

# Data Collection Considerations

Lessons from the  
BC Healthy Connections Project

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

#### **Citing This Manual**

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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.

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#### **BC Healthy Connections Project**

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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

## 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.<sup>1</sup> 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.<sup>2,3</sup> 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.<sup>4</sup>

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

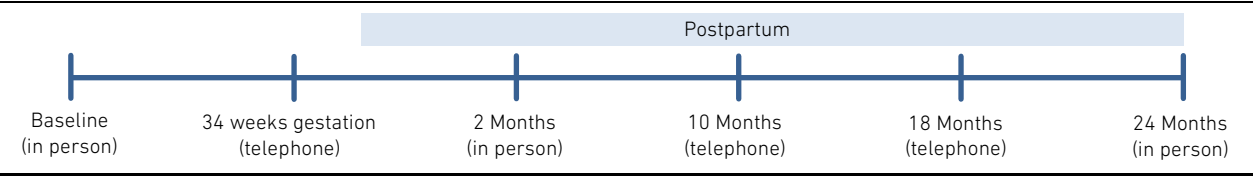
- Childhood injuries by age two years

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).<sup>5</sup>

# 1. Data Collection for Non-Standardized Measures

## 1.1 Introduction

Unlike standardized sections of the questionnaire, the non-standardized sections require a more nuanced approach to data collection. Such an approach ensures that data are consistent with BCHCP definitions and across different sections of the questionnaire. For example, collecting and coding income and service use data can be particularly challenging. This chapter provides several methods and considerations for rigorous data collection.

## 1.2 Collecting and Coding Consistent Data

When collecting data during the interview, it is important to keep in mind that you are in the best position to make decisions about data coding. You are able to clarify inconsistencies directly with the participant and ask follow-up questions as needed. Without the context provided during the interview, recoding done by the data team later is limited in scope, will often result in missing data, and uses additional resources.

When faced with inconsistencies between two pieces of information, the data team cannot make assumptions about which data are accurate, so both answers, along with their related follow-up questions, are recoded as missing data. The following sections outline strategies which can assist with addressing confusing or inconsistent answers from participants.

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*How can self-report be inconsistent?*

For meaningful analysis of data, we limit the answer options available to participants. This is often a “best fit” decision and the true complexity of participants’ lives can lead to inconsistencies within the survey.

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### 1.2.1 During the Interview

Gently probe the participant for more details:

- Attempt to obtain as much detail as possible on complex situations.
- Make neutral observations about any inconsistencies. This may prompt the participant to clarify, e.g., “You picked ‘unemployed’ here, but I seem to recall you mentioned a job earlier...”

If the participant is unable to make a clear choice, but you are certain their situation is consistent with BCHCP definitions, please code a participant’s answer accordingly. When recoding a participant’s response, keep in mind that:

- This may be necessary as participants do not know what information is relevant.
- This can only be done in sections of the questionnaire that are not standard scales.
- This should only be done when you have enough information to be certain that the participant’s situation is consistent with a given answer option. See inset for an example.

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#### *On the lookout for inconsistencies*

The participant describes her relationship with her baby’s father as “complicated.” In one section of the questionnaire she indicates she is “separated” from him. In a later section she chooses the option “closely involved.” Knowing this would result in inconsistent data, you clarify the situation. With some gentle probing you find out that, although it seems tenuous, she does consider them to be in a relationship right now. Thus you go back to recode to ensure both answers are consistent.

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### 1.2.2 After the Interview

- Review questionnaires within a few hours after the interview to ensure data are consistent across sections. Notes regarding discrepancies between what the participant said and what was coded are added to the Post-Interview Observations.
- If necessary, consult with the data team prior to submitting the interview to figure out how to code complex or seemingly inconsistent data.
- Using your discretion, contact the participant to clarify any inconsistent responses. This will only be done as a last resort; please strive to fully complete the questionnaire while in the home.

### 1.3 Collecting and Coding Relevant Data

Being familiar with the questionnaire and understanding the purpose of each section will help you in collecting the most pertinent data possible.

