

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.

Note: This interview guide preview is for planning purposes. To receive a free, modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

Table of Contents

A NOTE TO RESEARCHERS	1
START THE INTERVIEW	4
Get to know the participant and help them feel comfortable talking	7
Introduce the “Map My Experience” tool	8
Ask about their experiences before getting a diagnosis.....	12
Symptoms.....	13
Questions & Information Gathering.....	14
Emotional Health & Personal Goals.....	15
Life Factors	15
Seeking care	15
Genetic testing	16
Closing before getting a diagnosis	16
Ask about their experiences getting a diagnosis.....	16
Transition to getting a diagnosis	16
Follow-Up Care	18
Changed Diagnosis/Misdiagnosis.....	19
Treatments.....	19
Symptoms.....	20
Questions & Information Gathering.....	20
Emotional Health & Personal Goals.....	21
Life Factors	21
Closing before living with a diagnosis	22
Diagnosis prior to or at birth, or as a young child	22
Ask about their experiences living with a diagnosis	23
Transition to living with a diagnosis.....	23
Living with a diagnosis	24
Treatment they are currently getting	24
Treatment they have tried but stopped.....	26
Ideal Treatment.....	26
Surgeries and Procedures.....	26
Hospitalizations/Urgent Care Visits.....	27
Life Factors (Hospitalizations/Urgent Care Visits)	28
Clinical Trial Participation	28
Life Factors	29
Care Coordination & Multiple Chronic Conditions.....	29

Note: This interview guide preview is for planning purposes. To receive a free, modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/> 2

Wellbeing and burden of disease..... 30
Quality Measurement 32
Genetic testing 33
Desired Outcomes and Life Aspirations 34
Closing..... 35
Feedback on Tools..... 35
Conclusion & Post-Interview Logistics 36

PREVIEW



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.

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

Note: This interview guide preview is for planning purposes. To receive a free, 6 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

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.

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 the 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:

- Family and support system

Note: This interview guide preview is for planning purposes. To receive a free, 10 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

- 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.

Note: This interview guide preview is for planning purposes. To receive a free, 12 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

*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?

Note: This interview guide preview is for planning purposes. To receive a free, 13 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

	<p>How did your symptoms affect your daily routine, work, family or hobbies? Were there certain activities you couldn't do at all or as fully as you would have liked because of your [symptoms]?</p> <ul style="list-style-type: none"> • For example: work or school activities, sleeping through the night, energy levels, appetite, mood, daily hygiene, taking part in sports or social activities, or intimacy with a spouse or partner. • Were there things you did to avoid triggering the symptoms from your condition?
	<p>How often did you go to see a doctor or another health care provider before you first noticed symptoms?</p> <ul style="list-style-type: none"> • What was your routine? • Did you go for routine appointments or another reason?

Questions & Information Gathering

	<p>What questions did you have? What concerns did you have?</p> <p>Where did you look to find information?</p> <ul style="list-style-type: none"> • Did the information that you found answer your questions? • What sources of information did you trust or rely on most? What made the information trustworthy? • Were you concerned with misinformation? How did you tell the difference between “good” information and “misinformation”? • Are there resources you wish existed, but you couldn't find? • Are you involved in any sort of community or advocacy work related to your condition? A patient group?
--	---

Emotional Health & Personal Goals

	<p>How were you feeling emotionally during this time?</p> <p>Some people have mentioned feeling calm, worried, overwhelmed, relieved, or angry?</p>
	<p>Were there any personal goals in your life that changed because of your symptoms? What were they?</p>

Life Factors

<p> Point to “life factors” on the map.</p>	
	<p>How did any of the “life factors” affect your experiences before you got a diagnosis?</p>

Seeking care

	<p>What was the thing or thing(s) that made you seek a diagnosis, that made you go to the doctor?</p> <p>How did you decide which type of health care provider to go see?</p> <p>How often did you go see a doctor or another health care provider before receiving a diagnosis?</p>
	<p>Were there things that got in the way of seeing a provider?</p> <p>Did the life factors impact your decision to go see a health care provider?</p> <ul style="list-style-type: none">• For example, did your working hours prevent or allow you to see a health care provider, such as a doctor, nurse, chiropractor, or other?

