



46703

PARENT AND CAREGIVER INFORMATION SHEET

Study title: Survey of priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Sheffield Children's NHS Foundation Trust would like to invite you to take part in our research study.

Before you decide we would like you to understand why the research is being done and what it would involve.

One of our team will go through the information sheet with you and answer any questions you have.

Talk to others about the study if you wish.

Part 1: tells you the purpose of this study and what will happen if you take part.

Part 2: gives you more detailed information about the conduct of the study.

Please ask the person who gave you this information sheet, if there is anything that is not clear.

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers
Version 1.5
Date 17/03/26
Corresponding protocol version and date 1.3 27/02/26
IRAS ID 349476



46703

Part 1 – What is the purpose of this study and why have I been asked to take part?

1. What is the purpose of the PRISM SMA study?

1a: Background

We are looking to recruit parents and carers of children with Spinal Muscular Atrophy (SMA) to complete a single survey to tell us about your experiences and the treatment information you were given. We will also be asking healthcare professionals who work with patients and families with SMA to understand their experiences, and we might also ask your child to participate as well.

We are researching SMA patients, parents, carers and siblings of people with SMA, and healthcare professionals who treat patients with SMA to try to identify which areas of research and care are to be prioritised. We want to understand what information you were given at the time of diagnosis of the person you care for with an SMA diagnosis and whether you felt empowered to make the correct decisions about your child's subsequent care. We also want to understand what information is important to parents and carers of people with SMA and understand what healthcare professionals see as important to people with SMA and their families/carers to see if there are any discrepancies.

We know that the decisions that you have to make around the time of diagnosis can be extremely difficult and it is hard to process all the information you are given in such a short time. It is understandable then, that in hindsight, you may have wished you had more information or wished you had made a different choice with regards to management.

We're doing this research to hopefully create guidance for clinicians on what families and people with SMA prioritise and how we can better facilitate this in a clinical setting, especially with regards to those early consultations you have with your neuromuscular teams. This will help ensure they prioritise the most essential information that will hold the highest value to new parents/carers of children with SMA.

We are planning to involve a minimum of 70 participants in this research project. Of this total number we are aiming to involve:

- a minimum of 10 people with SMA aged between 6-25 years
- a minimum 30 parents and carers of a child with SMA and their siblings
- a minimum of 30 healthcare professionals who treat patients with SMA

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers

Version 1.5

Date 17/03/26

Corresponding protocol version and date 1.3 27/02/26

IRAS ID 349476



Trial Information Sheet

46703

After the survey, we would like to interview some of you to look into more depth the answers you have provided to give us more qualitative information. We also want to get a better understanding of the information you require at the point of diagnosis and what new treatment options are available. If you indicate at the end of the survey that you would be interested in taking part in the interview, you can provide your contact details for a member of the research team to contact you and provide you with a participant information sheet and consent form for this optional part of the study.

2. Why have I been chosen?

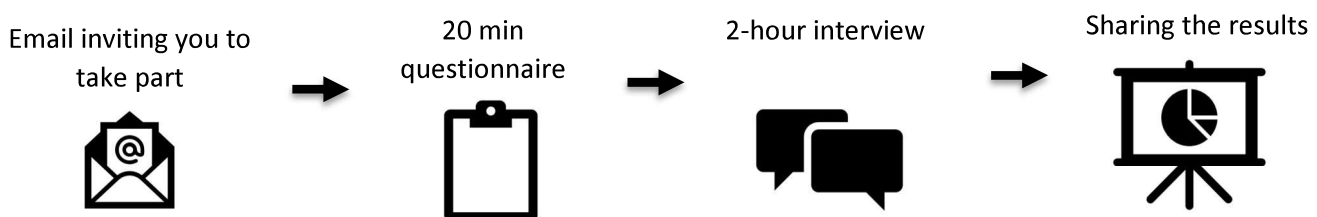
You have been chosen because your child has spinal muscular atrophy. We hope to have around 70 participants in this study, 30 of whom will be parents or caregivers of a child with spinal muscular atrophy.

3. Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form.

You will be given a copy of the information sheets and the signed consent form to keep for your records. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

4. What will happen to me if I agree take part?

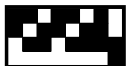


4a. Who will be leading the research visits

- This research is being conducted by the neuromuscular team at Sheffield Children's hospital. The interviews will be conducted by Dr William Quelch, a paediatric registrar.

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers
Version 1.5
Date 17/03/26
Corresponding protocol version and date 1.3 27/02/26
IRAS ID 349476



46703

4b. What will happen in this study?

If you would like to take part, we will ask you to read this participant information sheet and the consent form before deciding on whether you would like to participate. You should also take the time to think about the research and discuss it with your family and friends, before making a decision. If you feel your child or their siblings would like to take part, there are separate patient information sheets to fill in and forms to sign for their assent for the study and your consent for them to take part.

If you do decide to take part, you should complete the survey which is included in the email with this participant information sheet. When you click on the link to complete the survey, you will be asked some questions consenting you to the research. Please read these questions through carefully, and only if you are happy to provide consent should you proceed to do so and complete the survey. Completion of the survey will indicate your consent to taking part in the study.

Completing the survey should take you around 20 minutes and should be completed in one sitting. After you have completed the survey, you do not have to do anything else.

Please be aware, taking part in this survey is not part of your child's standard of care and you do not have to take part if you don't want to.