It can be tempting to code a participant's answers verbatim in order to capture the nuances of their situation. Many sections offer an "Other, please specify \_\_\_\_\_" answer option to account for answers that are different from the options provided. Keep in mind that reviewing the "Other, please specify" answers is time consuming for the data team so every effort should be made to utilize the given answer options. As mentioned above, you can select a more fitting answer option if you are certain it reflects the participant's situation and the purpose of the question. See inset for an example.

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#### *Understanding the Questionnaire*

A participant says she is "engaged" to her partner. Since this is not an answer option, you may be tempted to code her relationship status as "Other: engaged" in order to represent her self-report. However, the participant does not know what we are looking for with this question, which is an estimate of relationship stability measured through length of time together in cohabitation. Therefore, knowing the relevant details of her relationship, you can simply select the answer option "closely involved."

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## 1.4 Data Collection for Income

The questionnaire asks participants to estimate their annual income, the baby's father's annual income, and their partner's annual income (if different than the father) during the time since the last interview. These estimates may not be straightforward for the young people represented in our study population. Many may be working contract jobs, may not have consistent hours, and may not know their partner's or baby's father's income without checking on background information such as pay slips.

For this reason, questions are broken down to make estimating income easier. In addition, there are several ways in which income is asked in the questionnaire. This is to help the participant recall income details in a variety of ways. For example, a participant may not know their partner's annual income, but they may be able to accurately choose their income bracket from a given list.

- Step 1      Ask the participant to estimate their current annual income earned through working for pay or in self-employment, before taxes and deductions. This does not include any money from sources such as government or family support. If the participant is able to provide an estimate, you can skip to Step 3.
- Step 2      If the participant cannot estimate their annual income or has worked more than one job in the last year, you will use Table 2 (below) to gather details about their employment. This table helps you break down information on rate of pay, hours worked per week, and number of weeks worked for each job the participant had.

**Table 2. BC Healthy Connections Project Income Breakdown**

	What is/was your hourly pay? Please include an average amount per hour of tips or money earned through commission.	How many hours did you/do you typically work per week?	How many weeks did you work for this job in the time since the last interview?	Income (A x B x C)
Job 1	A1 =	B1 =	C1 =	
Job 2	A2 =	B2 =	C2 =	
Job 3	A3 =	B3 =	C3 =	

- Step 3      You will ask the participant to select their income group from a list of income brackets. This question is read out loud starting from the lowest income bracket. The participant is asked to stop you when you get to the appropriate group.
- There is no corresponding response card. The question is presented this way to prevent answers based on social desirability that may occur if the list is shown, i.e., choosing a higher income bracket out of embarrassment.
  - This question is asked of everyone regardless of their ability to answer the previous income questions in Steps 1 and 2.

## 1.5 Service Access and Use

### 1.5.1 Overview

The Service Access and Use section was developed to capture participants' receipt of current health and social services offered in BC. The section considers a broad array of potential services for both mothers and children starting in pregnancy and throughout the first 24 months of the child's life.

Access and use of services (and barriers to receiving essential services) is captured at each interview. Participants are asked to report the number of times they accessed each service and estimate the associated costs. Details about estimating costs are provided below in section 1.5.3 *Cost Codes*. The questionnaire also asks the rationale for not accessing some essential services. This section will eventually contribute towards determining whether the intervention resulted in cost savings.

#### BCHCP Service Access and Use Measures

- Public health nursing
- Screening and dental programs
- Primary healthcare including the use of ERs and walk-in clinics
- Prenatal services
- Parenting programs
- Income assistance, employment and education programs
- Hospital care
- Early child development programs
- Mental healthcare including substance misuse programs
- Crisis intervention
- Child protection services
- Youth and adult justice services

