

Patient experience mapping toolbox interview guide

A note to researchers

This interview guide is a collection of questions aimed at capturing patients' experiences with [a chronic health condition]. The questions cover a patient's experiences from pre-diagnosis, through diagnosis and treatment, up to the present day.

What is the purpose of this interview guide?

The purpose of this guide is to help researchers engage patients to learn more about their experiences from before they got a diagnosis through their experiences living with and treating a health condition. You can use the data collected during these interviews to better gain a better understanding into patients' lived experiences, including, but not limited to their experiences with the health care system.

How do I use this interview guide?

Use the template questions provided in this interview guide to create a customized interview guide that fits the specific purpose of your study. You can tailor the questions to the individual participant, participant group, and health condition you are studying.

This interview guide is intended to be used with a visual aid "Map My Experience." The visual aid is used throughout interviews to help participants follow along and describe their experience.

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.

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Start the interview

Introduce yourself and explain the interview's purpose

Hello, my name is [Interviewer]. Thank you for speaking with me today. I am conducting this interview for [organization name]. This interview will take about [x time] to complete.

The purpose of this interview is to learn about your experience with [condition] from the time before you got a diagnosis up until today. I also will ask for your feedback on the “Map My Experience” picture and on the questions I’ve asked you during the interview. We will use your feedback to make the map and the interview questions better for future interviews. We plan to make the map and the interview questions available to other researchers so they can understand what it is like to be a patient. As researchers and health care providers better understand your and other patients’ experiences, they can develop better treatments and improve the quality of health care.

- To get started, we will go through the privacy disclosures and I’ll get your consent to participate. Then, I’ll ask some general questions about you. After that, I will introduce the “Map My Experience” tool that will help guide the interview. Lastly, I’ll be asking you a wide range of questions about your condition. We are interested in your thoughts and opinions. There are no right or wrong answers. You do not have to answer any questions that make you feel uncomfortable. Just tell me when there is a question you prefer to not answer and I will skip to the next question.

This work is funded by [funder]. You will receive payment for your time participating in this interview. You should expect payment in [XX] days.

Give privacy disclosures

(Adjust text to fit your study specifics)

Before we start our discussion, let's talk about privacy of everything you tell us during this interview.

We will be careful to protect your privacy in these ways:

- All the information you provide will be used for the purpose of this research project only.
- With your permission, I will be audio-recording this interview. Please speak loudly and clearly so that all your comments will be captured on the audio-recording.
- The recording will be kept private. We will use the recording to create a written version of our discussion to be reviewed later and to take complete notes.
- Recordings will be stored until the written version has been created and analyzed.
- We will not associate your name with any of your comments. Instead, you will be identified with an ID number to protect your identity and confidentiality.
- When we present study results, we will combine the data from all patients and present it as group data, not individual responses.
- In some cases, we might want to highlight or quote a statement you made because it conveys an important point. However, we would never use your name with any statement.

[This document is a preview of the full interview guide]

Get consent

Before we start, what questions do you have for me?

Answer any questions they have.

Do you agree to take part in this interview?

Wait for response.

If 'No':

Okay, I understand you have decided not to take part. What could we do next time to make it easier for you to take part in an interview?

Write the reason, try to clarify any questions so they might agree to take part. Thank them for taking the time to speak with you today.

If 'Yes':

Thank you for agreeing to take part and be recorded. Also, I wanted to let you know I may be taking notes throughout the interview as you will be providing a lot of beneficial information. As a result, there may be times that I am silent. Please don't think I am not listening if that happens.

Ok, I will start recording now. You can skip (or not answer) any questions you do not feel comfortable answering, and you can stop the interview at any time.

Start recording.



Check recording is in progress.

[This document is a preview of the full interview guide]

This is participant [ID] and today's date is [date]. Could you please confirm once more for me that you agree to be recorded?

Wait for response.

Thank you.

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.

Great, thank you. Next, I am going to show you and explain a tool that will help with our interview.

[This document is a preview of the full interview guide]

Introduce the “Map My Experience” tool

For virtual interviews, pull up the “Map My Experience” tool on your screen.

For in-person interviews, hand a paper copy to the participant.

If virtual:

Let’s look at the screen now. Can you see it okay?

Wait for response.

This is called the “Map My Experience” tool. It’s a tool to help guide discussions with patients about their experiences to make sure we don’t forget to talk about important parts of a patient’s journey.

Keep in mind, the purpose of the map is just to help guide our discussion. We will note the things that you have experienced and be sure to focus on those during our conversation. As we go through these items, if you have a question or if something does not make sense, please let me know and we can talk more to be sure it is clear.

Let’s begin on the left side of the map with a general overview. As you can see, the map has three islands and has two starting points on the first island. From there, you can follow two different paths going from island to island to help you talk about your own patient experience.

I will now be taking a closer look at symbols and icons on each island.

➤ **Point to the red icon, “Life Before Getting a Diagnosis”.**

The to the left island that is called, “Life Before Getting a Diagnosis,” is meant to represent your experiences before you got your diagnosis, the time before a doctor telling you that you have a health condition.

➤ **Point to the purple section, “Getting a diagnosis”.**

The purple icon on the middle island shows experiences getting a diagnosis, and

➤ **Point to green section, “Living with a Diagnosis.”**

The green icon on the island to right represents your life after your condition was diagnosed.

