

## Frequently Asked Questions - SMA Daily Life Study

Below, please find answers to our FAQs:

- When will I receive my questionnaires?
- How much time do you have to answer my questionnaires?
- What happens if I miss a questionnaire?
- What is my participant number and where can I find it?
- Who can participate?
- What do I get for participating?
- How about privacy?

### When will I receive my questionnaires?

Your daily questionnaires will be delivered to your smartphone application at **random times** during the day, except for your **first and last questionnaire** of the day, which will be delivered at the **same time every day**.

### How much time do I have to answer my questionnaires?

You need to respond to each short questionnaire **within 30 minutes** from reception of the notification. For your last questionnaire of the day, you have **2 hours** to respond.

### What happens if I miss a questionnaire?

At times, it will not be possible to answer a questionnaire. That is ok! However, **it is important that you answer as many questionnaires as you can**. Please make sure you always have your smartphone on you.

### What is my participant number and where can I find it?

Participant numbers allow us to recognize participants as they fill in questionnaires on different digital platforms (i.e., the start and end questionnaires and your m-Path data). In our data, however, this number will not be linked to your identifying information.

**You will receive your participant number by email** alongside your participation instructions and the link to start your survey, from the following address: [survey@sma-europe.eu](mailto:survey@sma-europe.eu)

**Your participant number is unique to you and should not be shared with others.**

It is very important that you keep this number handy. **You will need to fill in your participant number on three occasions:**

- at the beginning of the start survey.
- when you set up your m-Path application. Please use your participant number as your ID/nickname.
- at the beginning of the end survey.

You will also need this number in case you have any trouble and need to communicate with us about your participation.

For any questions or concerns, please do not hesitate to contact us at [survey@sma-europe.eu](mailto:survey@sma-europe.eu)

## 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).

## 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**

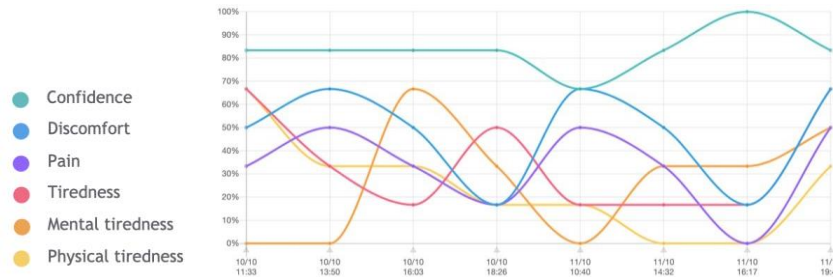
Participants will receive a financial reimbursement up to 50 USD for participating in our study. You will receive more detailed information about reward levels, which depend on the percentage of questionnaires you complete, before you start your first survey. The financial reimbursement will consist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

## How about privacy?

This study has been reviewed and approved by the Ethics Review Board at Tilburg University and complies with the General Data Protection Regulation (GDPR) (EU) 2016/679.

Before beginning your surveys, you will read about your rights as a participant in detail. If you have any questions after reading this information, please do not hesitate to contact us at [survey@sma-europe.eu](mailto:survey@sma-europe.eu) before signing your informed consent. We are here to clarify any doubts for you.