Note: This interview guide preview is for planning purposes. To receive a free, 15 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

	<ul style="list-style-type: none"> ○ Other examples could include: lack of insurance, cost concerns, not being able to take time off work, lack of family support, transportation issues, or lack of access to a nearby specialist. ● Did you know any health care providers socially or among family or friends who you turned to for advice? ● Was it easy or difficult to schedule a visit with this provider? If not, why wasn't it easy to schedule?
--	--

Genetic testing

	<p>Did you consider getting genetic testing? Why or why not?</p> <p>Was it ever suggested to you by a health care provider?</p>
--	---

Closing before getting a diagnosis

	<p>Before we move on, do you have anything else you'd like to tell me about your experiences before you got a diagnosis?</p> <ul style="list-style-type: none"> ● Do you feel the highway or winding path better reflect your experience before getting a diagnosis? Why is that?
--	---

Ask about their experiences getting a diagnosis

Transition to getting a diagnosis

 Point to visit health care provider	
	<p>You've described your experiences leading up to visiting a doctor or other type of health care provider. Now let's move along the path to the purple icon on the middle</p>

	island and talk about getting a diagnosis. During this part of the interview, I'd like to hear how you found out you had [condition] . It may be hard to remember and describe it, but please just do your best.
--	---

 **Point to clinic on center island**

	Once you decided to seek care, could you tell me about where you went first (e.g., clinic, hospital, etc.) and how you ended up there (e.g., did you have an appointment with a provider for a wellness visit or a visit for an unrelated condition, were you taken to the emergency department)?
--	---

[Skip if starting point 1]

	You said a health care provider found a problem. Can you tell me more—where you were (e.g., clinic, hospital, etc.) and how you ended up there (e.g., did you have an appointment with a provider for a wellness visit or a visit for an unrelated condition, were you taken to the emergency department)?
---	--

Start here for Starting Point 2

[Continue starting points 1 & 2]

	<p>What happened during the appointment/emergency/hospital admission?</p> <ul style="list-style-type: none"> • Were you able to get a diagnosis of [condition] at that appointment/during this admission? • Did they notice something during your physical exam? Did they have results from lab work?
	<p>Did you feel like you left the office/emergency department/hospital with an understanding of [condition] or what the next steps were for [add from list below]? Why or why not?</p> <ul style="list-style-type: none"> • Confirming the diagnosis • Getting treated • Seeing a specialist • Where to look for information

Follow-Up Care

	<p>What happened after you left the appointment/emergency department/hospital?</p> <ul style="list-style-type: none"> • Did the [provider type] recommend that you go to see somebody else next, such as to get a second opinion or to see a specialist? • Did you decide to go? Why or why not? How long did it take after your first visit with the [provider type] to see this [new provider type]? • Were you satisfied with the care that you received during this time?
--	---

	<p>Looking at the map and thinking about this time when you were trying to get a diagnosis, do you feel the highway or winding path better reflect your experience? Or something in between? Why is that?</p> <ul style="list-style-type: none"> • Was this process easy or difficult? Why do you say that? • Did anything get in the way of being able to act on the instructions from a health care provider? Could you please describe them for me?
--	---

Changed Diagnosis/Misdiagnosis

	<p>Did any of the providers you saw give you a diagnosis that was later changed – in other words, did you find out you had a different condition than you were first told? What made the provider change your diagnosis? Please tell me about how that impacted your experiences.</p>
--	--

Treatments

	<p>During the time when you were still trying to get a diagnosis, did you try any treatments prescribed by a health care provider?</p> <ul style="list-style-type: none"> • What, if any, lifestyle changes did you try? Could you please describe them for me? For example, exercise or diet changes. • What treatments did you try that were not prescribed by a health care provider? Could you please describe them for me?
--	--

	<ul style="list-style-type: none"> • What over-the-counter products did you try, such as [a pain reliever], herbals, vitamins, or supplements? Could you please describe them for me?
--	--

Symptoms

	<p>If prior symptoms</p> <p>You mentioned having some symptoms before, could you please describe if your symptoms changed over time while waiting to receive the diagnosis? If so, how?</p> <p>If prior symptoms not previously mentioned</p> <p>Thinking back, did you have any symptoms or other things related to your [condition] before this visit without realizing they were unusual or connecting them to a possible health problem?</p> <ul style="list-style-type: none"> • Could you please tell me more about [symptoms]? What did they feel like? • How long did the [symptoms] last? • Did the symptoms happen at certain times of the day? • What made the [symptoms] better? What made the [symptoms] worse? • How did you try to manage your symptoms? • How long did it take for you to receive a diagnosis following the onset of your symptoms? • Did you trust that this diagnosis was accurate?
--	--

