



# Consent sheet for an interview about your health experience

[Organization] is asking to interview you because you have . This consent sheet gives you information about the interview and what you will be asked to do.

## Here are a few things to know as you learn more:

- Taking part in the interview is voluntary – you can choose to take part or not.
- Before you decide, read this sheet carefully so you know what the interview involves.
- Take your time to decide – you may discuss it with your family and friends.
- You can ask the research staff any questions you may have.
- If you decide to take part in the interview, the research staff will ask you to verbally agree to the interview when the interview begins.
- You can choose to stop or pause the interview at any time.
- You can refuse to answer any questions you don't want to answer.

## What is the purpose of the interview?

The purpose of this interview is to help us better understand the experiences of people with . We learn more about from interviewing you and others with . We will create a summary document that describes people's experiences before getting a diagnosis, while getting a diagnosis, and living with . This summary will be shared with researchers and health care providers to improve the work they do by having a better understanding of the lives of people with .

## What will I be asked to do?

We will ask you to:

- Answer questions about your experience with , including your:
  - Daily life with ; how it makes you feel, your symptoms, and its impact on your daily life,
  - Path to getting a diagnosis and how that happened,
  - Treatments (drugs, procedures, other therapies) and
  - Current health.
- Answer to the best of your ability – you do not have to answer any questions that you do not feel comfortable answering
- Let us record the interview and then create a written version of the interview – the written version will not include any details that could be used to identify you. We will delete the audio recording once we have the written version.

The interview will take about minutes to complete.



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## Are there any benefits to taking part?

You will not benefit directly from taking part in this interview. However, we will use the information we learn from the interviews to help improve care for people with \_\_\_\_\_ in the future.

## What are the risks from taking part?

Possible risks include:

- Loss of confidentiality or privacy. This risk is unlikely. To keep your interview confidential and private, our research team will:
  - Not ask questions about confidential information (for example, hometown or employer)
  - Remove any personal information if you mention any when answering questions (for example, your name, your doctor's name, etc.) from the written transcription – we will then replace your name with a unique number code, such as ID #
  - Save interview files in a password-protected file that only certain research staff can access
- Feeling uncomfortable with some of the topics or questions asked during the interview. This risk is also unlikely. To prevent this risk, you can:
  - Skip (not answer) any questions that you do not feel comfortable answering
  - Stop the interview at any time

## Will the information I share during the interview stay private?

Yes. We may publish data from the interviews, such as in xx. When we write and publish reports, we will combine the data from all interviews to present the results as a group. If we include a quote of an exact statement you made, we will not include your name.

## Will I be paid?

You will be paid \_\_\_\_\_ for completing your interview. It will not cost you anything to take part in this interview.

## Can I stop the interview if I change my mind?

Yes. You can choose to stop the interview at any time. Choosing not to participate or choosing to stop the interview will not harm you in any way or change your regular care from your doctors. If you decide to stop taking part, please contact \_\_\_\_\_ at \_\_\_\_\_.

## Can the research staff stop my interview?

Yes. The research staff may stop your interview early if you are unable to follow their instructions.

## Who can I contact if I have questions, concerns, or complaints?

Please contact \_\_\_\_\_ at \_\_\_\_\_ if you have any questions, concerns, or complaints.

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## Study information

Protocol title:

Protocol number:

Principal investigator:

Date: mm/dd/yyyy

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