and response options in black are read aloud to participants. Questions and response options should be read verbatim.

Some notes in grey are private instructions for the SFI and are not read aloud. However, if a question has prompting information written in grey, then you can use those prompts to encourage a participant's understanding of the question. Further, *Skip Functions* are also presented in grey. These instructions indicate when to skip certain questions, depending on a participant's answer.



EI15: **Have you worked for pay or in self-employment in the time since our last interview?**

1: Yes
2: No Skip to EI21
-88888: -88888
-99999: -99999

EI16: **Has your work or occupation changed in the time since the last interview?** SFIs, it may be helpful to remind the participant that this amount of money may have changed through changes in total hours worked, promotions, job/wage changes, and so on.

1: Yes
2: No Skip to EI21
-88888: -88888
-99999: -99999

Skip Function

If a participant answers "no" you can skip to the next relevant question. Skip functions prevent nonsensical questioning and limit participant burden. Ensure you are following these correctly as skipping questions inappropriately may result in missed data.

SFI Notes

Not read aloud. Includes notes on additional considerations you can use to prompt the participant.

1.4 Response Cards

Response cards are visual aids to guide participants with questions that have more than three response options. As you ask a question with an associated response card, hold up the card for the participant to see and ask them to choose the answer that best applies. Each response card is labeled with the associated question number. Some cards are used for multiple questions (such as for standard assessments that rely on a response scale).

1.5 Response Codes

All items must be filled out in the questionnaire. In cases where participants do not know an answer or decline to respond, response codes indicate the reason for the missing data. Table 2 outlines the standard response codes used in the BCHCP questionnaires.

Table 2. BC Healthy Connections Project Response Codes

Response Code	Description
-88888	**Participant explicitly chooses not to respond to a question.** Participants may decline to respond to a question because they find it too personal or upsetting. In these cases fill in any blank items with the code "-88888" or select this response from the answer options.
-99999	**Participant or SFI missed a response**. It is imperative to keep track of questions and skip logic to avoid missed responses when possible. If an answer has been skipped, fill in any blank items with the code "-99999" or select this response from the answer options.
-77777	**Participant is unsure or doesn't know the answer.** If the participant is unable to answer a question, fill in any blank items with the code "-77777" or select this from the answer options.

1.6 Standardized Assessments

Standardized measures allow for higher consistency across different interviewers and interview circumstances. The words and phrasing have been carefully chosen and tested, so it is important that these assessments be administered as intended. The primary objective is to obtain results that are directly comparable across group assignments. If an interviewer administers the standardized measures differently than intended, it could lead to interviewer effects and cause inaccurate conclusions to be drawn from the data.

The standardized assessments in the BCHCP questionnaires have been designed by other researchers. These assessments have been validated through careful testing. The researchers have devised questions and answers and have selected only those that are most reliable, valid, and sensitive with a representative group of participants.

BCHCP Standardized Assessments

- The Family Resources Scale[6]
- The Composite Abuse Scale[7]
- The Childhood Trauma Questionnaire[8]
- The Childhood Experiences of Violence Questionnaire[9]
- Generalized Self-Efficacy Scale[10]
- Pearlin Mastery Scale[11]
- Rand Mental Health Inventory[12]
- Kessler 10[13]
- The Child Behavior Checklist[14]
- The Bayley-III[15]

Reliability How consistent a measure is over time and across different researchers.

Validity How well an assessment measures what it is supposed to measure. For example, a clinically depressed person should score high on a questionnaire designed to measure depression. Validity is usually measured by correlating the scores of one assessment to other established assessments, e.g., other measures of depression.

Sensitivity How well the assessment can show differences in what's being measured. For example, a highly sensitive measure can detect differences between healthy people and mildy depressed people. Whereas a measure with low sensitivity can only detect differences between healthy people and those with high levels of depression.