Questions & Information Gathering

	<p>What questions did you have? What concerns did you have?</p> <p>Where did you look to find information following your appointment?</p>
--	--

Note: This interview guide preview is for planning purposes. To receive a free, 20 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

	<ul style="list-style-type: none"> • What information did you find? Did the information that you found answer your questions? • What sources of information did you trust or rely on most? • Did you connect with a community or another person with the same/similar condition? How did you find him/her/them? What information did they provide?
	Did you consider getting clinical genomic testing?

Emotional Health & Personal Goals

	<p>How were you feeling emotionally during this time?</p> <ul style="list-style-type: none"> • Some people have mentioned feeling calm, worried, overwhelmed, relieved, or angry?
	Were there any personal goals in your life that changed while you were trying to get a diagnosis? What were they?

Life Factors

<p> Point to “life factors” on the map.</p>	
	<p>How did any of the “life factors” affect your life when you were getting a diagnosis? If they changed from before your diagnosis, please tell me how. For example, if your insurance, job or family life changed.</p> <ul style="list-style-type: none"> • During the time of getting the diagnosis, what life factors made things easier? What life factors made things challenging?

	<ul style="list-style-type: none"> • For example: lack of insurance, cost concerns, not being able to take off work • Did you have experiences related to bias and discrimination when seeking a diagnosis? • For example, did you feel you were treated differently because of your race, age, or gender?
--	---

Closing before living with a diagnosis

	<p>Before we move on, do you have anything else you would like to tell me about what it was like getting this diagnosis?</p>
--	---

Diagnosis prior to or at birth, or as a young child

<p>If the participant was diagnosed before or at birth or as a young child, start here</p>	<p>Were you diagnosed prior to or at birth, or as a young child?</p> <ul style="list-style-type: none"> • How was the diagnosis discovered? Through genetic testing, symptoms at birth, etc.?
	<p>How did you learn about your diagnosis? What questions did you have? What concerns did you have?</p> <ul style="list-style-type: none"> • When did you first become aware of your condition? • Where did you look to find information following your awareness of the condition? • Did the information that you found answer your questions? Why or why not? • What sources of information did you trust or rely on most? • Did you connect with a patient community or another person with the same/similar condition?

Note: This interview guide preview is for planning purposes. To receive a free, 22 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

	<ul style="list-style-type: none"> • At what age do you feel that you became more involved in discussions and treatment decisions related to your condition?
	<p>Do you remember how you or your family were feeling during this time?</p> <ul style="list-style-type: none"> • How did the diagnosis affect your childhood? • Were mental health resources offered to you during that time?
	<p>Before we move on, do you have anything else you would like to tell me about this time?</p>

Continue to “Living with a diagnosis” section below.

Ask about their experiences living with a diagnosis

Transition to living with a diagnosis

<p>➡ Point to the green icon “living with a diagnosis” on the map.</p>	
	<p>Let’s continue along the path to the green icon on the last island, which is about your experiences living with [condition]. Please take a moment to look at the highway, winding path and the symbols.</p> <ul style="list-style-type: none"> • Where would you place yourself today? • Do you feel the highway or winding path better reflect your experiences after receiving a diagnosis? Why is that?

Living with a diagnosis

	<p>What are the most important impacts [condition] has on your daily life? How does it affect your everyday?</p> <p>What do you worry about because of [condition]?</p> <ul style="list-style-type: none">• What are the most important impacts on your [family or care partner?]
	<p>Which health care providers do you typically see since you received a diagnosis? Tell me about your usual routine.</p> <ul style="list-style-type: none">• What kind of specialists do you see? How often do you see them?
	<p>How satisfied are you with the health care you receive? What makes you say that? Your comments are kept private.</p> <ul style="list-style-type: none">• Do you have a good relationship with your provider? Why or why not?• Do you believe your providers understand what is important to you – like things you want to see happen in your life? Feel free to talk about past and current providers.• Is there anything that prevents you from keeping up with your appointments? Could you please describe it for me?