### 1.5.2 General Procedure

- Step 1      Ask participants if they have accessed any services in a particular category within the specified time frame. The participant selects all relevant services from the response card list.
- Please note that it is necessary to probe specifically for Medical Services Plan (MSP) Premium Assistance during the Financial Services section. If a participant's annual income is below a certain amount, they may not pay the monthly premium rate and therefore may forget that they receive this assistance.
- Step 2      Each service accessed will have follow-up questions to determine the participant's reason for accessing this service and the related costs.
- Prompt the participant with Cost Codes to assess the costs for accessing a service.
  - The "typical cost" to access a service includes the value of all costs identified through the cost codes. Additionally, if the participant has accessed a service several times in the specified time frame, you will calculate an average over all visits.
- Step 3      Many of the service categories include essential services, which are services that all pregnant women or new mothers and their children are expected or entitled to be accessing. If the participant has not accessed an essential service, you will ask the follow-up questions about why they did not access or attempt to access these services.
- Please note that such follow-up questions can lead participants to feel as though they "should" be accessing a service. Be very mindful in responding to such inquiries in a neutral and non-directive way. For more details see section 1.5.5 *Non-Intervention*.

### 1.5.3 Cost Codes

Table 3 outlines the Cost Codes used to record costs in the Service and Access Use section of the questionnaires. Please ensure that for every service accessed, at minimum, a cost is identified for transportation and for the service itself. If there is no cost for either transportation or the service, the appropriate codes must be used (e.g., 7, 8, 9) to indicate why there was no cost. If there is no code to identify a cost or lack of cost, data coders will need to assume the SFI did not probe for the information and will code this as missing information.

**Table 3. BC Healthy Connections Project Cost Codes**

Cost Code	Description	Cost Code	Description
1	Cost of transportation to/from service (e.g., taxi, bus fare, or parking). Includes an estimate of the cost of gas if they drove.	6	Other (please specify)_____. Costs not explained using other codes (use sparingly).
2	Cost of medication (e.g., not covered by PharmaCare plan). Includes the amount paid for medication out-of-pocket.	7	No cost to you because the service covers the cost. Includes any service covered through MSP. Allows us to calculate the cost paid by society for a service being accessed.
3	Cost for the service itself (e.g., professional fees not covered by MSP or any other insurance). If the participant or another individual did not pay, probe to determine how the cost was covered, e.g., with financial assistance program, First Nations status, ICBC, etc. In such cases, use cost code #8.	8	No cost to you because the government covers the cost. Aims to capture any extra benefits the participant is receiving from the government, e.g., through disability assistance, income assistance, youth agreement, etc.
4	Cost associated with taking time off work or school (e.g., lost wages or credits). Cost may be to participant or family members to access the service.	9	No cost for another reason (please specify) _____. May be used when someone other than the participant covers costs.
5	Purchase of other items associated with the service (e.g., purchase of medical supplies). Includes costs such as paying for an ultrasound picture.	10	Not applicable because the participant accessed the service alone. Used when assessing "costs to others" to indicate why there was no cost.

#### *1.5.4 Data Entry Notes*

NFP nurse visits are not included in the Service Access and Use section. Participants are told, prior to the start of this section, that these visits are not to be included in their answers. Participants may make comments about receiving nurse visits — keep in mind that there are a number of services available to pregnant women and new parents in the province which may include nurse visits. This does not necessarily mean you have been unmasked to the participant's group assignment.

Each occasion that a participant accessed a service should only be recorded once. Some categories overlap, so the participant may mention the same service more than once. You will choose the correct section for recording the service based on the participant's primary reason for accessing it.

#### *1.5.5 Non-Intervention*

As an objective observer, it is vital for you to not influence participants' lives. This is particularly crucial during the Service Access and Use section. Be careful to not make qualitative statements about the services in question or suggest other services you are aware of. We want to avoid influencing participants' perception of services and changing the likelihood that a participant may or may not access the services we are asking about or may avoid telling us about them in future.

By asking questions about services, participants may come to see you as an expert in service provision. If participants ask about services, you will remind the participants that you are not qualified to recommend services.

## 2. Field Notes and Post-Interview Observations

### 2.1 Field Notes

#### 2.1.1 Overview

Along with questionnaire administration, you have an important responsibility to keep notes about the interview conditions. Field notes are “shorthand reconstructions of events, observations, and conversations that took place in the field. [They] are the product of observation and participation at the research site, as well as considered reflection thereafter.”<sup>6</sup> The experiences and perspectives of the interviewer and interviewee will influence which data are collected and how they are interpreted. The context of the interview will also influence which data are shared with the interviewer and how they are shared.

