



Patient Experience Mapping Toolbox Interviewer Training Guide

Welcome to the National Health Council’s (NHC’s) Patient Experience Mapping Toolbox (PEMT). This Guide can assist in familiarizing the individual(s) who will be conducting PEMT interviews with the Interview Guide and “Map My Experience” visual. It is not a substitute for partnering with an experienced interviewer. For background information and an overview of the PEMT, please visit our website and click on [About the Toolbox](#).

Table of Contents

Introduction	2
Interview Guide	2
How do I use the interview guide?.....	2
Getting to know the participant and help them feel comfortable talking	3
Experiences Before Getting a Diagnosis	4
Experiences Getting a Diagnosis.....	5
Note on the Misdiagnosis Loop	5
Experiences Living with a Diagnosis	5
Note on Interactions with Health System.....	6
Note on the Desired Outcomes and Life Aspirations.....	6
Note on Special Considerations/Topics.....	6
“Map My Experience” Visual	7
Life Factors	10
General Interviewing Tips	10



Introduction

Welcome to the National Health Council’s Patient Experience Mapping Toolbox. This Interviewer Guide provides background and instructions for the interviewer. It introduces the Interview Guide and “Map My Experience” Visual. For an overview of the Patient Experience Mapping Toolbox, please see the Overview Infographic. The toolbox is located on our [website](#).

Interview Guide

The interview guide is a semi-structured set of questions intended to facilitate a meaningful conversation with a patient about his or her experiences with a chronic health condition. The questions are designed to elicit information regarding a patient’s experiences prior to receiving a diagnosis, while receiving the diagnosis, and subsequently living with the diagnosis. This guide is meant to facilitate conversations or assist the researcher in formulating questions, but is not intended to be followed verbatim.

Many questions refer back to the corresponding “Map My Experience” visual (see Figure), therefore it is crucial that the two resources are used together. Depending on the specific study objective and the available time with the patient, you may decide that the Patient Experience Mapping interview guide goes into greater detail than is needed. If this is the case, please tailor the interview guide to your specific needs by removing and/or adapting questions. To ensure you are capturing sufficient information about a patient’s experience, we recommend including, at a minimum, all of the bolded questions in the interview guide.

The interview guide is divided into the following sections:

- Introduction
 - Start the interview: Introduce yourself and explain the interview’s purpose
 - Privacy Disclosures and Consent
- Get to know the participant and help them feel comfortable talking
- Introduction to “Map my Experience” tool
- Ask about their experiences before getting a diagnosis
- Ask about their experiences getting a diagnosis
- Ask about their experiences living with a diagnosis
- Wrap-Up
- Feedback on Tools
- Conclusion

How do I use the interview guide?

You can use the questions in this interview guide to create a personalized interview guide that fits the specific purpose of your study. You can tailor the questions to the



individual participant, participant group, and/or health condition you are interested in studying. It is vital that you or the interviewer reads through the entirety of the interview guide, selects the relevant questions for the study objective and allotted time, and becomes extensively familiar with the interview guide prior to conducting the interview. The interviewer should also comprehensively research the individuals condition(s), associated signs and symptoms, its impacts, and typical treatments prior to beginning the interview.

Here's what you should know:

- Instructions for you to follow during interviews, such as prompts to point to the patient experience map, are in **blue font**.
- You can pick and choose from the questions in this guide to fit your study objective.
- Questions every researcher should ask are marked in **bold font**. Optional questions are not bolded.

Getting to know the participant and help them feel comfortable talking

The warm up questions are not only intended to start the conversation, but also provide you with insights into the interviewees day-to-day life (see Table 1). The information provided during the warm-up should tie into your later questions and “probes.” For example, if a participant answers that they work a stressful job and travel, you can tie that information in when understanding barriers to going to see a health care professional. This is also an opportunity for you to gather any needed demographic information (e.g., age, locale). It is recommended to take notes as the patient may provide a lot of valuable information that can be used throughout the interview.

Table1. Example Warm Up Questions

Get to know the participant and help them feel comfortable talking

To start off, could you please tell me a little about yourself? For example, do you have any hobbies, do you work, volunteer, or go to school?

Do you have family members that you rely on? Do they live close by? How about friends or caregivers?

- What part of the country do you live in?



- Could you please describe where you live in a little detail, for example, do you live in the city, suburbs, a small town, or in a rural area?
- How convenient is it for you to get to and from [work, grocery store, school, etc.]?

Choose 1 of the following:

- What other kinds of activities are you or your family members involved in?
- Do you have a set routine or does your schedule vary?
- What takes up most of your time on an average day?
- What is a typical day for you?
- What is a good day for you? What is a bad day for you?
- Variation: What is a perfect day for you?

Capture additional demographic information here as needed.