Every patient has different experiences, so you might not have experienced everything on this map. That’s OK. For example, some people get a diagnosis in 10 minutes, and for others it might take years and many doctor visits.

Let’s take an in-depth look at the items and symbols on each island.

➤ **Point to the lifestyle changes on island 1, then to yogis on islands 2 & 3**

The farm stand, no smoking sign, and person doing yoga — are a place to think about any lifestyle changes you may have made. For example, perhaps you worked to improve your diet, increased your physical activity, tried to reduce stress levels, or changed your alcohol habits. Throughout the interview, I’d like to hear about those changes.

➤ **Point to the information booths on each island**

The information booths on each island represent getting information — these booths are a place to think about where you went to get information about your symptoms, **[condition]**, or side effects from treatments. It could be from a person, website, online forum, patient community, book, or any other source of information.

➤ **Point to the health care buildings on each island**

There are also health care buildings on each island, including those buildings with the red cross on them that say “clinic” as well as the pharmacy on the third island. These buildings represent any interaction you may have had with any health care professional—whether that be at a hospital, clinic, rehabilitation center, pharmacy, acupuncturist, or another place you go to for care.

➤ **Point to the dark blue section, “Desired outcomes and life aspirations”.**

You can see blue boxes on every island that say “personal goals,” These correspond to any personal goals you may have or may have had. The dark blue box at the end of the path that says, “desired outcomes and life aspirations,” is a place to think about your everyday goals and hopes. This could include being able to do a hobby, being able to attend an event, or being able to spend more time with friends and family.

➤ **Point to each of the white loops and mountains that diverge from the main path**

The mountains and the loop on the second island represent having a difficult and/or lengthy time trying to receive a diagnosis. The loop on the third island represents any bad experiences or outcomes that might have happened with your treatment or condition. These might help you think about times in your patient experience when things have been more difficult. We can talk about those times later during the interview, if you are comfortable with it.

➤ **Point to each of the brown bridges**

You will also notice 2 brown colored bridges on the map. These bridges allow you to go back to the previous island if needed to allow for any setbacks (for example, a change in diagnosis or if you stopped seeking a diagnosis).

Specifically, the brown bridge that connects the second and third island represents a misdiagnosis, a diagnosis that a doctor later changed, and it put you back on the second island.

➤ **Point to “life factors” at the top.**

One more thing about the map: At the top of this map, we have a row called “life factors.” They include:

[This document is a preview of the full interview guide]

- Family and support system
- Work or student life
- Geography, housing, and transportation
- Health care
- Insurance and access to health care
- Mental health and other health conditions
- Finances and other costs
- Ethnicity, age, or gender

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?

If 'No', give further examples until meaning is clear.

Do you have any questions before we continue?

Answer any questions they have.

Ask about their experiences before getting a diagnosis

To begin, I'd like to spend a little time learning about your life before you were diagnosed with [condition]. This may have been a difficult time for you, and I know it can be hard to share private information. Please share only what you feel comfortable sharing and let me know if you need to take a break or stop at any time.

➤ **Point to the two starting points on the map.**

You'll notice the map shows 2 possible experiences for starting a patient journey:

➤ **Point to "I or someone close to me noticed something was different or I didn't feel right"**

1st Starting Point: Some patients might notice something is wrong, or even just different, on their own. For example, they notice symptoms and start doing research at home or make a doctor's appointment. Additionally, someone close to them, such as a spouse, a family friend, or maybe an acquaintance, may have noticed something. It's also possible you were diagnosed before or at birth, or as a young child and found out from someone at some point in your life.*

➤ **Point to Path 2, "A health care provider found a problem"**

2nd Starting Point: Other patients might have found out about their condition from a doctor or other health care professional during a visit, or after lab work or completing a test.

Which of these starting points best fits the beginning of your journey?

If 1st starting point, go to: "I or someone close to me noticed something was different or I didn't feel right" section below.

If 2nd starting point, go to: "A health care provider found a problem" on page 17.

[This document is a preview of the full interview guide]

*If the participant was diagnosed before or at birth, or as a young child, go to “Diagnosis prior to or at birth, or as a young child” on page 22.

Symptoms

<p>If Starting Point 1, start here</p>	<p>You said you (or someone close to you) noticed something was different and didn't feel right. Could you please tell me more about that?</p> <ul style="list-style-type: none">• What did you notice? What did it feel like?• How long did the [symptoms] last? How often did they occur?• Did the symptoms happen at certain times of the day?• What were your symptoms like on a good day? Bad day? Does this affect your daily life on those days? Of all the symptoms that you experience because of your condition, which 1-3 symptoms have the most significant impact on your life? Why is that?• Did you notice anything “triggered” the symptoms?<ul style="list-style-type: none">○ For example: caffeine or sleep loss• What made the [symptoms] better? What made the [symptoms] worse?
	<p>How did you try to manage your [symptoms]?</p> <ul style="list-style-type: none">• Did you try making any lifestyle changes to help with symptoms? Could you please describe them for me?• Did you try any over-the-counter products such as a pain reliever, herbals, vitamins, or supplements?• How long did you try to manage your symptoms before going to see a health care provider?

SAMPLE