1.6.1 Guidelines to Administering Standardized Assessments

- Ask the questions exactly as they are worded in the questionnaire
- Ask the questions in the order in which they are presented in the questionnaire
- Ask every question in the questionnaire
- Read each question slowly
- Read the complete question (even if participant interrupts before the question is finished)
- Read all introductory and transitional statements as they appear in the questionnaire
- Repeat questions that are misunderstood or misinterpreted
- Do not let the respondent stray from the questions in the interview
- Do not suggest answers for participants
- Keep nonverbal cues as neutral as possible

1.6.2 Forced Choice for Standardized Assessments

For many standard assessment scales, the participant cannot indicate that they are "unsure," "neutral" or that the question is "not applicable." In this way, no *average* responses are offered and participants are "forced" to choose.

As you can see in the inset example, a participant cannot answer "neither agree nor disagree" to the question. This was a purposeful omission on the part of the developers. Researchers removed the neutral option to make it easier to differentiate between people who feel that they have control and those who feel they do not.

Forced Choice Question Example

PM1: I have little control over the things that happen to me.[11]

1: Strongly agree
2: Agree
3: Disagree
4: Strongly disagree

If a participant questions the answers provided to a standardized assessment, or insists that she feels neutral about the topic, encourage her to select the answer that "best fits" her beliefs. You should never write down an answer that is not present or skip such a question because the participant is hesitant to choose. When the answer options are not followed, the item or measure may be invalid.

1.7 Misunderstanding the Question

At times, participants may not understand questions during the interview. They may communicate their confusion directly. However, not answering a question or providing answers that seem incorrect or illogical are also indicators that a participant has not understood the question. Rephrasing the question or adding new questions should be avoided unless otherwise stated by the administration instructions. Rephrasing or paraphrasing can inadvertently change the meaning of questions, and therefore affect the type of answer a participant provides. This would also influence the reliability, validity, and sensitivity of the data.

Probing techniques to assist with misunderstandings:

- Repeat the question
- Give an expectant pause
- Repeat the respondent's reply
- Ask for clarification (especially when faced with contradictory answers)
- Ask neutral/non-directive questions

Examples of Neutral, Non-Directive Questions

- "Anything else?"
- "Any other reason?"
- "How do you mean?"
- "Could you tell me more about your thinking on that?"
- "Would you tell me what you have in mind?"
- "What do you mean?"
- "Why do you feel that way?"
- "Which option would be closer to the way you feel?"

To retain the meaning of the question and avoid biasing the participant, this probing must be done with care. Probes should be thought out and practiced beforehand to avoid improvising questions or prompts that are too directive in nature. It can be challenging to interact with participants in such a neutral manner especially while also attempting to build a positive rapport. It requires time and practice to hone this skill. The BCHCP manual *The Field Interviewer Role* (available through the Children's Health Policy Centre; see childhealthpolicy.ca) includes more details on impartiality and maintaining a neutral attitude during questionnaire administration.

If probes have been tried and the participant still does not understand a question, you can rephrase or add follow-up questions if you believe you will not be able to collect the data otherwise. Please take notes on the questions the participant had difficulty with and whether these questions were rephrased. These notes are added to the Post-Interview Observations at the end of the questionnaire.

1.8 "I don't know" Responses

When the participant says, "I don't know," it can mean they are unsure of an answer and need more time to think, or they actually do not know how to answer the question. A participant may also say, "I don't know," when asked to offer an opinion or attitude. They may find it difficult to put feelings into words. You must be prepared to distinguish between a true unknown and an uncertainty or hesitancy. If you suspect there may be uncertainty or hesitancy, you can put the participant at ease by saying something such as, "There is no right or wrong answer. Just tell me how you feel about this." Similarly, if a participant is unsure about an answer in a forced choice scenario, encourage them to provide a best estimate.

When a participant is uncomfortable answering a question, they may also respond, "I don't know," in an effort to avoid the question. If this appears to be the case, please attempt to put the participant at ease, reassuring them that the answers are confidential and are very important to the study.