Treatment they are currently getting

 Point to “Tried a treatment” on the map.	
	<p>I am interested in learning about treatments you have considered, tried in the past or are currently using. Treatment can be a medication, device, diet change, surgery or another procedure, physical therapy, acupuncture, etc. Treatment could also include non-</p>

Note: This interview guide preview is for planning purposes. To receive a free, 24 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

	<p>medical interventions such as stress relief or massage therapy. If you took part in a clinical trial, I am also interested in hearing about that.</p> <p>Could you please describe what treatment(s) – if any - are you currently taking/getting for your [condition]?</p> <ul style="list-style-type: none"> ○ What made you decide to start this treatment? ○ Who helped you decide on this treatment?
	<p>What are the biggest benefits of the treatment?</p>
	<p>What are the biggest downsides or not-so-good things about the treatment?</p> <ul style="list-style-type: none"> • Do you have any side effects from this treatment? • When you experience a side effect, is it clear what causes this side effect? Are there side effects from the treatment that affect your daily routine? If yes, how so?
	<p>Describe for me how easy or difficult it is for you to take your medicines as prescribed? In other words, do you follow all the instructions given by your doctor or printed on the pharmacy label?</p> <ul style="list-style-type: none"> • Can you tell me more why the medicine(s) is/are not easy to take? • Do you ever miss doses of your medicine? If you do, on average how many doses of your medicine would you say you miss in a week? • What do you think would make it easier for you to take your medicines as prescribed? • Has the medicine for this condition interacted with other treatments you're taking for something else?

Note: This interview guide preview is for planning purposes. To receive a free, 25 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

	<ul style="list-style-type: none"> ○ For example, have there been any unusual side effects that could be related to taking 2 different medicines together? • [If you have a device] Has your device interfered with the activities of your daily life? • [If diet change] Has changing your diet interfered with your daily life or affected things like your finances?
--	--

Treatment they have tried but stopped

	<p>Could you please tell me about any treatments you tried for your [condition], but have stopped? What made you decide to stop the treatment?</p> <ul style="list-style-type: none"> • Could you please describe the good or not-so-good things about the treatment you stopped? • Did you experience any side effects from the treatment? Could you describe it for me? • Would you consider trying this treatment again in the future? Why or why not?
	<p>Is there anything related to the “life factors” that affected your decision to stop this treatment?</p>

Ideal Treatment

	<p>If you had a perfect treatment that wasn't a cure, what would it do for you? How would your life improve if you had a more effective (or better) treatment?</p>
--	--

Surgeries and Procedures

	<p>Could you please tell me about any surgeries or procedures you have considered?</p>
--	---

	<p>What, if any surgeries or procedures related to [condition], have you had?</p> <ul style="list-style-type: none"> • Do you consider that [surgery or procedure] to be successful? Why or why not? • When did you have the [surgery or procedure]?
--	---

Hospitalizations/Urgent Care Visits

	<p>Okay thank you, I know I'm asking a lot of questions. I'd like to ask you a few questions about any hospital visits now.</p>
	<p>Have you sought emergency care, or gone to an urgent care facility due to your condition? Have you been hospitalized for any reason related to [condition]? Hospitalization is typically defined as spending more than 24 hours in a hospital (even if you sought emergency care originally).</p> <ul style="list-style-type: none"> • How long was your stay? • How many times were you hospitalized in the first year after your diagnosis? • How many times have you been hospitalized in the past year due to your condition? • Did the providers in the hospital communicate with and coordinate your care with your specialist? • Did the care you received interfere with another treatment? • Were you transferred to an outpatient facility or rehabilitation center? If so, how long was your stay there? • Did you follow-up with your health care provider afterwards? • Were you satisfied with the care you received?

	<ul style="list-style-type: none"> • Did you experience any bias or stigma in the urgent care or emergency room?
--	---

Life Factors (Hospitalizations/Urgent Care Visits)

<p> Point to “life factors” on the map.</p>	
	<p>How did the “life factors” affect your experience at the hospital? Did these life factors make your experience easier or harder?</p> <p>How did the “life factors” affect your decision to seek emergency care/urgent care? Did these life factors make your experience easier or harder?</p>

Clinical Trial Participation

	<p>And now I have a few questions about clinical trials. A clinical trial is a type of research designed to learn more about how our bodies respond to medicines or other treatments.</p> <p>Have you ever explored the possibility of taking part in a clinical trial? Why or why not?</p> <p>If yes:</p> <ul style="list-style-type: none"> • How did you learn about clinical trials? • Did you learn about clinical trials related to your condition generally or was there a specific clinical trial that prompted your interest? • Did you tell your health care provider you were interested in participating in a clinical trial? Or did your health care provider suggest one? <ul style="list-style-type: none"> ○ Did you end up doing that clinical trial?
--	--

