

Participants' instructions - SMA Daily Life Study

Who can participate?

This study is directed to **teenagers, young adults and adults living with SMA**. Surveys and questionnaires may be filled in by the person living with SMA themselves, or by a personal assistant with answers provided by the person living with SMA.

Participants need to be **16 years of age or older**.

Participation is open to **anyone in Europe who speaks English**. If you have an intermediate level of English (or above), you will be comfortable filling in the questionnaires.

Participants need to own a **smartphone**, which they need to carry with them, and they need to have an Internet connection (data or Wi-Fi).

How does it work?

The study runs for **12 days** and is made of **three parts**.

On the first and last day, you will respond to a longer survey. During the rest of the time, you will fill in 6 short questionnaires a day for 10 consecutive days.

- Day 1: Start survey (less than 30 minutes)
- Days 2-11: 6 short (3 minutes) questionnaires per day
- Day 12: Final survey (less than 30 minutes)

We suggest taking the start and final survey on a computer, for your ease. These surveys can also be taken on a smartphone, if that is more convenient to you.

For the short questionnaires, you will need to download the smartphone app “m-Path” (please see instructions on our [website](#)).

How do I start?

If you would like to participate, **please email us at** survey@sma-europe.eu stating your interest.

Then:

- 1. Welcome email**
You will receive an email with detailed instructions, your participant number, and a link to start participating.
Please store your participant number safely: you will need it at different stages of the study.
- 2. Informed consent**
The link you received in our email will lead you to an information letter that explains your rights as a participant. Please read this document carefully. After this, you can decide whether to express your consent to participation. If you agree, you will be prompted to begin your start survey.
- 3. Start survey**
Fill in your start survey. This will take less than 30 minutes.
- 4. Download and set up m-Path**
After the start survey, you will receive instructions on how to download and use the free application “m-Path”. You can also see these instructions on the [SMA Daily Life Study website](#).
- 5. Take your daily questionnaires**
Once you are set up, you will receive notifications to respond to six questionnaires every day, for ten days.
- 6. Final survey**
On day 12, you will receive our final survey via email. Completing this survey takes less than 30 minutes. After you have completed this, we will be in touch about your rewards!

What do I get for participating?

We are very grateful for the time you will invest in participating in our study! To thank you, we offer our participants two rewards:

1. Financial reimbursement

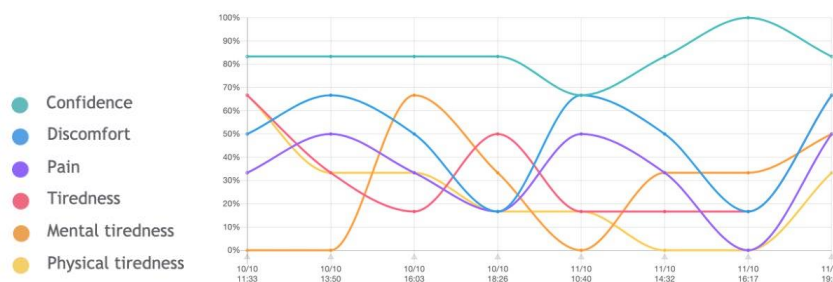
Participants will receive a financial reimbursement up to 50 USD for participating in our study. You will receive more detailed information about reward levels, which depend on the percentage of questionnaires you complete, before you start your first survey.

The financial reimbursement will consist of a virtual debit card that you can use worldwide for online purchases in your local currency.

2. Graphic visualization of your survey data

People living with SMA who will take part to this survey may learn more about themselves and what factors play into their daily well-being. For this reason, we will produce an infographic of individual results and deliver it to the participants who are interested in receiving a first-hand look into their personal data.

For instance, your infographic may look like this:



3. Indirect benefits

This study has the goal to identify how patient-relevant outcomes present in the everyday life of people living with SMA. In the future, we want to design new instruments to better measure these outcomes. Once we can better quantify patient-relevant outcomes, we will be more successful in lobbying to include them as measures for treatment success for people living with SMA. Thank you for contributing to this important mission that can improve many lives!