Despite your efforts, the participant may nevertheless insist that they do not know how to answer a particular question. Once you have properly probed for an answer, accept this response in the interest of not alienating the participant, even if they may be avoiding the question. This answer is coded as "-77777" or "Participant is unsure or doesn't know."

Participants can decline to give an answer on any item. A participant may respond, "I don't want to answer that question," or "I'm uncomfortable answering that." Gently reassure them that the answers are confidential and important to the study. If they still do not want to answer the question, it is coded as "-88888" or "Participant explicitly chose not to respond."

1.9 Questionnaire Definitions

Administering the questionnaire uniformly across participants means not only presenting the questions as written, but also using consistent definitions to help participants identify which response option best applies. Therefore, it is imperative that definitions are used consistently throughout all activities related to the BCHCP (e.g., assessing eligibility, administering questionnaires, etc.) and that SFIs are familiar with these definitions. For example, whenever a participant is asked about relationships, you will probe until you have enough information to determine whether a situation fits the BCHCP definition of "relationship."

Relationship — An individual has been with their husband/wife, partner, or boyfriend/girlfriend for longer than one month.

Separated — Individuals who were in a relationship (longer than one month), but are no longer together:

- This can also apply to individuals who are married and are now living apart if the participant self-identifies as being separated.
- This category is designed to measure social support; so it is the participant's self-assessment of their relationship status.

Partner — An individual's husband/wife, boyfriend/girlfriend for longer than one month.

Live-In Partner — Someone who sleeps in the same house as their partner for at least four nights per week.

Common Law — An individual has lived with their current partner for one year or more. When using this definition, it is important to consistently follow these points:

- The relationship is only considered common-law at the end of the one year period, e.g., living together for 11 months and 26 days does not count as common-law.
- They must have lived with their partner consecutively for one year or more. If, at any time, someone moved out (based on the participant's perception) this clock "resets." The time period apart is irrelevant.
- If someone works in a different city, but still self-identifies their partner's home as their home address, this counts towards living together.
- A person who is homeless cannot, by our definition, be in a common-law relationship. Thus, an assessment of homeless precludes being in a common-law relationship.

Home Address — Home address is self-reported by the participant. If the participant leaves home for a period of time (e.g., for an extended vacation) or works in another city but does not change her home address, then she has not moved out.

Homeless — A person is experiencing homelessness if they are living on the streets, living in a place not meant for people to live in (e.g., car or tent), staying in an emergency/homeless shelter, or staying with someone temporarily because they have no permanent address or anywhere else to live (e.g., couch surfing).[16,17]

- If the participant does not self-identify as homeless, but based on the description of her living situation they meet the BCHCP definition of homeless, please identify the participant as homeless.

Couch Surfing	A person is considered couch surfing when they: a) do not have a fixed place to live where they can stay for more than 30 days consecutively, and b) do not pay rent. ▪ The participant must meet both of these conditions to fall under the BCHCP definition of couch surfing. This includes couch surfing with relatives/parents. ▪ In lieu of rent, the participant may make other contributions, e.g., buying groceries, paying for the hydro bill, housekeeping, etc. A definition of rent has not been provided, so make note of all relevant details to be assessed later.
Secondary (High) School Equivalency Program	A certificate or program equivalent to a secondary school diploma. General Educational Development (GED) and the Adult Graduation Diploma (Adult Dogwood) are secondary school equivalency certificates. For the purposes of the BCHCP, the School Completion Certificate (Evergreen) is *not* considered a secondary school equivalency certificate.
Elementary School / High School	In BC, *elementary school* is grades K-7 and *high school* is grades 8-12. If the participant asks about *middle school/junior high*, provide the BC definitions of elementary and high school.
Smoke Exposure	The BCHCP definition of cigarette smoke exposure is spending at least 10 minutes in a room where people are smoking whether inside of the home or elsewhere. ▪ This does <u>not</u> include direct exposure via smoking, but rather secondary exposure from being in an enclosed area with the smoke from a cigarette. i.e., it does not count as "exposure" if the participant smokes outdoors. ▪ "Elsewhere" is a building other than home, e.g., an office or restaurant. This does not include outdoor smoking as the health risk associated with exposure to cigarette smoke outdoors is less significant than indoor exposure.
Essential Services	Services that all participants will have a need for and can easily access (at no cost). This definition is important to administering the Service Access and Use section.
Child	For the majority of BCHCP purposes, a child is 18 years of age or younger. However, two questionnaire measures ask participants to reflect on experiences that happened when they were a child and specifically define child as 16 years of age or younger.
Full-Time Employment	Working 30 hours a week or more.
Part-Time Employment	Working fewer than 30 hours a week.
Time Since the Last Interview	The time period since the last completed interview. If an interview is missed, this will be the date of the last completed interview. This allows the BCHCP to track life changes over the course of study participation.