	<ul style="list-style-type: none"> • What made you decide if you would or would not take part in a clinical trial? <p>If they did take part in a clinical trial:</p> <ul style="list-style-type: none"> • How many clinical trials have you participated in? • Describe your experiences, good and bad. • Did you feel like you fully understood what was expected from you as a participant in the trial? Why or why not? • Was there anything about the process/experience that you would change? • At the end of the process, did you still have questions or concerns that were never answered?
--	--

Life Factors

<p>➡ Point to “life factors” on the map.</p>	
	<p>Let’s go back to the “life factors” and how they may have affected your life after you got a diagnosis? Tell me about what was going on with them at the time after diagnosis. For example, did family support, access to insurance, financial concerns, or multiple conditions affect your experience?</p> <ul style="list-style-type: none"> • What life factors made things easier? How? • What life factors made things more challenging? How?

Care Coordination & Multiple Chronic Conditions

	<p>If you have more than one chronic condition, how do you coordinate your care for these conditions?</p> <ul style="list-style-type: none"> • How has having multiple chronic conditions affected your life?
--	---

Note: This interview guide preview is for planning purposes. To receive a free, 29 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

	<ul style="list-style-type: none"> • Do your providers communicate with each other and coordinate your care when exploring treatment options? • Please describe for me how having more than one condition affected your <ul style="list-style-type: none"> ○ finances ○ profession or career ○ family ○ lifestyle ○ mental or emotional well being <p>How has the way you are experiencing [condition] changed over time? How has your care adapted to those changes? Have treatments built upon one another?</p> <ul style="list-style-type: none"> • Have you had any negative effects occur because your care was not coordinated?
--	---

Wellbeing and burden of disease

	<p>I'd like to hear about your overall wellbeing now. Please talk to me about how [condition] effects your emotional wellbeing or mental health. Please share as much as you feel comfortable sharing. I know this can be a difficult topic.</p> <ul style="list-style-type: none"> • Have you experienced feeling less motivated, down, overwhelmed, or depressed? Would you feel comfortable telling me more about these feelings? • Does it affect your concentration or ability to complete tasks? • Have you felt any stigma or bias due to your specific condition? Or symptoms? • How is your ability sleep?
--	--

	<ul style="list-style-type: none"> • Have you sought help to address any mental health concerns? If so, how do you feel about the quality of mental health care you have received? • Is there anything else related to emotional or mental health or sleep you would like to add?
	<p>Please think about the daily activities that are important to you or that you like to do. How has [condition] impacted your ability to those things?</p> <ul style="list-style-type: none"> • How is your ability to move around affected by having [condition]? <p>Do you find yourself needing more help around the house or with things like getting dressed?</p>
	<p>How has having [condition], or symptoms related to it, affected your family or other loved ones?</p> <ul style="list-style-type: none"> • How about your family's finances? What types of expenses do you have now that you didn't have before you were diagnosed? • How has your condition affected your relationships? This could be with a spouse or significant other, friends, work colleagues. • How does having [condition] impact your social interactions? Such as day-to-day interactions with people outside your home? • Are there things that you would like to do that aren't possible because of your [condition]? <p>Probe: This could be things like furthering your education, going on vacations, or sending your children (or grandchildren) to summer camp.</p>

	<ul style="list-style-type: none"> • What are the barriers you are experiencing that make these things not possible?
	<p>How has the way you are experiencing [condition] changed over time?</p>
	<p>What do you know now that you wish you would have known at the start of your journey? When all this began.</p>
	<p>What worries you most about your condition?</p>
	<p>Did you have any positive or negative experiences you would like health care providers and researchers to know about? This could be anything to do with your condition such as an experience with symptoms, medication, health care providers, stigma or bias, etc.</p>

Quality Measurement

	<p>When you think about the health care system, what do you think are signs of “good” quality care?</p> <p>And what do you think are signs of “bad” quality care?</p>
	<p>We have choices in what provider we see and what hospital or clinic we go to.</p> <ul style="list-style-type: none"> • If a friend or family member needed a recommendation, what would be most important things you would tell them in making a recommendation for a doctor, clinic, or hospital? • If you needed a recommendation from a friend or family member, what are the things that would be most important to you that you would want to know about a doctor, clinic, or hospital?