Lastly, it is recommended that you limit the number of warm-up questions asked to 1-2 questions, depending on the time available for the interview and the patient's response. Additionally, please note that if you choose to ask the warm-up question, "What is a good day for you?", it is important to also ask "What is a bad day for you?" to counterbalance the initial question.

Experiences Before Getting a Diagnosis

This section of the interview guide has questions intended to highlight the patient's life before their diagnosis. You will notice that there are two starting points located on the left island, corresponding with the two different starting points on the "Map My Experience" Visual.

The first starting point is titled, "I or someone close to me noticed something was different or I didn't feel right." Some patients might notice something is wrong, or even just different, on their own – for example, they may notice signs or experience symptoms (e.g increased fatigue or a visible skin condition) and start doing research at home or make a doctor's appointment. Alternatively, someone close to the patient, such as a spouse, a family friend, or maybe an acquaintance, may have noticed something was different and early signs of the health condition.

The second starting point is titled, "A health care provider found a problem." This path is for patients who did not experience noticeable signs or symptoms prior to their provider



visit. In this case, the patient discovered something was wrong during a provider visit including a routine check-up, a visit unrelated to the diagnosed health condition, or at the emergency department or hospitalization.

If a patient states that neither one of the paths represent their patient experience starting point, choose the path that best fits the patient's experience. You may advise the patient by stating, "Based on the information you have provided, it sounds like this path would be the best fit, do you agree?"

Finally, if a patient was **diagnosed prior to, at birth, or as a young child**, many of the questions in the "Before Diagnosis" and following "Experiences Getting a Diagnosis" sections may not be applicable. Patients may not remember or have experienced a time prior to their diagnosis. Furthermore, patients may not remember when they received the diagnosis but instead may remember how they became aware of their diagnosis as they got older. When interviewing these patients, you may, therefore, skip to the **"Diagnosis prior to or at birth, or as a young child" on page 21** that specifically addresses this scenario.

Experiences Getting a Diagnosis

This section of the Interview Guide contains questions regarding the patient's experience seeking and receiving a diagnosis. Participants may have been diagnosed with multiple chronic conditions or disabilities. As you are preparing for the interview, be sure you understand which is the "primary" disease or disability of interest for the study. It should be specified throughout the interview guide in places marked [condition name] in the original interview guide. The interview guide has probes and the visual has queues to capture information about secondary diagnoses and their impact on the primary disease or disability.

The questions in this section correspond with the middle island within the "Map My Experience" Visual. For some patients, they might receive a diagnosis within one visit with a health care provider, while others might undergo years of testing and various appointments with different providers and specialists to receive a diagnosis.

Note on the Misdiagnosis Loop

This section includes questions concerning the "Misdiagnosis Loop" seen on the Visual.

As you are interviewing the participant, this experience might come up earlier within the conversation, especially if the patient is telling their story in a chronological order. If it does come up earlier in the conversation, please move to this section for helpful discussion questions (see page 18).

Experiences Living with a Diagnosis

This section provides interview questions concerning the patient's experience after receiving a diagnosis. Topics include their treatment, interactions with the health care system, surgeries and procedures, hospitalizations and/or urgent care visits, wellbeing



and burden of disease, and desired outcomes and life aspirations. Following a diagnosis, patients often try different treatment regimens, have regular or frequent provider appointments, and experience a range of side effects and outcomes related to their condition and/or treatments that affect their daily life. The questions in this section are intended to complement the right island of the “Map My Experience” Visual.

Note on Interactions with Health System

The quantity and types of interactions with the health system are dependent upon the diagnosis (or multiple diagnoses) and treatment(s) schedule of a patient. For example, a patient with metastatic cancer might go to multiple specialists and visit the treatment center weekly for chemotherapy, whereas someone with moderate psoriasis might only have to go to a specialist a few times a year. Having a general knowledge of treatment schedules for the condition will help you better understand the patients’ experiences, ask more targeted and relevant questions, and can help you identify any difficulties the patient experienced while receiving care.

Note on the Desired Outcomes and Life Aspirations

This section of questioning is placed within the larger section of “Experiences Living with a Diagnosis;” however, patients will likely have goals and aspirations throughout their patient journey. Therefore, blue “personal goals” boxes are located on the left and middle island to capture these goals. It can be helpful to return to these questions when discussing their experience after receiving a diagnosis to be able to understand how the patient’s goals and aspirations have changed over time and what could have influenced those changes.

The patient’s desired outcomes and life aspirations can be dependent on their diagnosis, treatment regimen, as well as their relationship with the health care system. For example, if the patient has a treatable cancer, they might undergo a chemotherapy treatment. Their desired outcomes might center on eradicating the cancer or tumor, as well as having minimal side effects from chemotherapy. If the patient has a non-curable chronic condition such as diabetes, the desired outcomes might be focused on managing their day-to-day blood sugar levels and reducing the risks of other complications such as neuropathy, vision loss, and/or kidney failure. Since outcomes are dependent on the condition and the patient’s individualized treatment, it will be important for you as the researcher to prepare a list of potential outcomes specific to the patient community that you will be interviewing. Having this list ready as you interview can help guide the patient through this section.