Field notes are your observations of events that occur during all phases of the interview process and commonly include descriptions of salient interactions. These notes are meant to inform the data collected and not transcribe entire events. After the interview you will review these notes and decide what to include in the Post-Interview Observations and/or discuss with the Study Team.

Notes submitted along with the interview data, i.e., in the Post-Interview Observations and field notes written in the field notebook are not necessarily identical. Field notes may be helpful in maintaining rapport with a participant, but are not essential to communicate to the Study Team. For instance, you may want to keep track of an informal conversation about a participant’s interests so you can bring it up again in subsequent interactions, thus building rapport.

### 2.1.2 Participant Comments or Observations

Participants may make comments that seem relevant to interpreting their data. You are, of course, encouraged to clarify answers with participants when needed. However, sometimes your ability to probe is limited when the topic is sensitive or if the interview process is becoming burdensome for the participant.

For example, recalling details about past employment can be difficult for participants. Although some uncertainty is expected when making estimates about their or their partner's income, it should be noted when participants are very uncertain about information or their estimates seems unreasonable. Table 4 provides examples of interpreting observations.

**Table 4. Example Notes for Interpreting Participant Responses**

Example observations to note	Example observations that do not need to be noted
The participant seems very uncertain about her partner's income and says: "I have no idea. I'm really just guessing."	The participant says she is uncertain about her partner's income, but is able to confidently say their wage is either \$15-16/hour.
The participant chooses the highest income bracket for someone who is working part time at a minimum wage job.	The participant chooses an income group which is a little above their calculated income.

### 2.1.3 Environmental Distractions

You will also need to make note of environmental distractions (e.g., participant took a call, partner arrived) that may affect quality of the data. These distractions are relevant only if you believe they distracted or distressed the participant enough to have affected their ability to provide accurate data. For example, interviews are meant to be private, but the presence of another needs to be noted only if you believe it resulted in the participant being uncomfortable, thus potentially providing inaccurate information. Table 5 provides examples of interpreting observations.

**Table 5. Example Notes on Environmental Distractions**

Example observations to note	Example observations that do not need to be noted
The participant's partner arrived during the Sensitive Measures administration and the participant's demeanour changed (they were distressed or otherwise affected by their arrival).	The participant seemed unaffected by her partner's arrival. The partner occupied themselves in another room while the interview was completed.
A fire alarm interrupts a cognitive task and it has to be re-administered.	The participant's phone rings during a cognitive task, but she ignores it and continues the task smoothly.

#### 2.1.4 Mechanics

- Jot down key words during the interview to act as prompts for when you review the field notes after the interview.
- Use quotes to indicate participant's words only if you recall exact wording.
- Demarcate data from your interpretation of the data. In some cases you will have to “interpret” a participant's answer, e.g., their situation was complex and difficult to code in real time, or the participant was difficult to understand during a phone interview. In these cases, it is necessary to distinguish between what was said and your interpretation of the data.
- Plan post-interview time for writing out field notes. It is suggested this occurs within 2–3 hours of the interview.

#### 2.1.5 Content

- Informal observations and impressions.
- Include some sense of chronology to help with interpreting events later.
- Can be as short or long as needed — the most important notes will inform data interpretation, participant/SFI safety, or participant tracking.

### 2.1.6 Situations to Discuss with the Study Team

Certain situations and observations that may come up during an interview need to be discussed with the Study Team as soon as possible after the interview. These include topics that may affect the interpretation or validity of the data collected as well as safety concerns that will need to be taken into account for future interviews. Table 6 provides a complete description of these situations.