1.10 Questionnaire Confidentiality

Please keep in mind that all our questionnaires and tools are confidential documents. Some of these questionnaires contain copyrighted tests and are otherwise the intellectual property of the BCHCP Scientific Team. During interviews do not:

- allow participants to take pictures of the questionnaires
- give participants copies of the questionnaires
- allow participants to copy parts of the questionnaire

2. Sensitive Measures Administration During Home Interviews

2.1 Overview

Several questionnaire sections require careful administration due to their sensitive topics. Topics should be considered sensitive if they have the potential to trigger strong emotions, feel intrusive, or raise concerns about the repercussions of disclosing the information. All sensitive measure sections are denoted by the code "SS" in front of the section title in the questionnaire, e.g., *SS: Maternal Exposure to Intimate Partner Violence*. When asked to answer questions on sensitive issues, participants can become emotionally distressed, refuse to answer, or demonstrate social desirability bias — meaning they falsely answer questions in a way that they believe would be viewed favourably by the interviewer.[18]

Past research has demonstrated that the following steps minimize inaccurate responses to Sensitive Measures:

- Rapport building with participants[19]
- Administering questions in a neutral, non-judgmental tone[20]
- Reducing the amount of potential eavesdropping by bystanders[20]
- Providing a sense of anonymity, through privately recorded and sealed responses, or over the telephone[21]

BCHCP Measures that Address Sensitive Topics

- The Composite Abuse Scale[7]
- The Childhood Trauma Questionnaire[8]
- The Childhood Experiences of Violence Questionnaire[9]
- Tobacco Use History
- Tobacco Use (Prenatal and Postpartum)
- Alcohol Use (Prenatal and Postpartum)
- Illicit Drug Use (Prenatal and Postpartum)
- Rand Mental Health Inventory[12]

You will incorporate these evidence-based techniques into the administration of Sensitive Measures questionnaires. The administration will differ depending on whether questionnaires are in-person or over the phone.

During in-person interviews, you will follow a standard procedure to minimize potential emotional distress and false responses. You will provide participants with a printed answer sheet in order for them to privately record answers using paper and pencil. This paper will be placed in an envelope and sealed so that you cannot read the participant's response. Further, these questions will not be read aloud; questions are audiotaped prior to the interview and are administered through headphones connected to the laptop. The use of headphones helps to reduce the amount of eavesdropping by bystanders and further ensure participant privacy.

The most difficult administration is expected to be the baseline interview, as this will be your first in-person contact with the participant and you will have had minimal time to build a relationship with them. You are, therefore, encouraged to spend time at the beginning of the baseline interview engaging in friendly discussion and using rapport-building techniques. Keep in mind that rapport building is equally important for the Sensitive Measures administration during phone interviews as audio recordings cannot be used.