Note on Special Considerations/Topics

This section of the interview guide consists of topics that are important in a patient’s journey, but may not apply to all chronic health conditions and/or all patients’ experiences such as genomic testing and clinical trials.



In regards to genomic testing and clinical trials, the patient may not know what these terms mean and may not admit that they are unfamiliar with the term. Make sure to define the term and ask the patient if they understand the term following the definition. The following are plain language definitions you can read to the patient if they are unfamiliar with these terms:

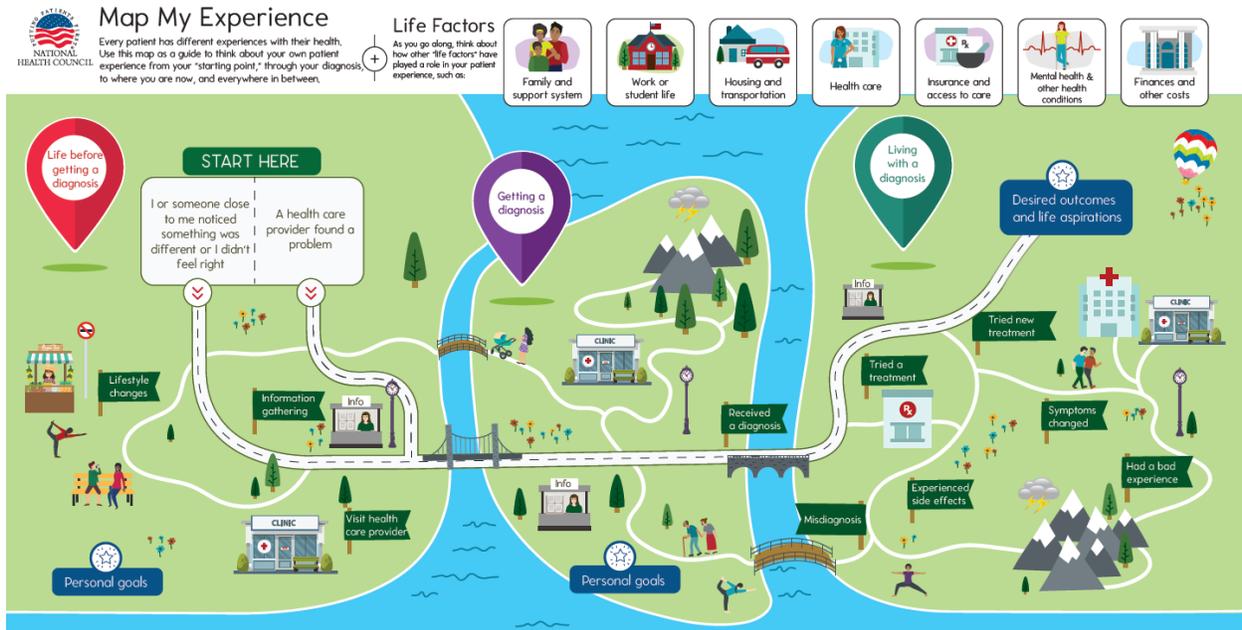
A clinical trial is a type of research designed to learn more about how our bodies respond to medicines or other treatments. Genomic testing are tests where health care providers take a small sample of your blood, skin, or other tissue to test your genes for problems (genes are chemical codes in your body that you inherit from your parents). Testing may lead to finding your health condition earlier, understanding more about it, and making decisions about treatment. Generally, it takes about 1 month to complete the process, which includes meeting with a gene specialist and having a blood test.

“Map My Experience” Visual

The “Map My Experience” Visual (see Figure) is a participant-facing supplement to your interview guide. The Visual provides participants with a tool to follow along and can help provide insights into their:

- Left Island: Life Before Getting a Diagnosis
- Middle Island: Getting a Diagnosis
- Right Island: Living with a Diagnosis

The island order goes from left to right, and the name designations are on the colored icons near the top of each island. The map is intended to guide your discussion and to make sure that important aspects of the patient journey are not forgotten. It also provides a clear visual for the interviewee and may help the patient remember events that happened years ago. Every patient may not have experienced everything on this map and that is OK.



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At the beginning of the interview when the map is being explained to the patient, it is important to pause after each section to confirm that the patient understands each island and avoid overwhelming the patient with information.