	<ul style="list-style-type: none"> • What things would make you recommend a provider or service to someone else? • What things would make you NOT recommend a health care provider or service to someone else?
--	--

Genetic testing

	<p>If the participant's condition is hereditary or if there are gene-specific therapies available</p> <p>Have you heard of genetic testing?</p> <p>If no, give description:</p> <p>Genetic testing is when a health care provider takes a small sample of your blood, skin, or other tissue to test your genes. Genes are chemical codes in your body that you inherit from your parents. Some diseases are caused by abnormalities or changes in a person's genes. Genetic testing can lead to finding a disease earlier, understanding more about it, or helping to make decisions about which treatment will work best. Generally, it takes about 1 month to complete the process, which includes meeting with a gene specialist.</p> <ul style="list-style-type: none"> • Knowing what you know now, would you have wanted to have genetic testing done before your diagnosis? <p>If yes:</p> <p>Would you have wanted to have genetic testing done:</p> <ul style="list-style-type: none"> • Before any symptoms appeared so you could understand your risks for certain health conditions and medication-related problems?
--	---

	<ul style="list-style-type: none"> • OR as soon as symptoms appeared so you could understand your risks for other health conditions and possible available treatment options? <ul style="list-style-type: none"> ○ What concerns do you have about genetic testing? ○ What do you think are possible benefits of genetic testing?
--	---

Desired Outcomes and Life Aspirations

<p> Point to the blue box on the right island “Desired outcomes and life aspirations” box at the end of the path.</p>	
	<p>We have reached the last few questions. I’d like to talk about your everyday aspirations or goals, and desired outcomes. These are things such as wanting to spending time in your garden, with your kids (or grandkids), riding a bike, or keeping your balance as you walk.</p> <p>Could you speak a little about the everyday goals and hopes you have and use as motivation on tough days?</p>
	<p>Which outcomes are most important to you when it comes to your [condition]?</p> <ul style="list-style-type: none"> • Outcomes might relate to how you feel, for example fewer symptoms; how you function, such as being able to exercise or walk to work; or living longer.
	<p>What were your aspirations before your condition was diagnosed?</p> <ul style="list-style-type: none"> • How have your aspirations changed because of your diagnosis? How have they changed across the map over time?

Note: This interview guide preview is for planning purposes. To receive a free, 34 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

	<ul style="list-style-type: none"> • What influenced those changes?
	<p>Was there something that gave you hope or motivation since [beginning of patient journey – refer to symptoms or first visit with provider]?</p> <ul style="list-style-type: none"> • For example, is there an outcome that you are trying to reach that kept you going through treatment or pushed you to get a diagnosis?

Closing

	<p>Is there anything else you would like to add about your experience with [condition] that we didn't touch on but you think is important?</p>
	<p>Is there anything else you would like to tell researchers about having your condition?</p> <p>Is there anything you would like to tell policymakers about having your condition?</p>
	<p>Are there resources you wish existed, but you haven't been able to find?</p>

Feedback on Tools

	<p>Before we end this session, I would like to just ask a few questions about the tools and interview itself. We are always trying to improve the way we do things.</p> <p>Do you have any feedback on the Map we used during this interview?</p> <ul style="list-style-type: none"> • Was it helpful in answering my questions?
--	---

Note: This interview guide preview is for planning purposes. To receive a free, 35 modifiable version as a word document, visit <https://nationalhealthcouncil.org/resources/pemt-interview-guide-survey/>

	<ul style="list-style-type: none"> • Are there things you think we should change on the map? • We used the map to help guide this interview. Are there any other uses you think it could be helpful for?
	<p>How about the questions that I asked – is there anything that struck you as confusing or not clear? Or questions that you think I should have asked, but didn't?</p> <p>Do you have any other comments, suggestions, or questions before we end?</p>

Conclusion & Post-Interview Logistics

	<p>Thank you so much for your time so far. We are just about finished with this interview.</p>
	<p>[Organization or individual's name] will follow up with you by email about your payment for taking part in this interview and the results of this study.</p> <p>If you have any questions or comments, please feel free to contact [contact name] at email: [email address] or by phone at [telephone number].</p> <p>Thank you again for taking part in this interview and sharing all about your experiences – it has been very helpful.</p>