**Table 6. Interview Situations to Discuss with the Study Team**

Topic	Examples
Things that could influence the data	<p>Situational distractions or interruptions, e.g., a fire alarm that caused a significant delay. Note where in the interview it occurred and what questions may have been influenced.</p> <p>Topics that could provide insight for data interpretation, for example, if a participant had difficulty understanding questions due to language difficulties. Failing to understand the questions could influence the validity of data collected.</p>
Issues that come up repeatedly	<p>Questions that consistently cause confusion among participants and may require rewording.</p> <p>Regular objections to the Sensitive Measures administration which may require revising the administration procedure.</p> <p>Participants frequently finding the interview too long.</p> <p>Participants often being reluctant to schedule the next interview.</p>
Unique participant cases	<p>These are rare situations, such as a participant requesting to have home interviews instead of phone interviews due to difficulties she has over the phone.</p> <p>A senior Study Team member will identify whether the issue should be added to the Unique Participant Cases Log.</p>
Safety concerns	<p>Safety concerns should be discussed immediately with the Research Coordinator.</p> <p>Issues that are not imminent, but could result in a safety concern, should be noted and discussed with the Research Coordinator, e.g., the participant has a large, uncontrollable dog, which may be problematic for some SFIs.</p>
Unmasking	<p>Follow procedures for informing the Study Team.</p>

## 2.2 Post-Interview Observations I

There are two sections of Post-Interview Observations that must be completed after the main interview sections. Take notes throughout the interview in order to answer these questions. Questions in the Post-Interview Observations Section I are asked of the participant at the end of the questionnaire.

### 2.2.1 *Involvement in Other Research Studies*

At the end of the interview there are a series of questions asking about other research studies that participants may be taking part in. This is being tracked because it is possible other research studies may include a program, treatment or intervention that could influence the trial's ability to examine the effectiveness of NFP plus existing services (intervention group) with existing services only (comparison group).

### 2.2.2 *Acquaintance With Other BCHCP Participants*

- Allows us to track potential sharing of information between or within treatment groups.
- Everyone's participation is confidential, so when gathering this information be careful to not confirm or deny whether someone is participating in the BCHCP.
- Include notes on whether the participant knows the treatment allocation of the acquaintance. However, ask the participant not to tell you these details.

### 2.2.3 *Positive Aspects of Parenting*

At the very end of data collection, participants are asked to reflect on something they look forward to or enjoy about parenting. This question is to help end interviews on a positive note and provide an opportunity to maintain rapport. Encourage the participant to speak candidly and, possibly excitedly, about parenting. Do note however that there are many contexts that could make the experience of parenting challenging for any parent (i.e., loss of custody, child experiencing a severe illness, etc.). If a participant is having a hard time identifying something she enjoys about parenting, maintain a non-judgmental tone and allow her to express her feelings.

## 2.3. Post-Interview Observations II

This section, completed post-interview, covers administration of the survey and how it was received by the participant.

### *2.3.1 Situations That May Affect Data Collection*

Includes participant — or SFI reactions — or unusual circumstances. For example, you have to take a break/go outside, or perhaps fall ill and cannot concentrate. These unique cases should be noted. Again, this is only if you believe it could have affected data. Of course, if you are having significant difficulties, e.g., feeling ill or upset, the interview should simply be rescheduled.

### *2.3.2 Challenging Questionnaire Items*

Knowing about common difficulties can help inform the data team. For example, if a participant does not understand a key term in a standardized measure, note the question number and the problem in your field notebook. After the interview, transfer these notes to the Post-Interview Observations. If this problem comes up often, the data team may decide more standardized prompts are necessary.

### *2.3.3 Child Information Relevant to Data Interpretation*

For example, a participant may disclose that her child is not learning English as a first language. This could influence data collection, e.g., child language questions, or the decision to administer child-related items at subsequent interviews using observational measures of child cognition and language.

## 2.4. Unmasking

There may be times you are, or believe you have been, unmasked (i.e., you discover a participant's treatment group allocation). This information would typically come from a participant or a participant's partner, family member, friend, etc., but may also inadvertently come from the Study Team.

If you believe you have been unmasked, notify an unmasked Study Team member by email. Include the date you were unmasked, the general context in which it occurred (e.g., during the 2-month interview), who unmasked you, and the treatment allocation that you believe the participant is assigned to. This information allows the Study Team to track unmasking and whether it systematically influences data quality.

Details of the unmasking situation also assist the Study Team in knowing whether interviewing techniques need to be modified to avoid frequent unmasking. For example, SFIs may be asked to remind participants not to mention NFP visits before questionnaire sections that ask about the services they use. For the duration of research interview data collection (2013–2019), the rate of unmasking has been low.



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