2.2 Sensitive Measures Administration Steps

Step 1 Prepare prior to the interview:

- Copy Sensitive Measures PowerPoint files onto laptop/desktop.
- Test that the audio recordings play properly and adjust the volume.
- Wipe the headphones with an alcohol pad. This can be done in front of participant to alleviate hygiene concerns.

Step 2 Introduce the participant to the Sensitive Measures. Key highlights are:

- The questions are personal in nature so they will not respond aloud.
- They will listen to the questions through headphones so only they can hear them.
- There is no need to discuss the questions with you or anyone else; however, if they have concerns or uncertainties, you are happy to help.
- The participant is not obligated to answer all questions; however, their answers are confidential and highly valued.
- Remind them of the participant Support Resources (Appendix 1)

Step 3 Provide the administration instructions:

- How to navigate through the PowerPoint slides.
- How answers are recorded in the answer sheet:
  - Rather than scratching out mistakes, circle correct answers.
  - Cross out the question number if they choose not to answer. These instructions are important so that the independent Study Team member who reviews responses can decipher them correctly.
- Explain that the answer sheet will be sealed when completed, and the SFI will not see the participant's answers.

Step 4 Give the participant the answer sheet and a pencil. Ensure they feel comfortable with the setup and are ready to start.

Step 5 Busy yourself with other things while the participant listens to/answers the questions.

- Details on how to handle distress or emotional reactions can be found in the BCHCP manual *The Field Interviewer Role* (available through the Children's Health Policy Centre; see childhealthpolicy.ca).

Step 6 When the participant is finished, fold the answer sheet and place it in the envelope. Steps 1–6 will be repeated for the administration of the second Sensitive Measures.

Step 7 Once both Sensitive Measures have been administered, seal the forms within the envelope and place the envelope in your bag.

Step 8 At the end of the questionnaire, determine whether it is necessary to debrief the participant by acknowledging the personal nature of some questions and reminding her of the Support Resources.

Step 9 After the interview, submit the sealed envelope to the Study Team.

Step 10 Confirm submission of the Sensitive Measures by updating the participant tracking database.

2.3. Alternative Sensitive Measures Administration

As previously mentioned, it is imperative that questionnaire administration is standardized to the greatest extent possible. This includes following the intended administration of the Sensitive Measures sections. Do not change the administration without a rationale for why it is necessary and will benefit the data.

There are circumstances that might make listening to the audio-recording difficult for the participant and therefore interfere with data collection. For example:

- You are concerned about the participant's ability to follow along with the recordings and answer sheets, e.g., low literacy or learning disability.
- The participant is finding it difficult to attend to both their child and the audio recording simultaneously.

In such situations, you can choose SFI-read administration, in which you read the questions aloud and the participant marks answers on the answer form. Privacy is required for SFI-read administration**,** as the questions will be read out loud**.** This technique should be used sparingly and only if you believe the audio-recorded administration would be too burdensome for the participant.

In the above situations, please:

- Use your discretion when offering the SFI-read administration, and only do so when there is an indication that this would be helpful.
- Offer both types of administration and let the participant choose.
- Only offer to help the participant write their answers if absolutely necessary and only if they are completely comfortable sharing their answers. This alternative should be used sparingly, and only if you believe the data could not be collected or would not be valid otherwise.
- Leave notes in the Post-Interview Observations about alternative administration used.

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Appendix 1:
Participant Support Resources

Support Resources

Emergency Telephone Number 911

In the event of an emergency, this number will connect you with police, fire and ambulance services.

HealthLink BC 811

Registered nurses, pharmacists and dieticians answer any non-emergency health-related questions and provide information and advice. (Pharmacists are available daily from 5 pm to 9 am and dieticians are available weekdays from 9 am to 5 pm.)

Crisis Line 1-800-SUICIDE (7842433)

Trained volunteers provide emotional support, crisis intervention, suicide prevention and community intervention. You can call a crisis line for any reason, including relationship conflicts, family violence, addiction issues, suicide or loneliness.