You will see there are two types of roads depicted on the Map. The first is a smooth “highway” that goes directly from the far left to the far right. The winding white loops leading to the mountains are a more challenging, rocky path. The intent is to understand the experiences that patients have across each of the islands. For example, a relatively quick or easy diagnosis would be symbolized by the highway. Alternatively, the loop on the second island could represent a patient having a difficult and lengthy time trying to receive a diagnosis (e.g., a patient may have experienced a misdiagnosis, had to see several different providers, or had to travel to a different part of the country to receive specialized care). Furthermore, the loop on the third island represents any bad experiences or outcomes that might have happened throughout patient’s treatment or condition. Ultimately, the mountains and white loops may help a patient think about times in their patient experience when things have been more difficult.

The experience map also uses many visual cues to explore experiences, twists, and turns a patient has had throughout his/her journey. For example, on the first island there are signs for “information gathering” and “lifestyle changes.” If the patient notices something is wrong, such as a specific symptom, they may use lifestyle changes to attempt to mitigate the symptoms. They may also research their symptoms on the internet or research them through resources provided by their health care provider. Understanding how and where patients access information may be important to you.

On each of the islands you can see information booths, clock towers, clinics, and people performing wellness activities (see Table 2). These features describe important parts of the patients’ journeys such as the time waiting for a diagnosis, the time spent researching their symptoms, or the time being unsure of whether or not to seek certain treatments or see medical professionals. The health care buildings are denoted by the red cross and say “clinic,” represent any interaction a patient may have had with any health care professional—whether that be at a hospital, clinic, rehabilitation center, pharmacy, acupuncturist, or another place someone could go to for care.

Table 1. Example Visual Cues

				
<p><i>Lifestyle changes (increase in physical activity, diet changes, stopping smoking, drinking more water, etc.)</i></p>	<p><i>Time passing (i.e., how long were you on this island)</i></p>	<p><i>Gathering information to help make decisions</i></p>	<p><i>A rough patch in the journey. Signals difficulty whether with the health care system, in terms of symptoms or outcomes, etc.</i></p>	<p><i>Hope that symptoms will improve, things will work out, etc.</i></p>

On the right island there are two health care buildings and a pharmacy. The health care buildings and pharmacy can be used to explore various treatment options or pathways. This includes identifying if the patient had to suspend their treatment for a period of time or return to their health care provider to try a new treatment. The health care building can also be used to denote hospitalizations that occurred during the patients treatment journey. It could also refer to hospitalizations that were not related to the condition they are currently being interviewed about.

In the top right corner of the right island there is also a hot air balloon with a blue box that says “Desired outcomes and life aspirations.” This section represents a patient’s everyday goals and hopes. This could be anything the patient may be working towards while living with their health condition such as spending more time in a garden, being able to attend an event, or spending more time with friends and family.



Life Factors

The life factors on the top row of the experience map include:

- *Family and support system*
- *Work or student life*
- *Housing and transportation*
- *Health care*
- *Insurance and access to health care*
- *Mental Health and other health conditions*
- *Finances and other costs*

These are known as social determinants of health and are deeply intertwined in the patient experience throughout their journey. They can have a dramatic impact on a patient's health outcomes. For example, a patient with a strong family and social support system and access to insurance may have a very different experience than someone who is isolated or does not have health insurance. The text from the interview guide introducing life factors is copied into Table 3. Other factors including bias and discrimination are included as potential probe questions in the interview guide.

Table 2. Life Factors Introductory Text from Interview Guide

As we go through the interview, I'll ask you about how these life factors are intertwined with your experience as a person with [condition]. For example, how your family or support system may be impacted by your condition but also how they help you managing [condition].

Does that make sense?

If 'No,' give example:

For example, your personal finances might affect your decision to go see a doctor because a visit can be expensive. It might also affect whether you decide to start a treatment or not. The same may be true for your family or support system – they might encourage you to seek care from a certain type of health care provider or get a certain treatment. This could affect your experiences after you get a diagnosis. Does this make sense to you?

General Interviewing Tips

- Be familiar with the interview guide prior to starting the interview.
- Research the condition of interest and related symptoms prior to initiating the interview.
- We strongly recommend doing a practice interview prior to the first formal interview. Use the interview guide that has been adapted for your study objective and follow all planned procedures, including interview mode and recording. Your



interviewee can be a colleague, but they should respond to questions to help you get comfortable using the probe questions. A practice interview will help you trouble shoot and potentially modify the number of questions based on your time constraints.

- Understand the interview parameters (type of interview, interview logistics, information the interviewer will be provided, sharing resources, follow-up, etc.).
- Consider having a back-up recorder.
- During the interview, only take notes that will assist you in conducting the interview (e.g., insights from “warm up,” symptoms).
- Pay attention to both verbal and non-verbal cues.
- If conducting a virtual interview, ensure that the technology is working prior to the interview. Log on about 10 minutes prior to the start of the interview to allow troubleshooting time in case any problems occur.