At the end of the survey, you will be asked if you would like to provide your contact details to discuss the possibility of taking part in a 2-hour interview. This interview will be a more in-depth look into the priorities, information sharing and decision-making processes you went through around the time of your child's diagnosis. If you wish to bring your child with SMA or their siblings to this interview to share their experiences, please read through the age appropriate PIS forms with them and contact the research team on the details below.

This can take place either face to face, or virtually, depending on your preference. This interview will be audio recorded and a transcript generated to aid with analysis. The interview will be transcribed by Dr William Quelch and once this has been performed the audio recording of the interview will be deleted.

4c. When will I be expected to participate?

- If you wish to take part in the 2-hour interview, this will be arranged at your convenience, either face to face or virtually depending on your preference.

4d. How will this research happen?

- Your participation in the research will encompass the survey and, if you wish to participate further, the 2 hour interview. No further visits are required.

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers
Version 1.5
Date 17/03/26
Corresponding protocol version and date 1.3 27/02/26
IRAS ID 349476



46703

4e. Where will the research take place?

- The research will be taking place at Sheffield Children's Hospital, although interviews can be arranged either face to face, or virtually.

5. What expenses and payments can be claimed?

Travel expenses for interviews will be covered by the research team. At the end of the interview participants will receive an Amazon Voucher to thank them for their involvement in the study.

6. What are the possible disadvantages, risks and benefits of taking part?**6a. Risks**

Whilst we do not envisage any risks of taking part, we recognise that thinking about the experiences of treatment you've encountered for the person with SMA you care for, it can be traumatic and distressing. If you do feel upset by answering the survey, please stop and do not continue. If you would like further support, you can contact scn-tr.prism-sma@nhs.net and one of the research team will be in touch. During the interview, if you become upset or distressed, we will pause the interview, give time for a break and if needed, end the interview at your request. We will ensure you are signposted to appropriate services prior to you leaving the interview.

6b. Benefits

Whilst there are no direct benefits to yourself, or to the person with SMA you care for, we hope there will be a benefit of you feeling that you have been able to express your experiences and opinions in an appropriate format. We hope the information we collect from this research will benefit families with SMA in the future and inform healthcare professionals in their consultations and treatment of people with SMA.

7. What happens when the research study stops?

We will collect all the information together and we will decide if it is useful in telling us if the doctors can manage spinal muscular atrophy better in the future.

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers
Version 1.5
Date 17/03/26
Corresponding protocol version and date 1.3 27/02/26
IRAS ID 349476



46703

8. What happens if any safeguarding concerns are raised during the study?

Any safeguarding concerns identified during the course of the research will be managed in accordance with the local NHS Trust Safeguarding Policy. If a participant discloses information indicating risk of harm to themselves or others, or risk of abuse or neglect, the researcher will escalate the concern promptly to their line manager and the Trust Safeguarding Lead. Appropriate documentation will be completed, and referrals will be made to the relevant safeguarding services in line with Trust procedures. Confidentiality may be breached if there is a safeguarding concern requiring escalation to ensure your safety or the safety of others.

This completes Part 1.

If the information in Part 1 has interested you and you are considering participating, please read the additional information in Part 2 before making any decision.

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers
Version 1.5
Date 17/03/26
Corresponding protocol version and date 1.3 27/02/26
IRAS ID 349476



46703

Part 2 – As Sponsor, how do Sheffield Children's Hospital conduct their research projects and make sure my best interests are put first?

1. Who is organising and funding the research?

Researchers at Sheffield Children's NHS Foundation Trust are organising this study. They will not get any extra money for doing this research.

2. How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

Sheffield Children's Hospital is the sponsor of this research.

Sheffield Children's Hospital is responsible for looking after your information. We will not share your information related to this research project with any other organisations.

We will keep all information about you safe and secure by:

- Storing all data on an encrypted NHS laptop
- Having only the study team will have access to your data
- We will remove identifiable information from datasets.
- Retain and dispose of data in accordance with GDPR, the Data Protection Act 2018, and NHS records management policies, including secure deletion and confidential destruction when the retention period ends

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers
Version 1.5
Date 17/03/26
Corresponding protocol version and date 1.3 27/02/26
IRAS ID 349476



46703

Trial Information Sheet

International transfers

Your data will not be shared outside the UK.

How will we use information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your study data for a maximum of 5 of years. The study data will then be fully anonymised and securely archived or destroyed.

What are your choices about how your information is used?

- you can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have
- you have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- our leaflet (QR codes below)
- by asking one of the research team
- by sending an email to scn-tr.prism-sma@nhs.net, or
- by ringing us on 01142717417

You can find out more about how we use your information at:
<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/>



Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers
Version 1.5
Date 17/03/26
Corresponding protocol version and date 1.3 27/02/26
IRAS ID 349476



46703

Or how Sheffield Children's NHS
Foundation Trust use your
information: <https://www.sheffieldchildrens.nhs.uk/your-information/>



3. What will happen if I lose capacity to consent after I have enrolled in the study?

If you were to lose the capacity to consent you will be withdrawn from the study. Identifiable data already collected with consent, such as from the surveys or interviews, would be retained and used in the study. No further data would be collected or any other research procedures carried out on or in relation to you.

4. What will happen to any samples I give?

We will not take any samples from you in this research study.

5. What will happen if genetic tests are completed?

We will perform no genetic tests in this research study.

6. What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have, as this will already be anonymised. If you would like to remove the transcript of your interview from the analysis prior to publication, please get into contact with the research team as soon as possible.

7. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by London - Fulham Research Ethics Committee. It has also been given approval by the Research Department to run at this hospital.

8. What will happen to the results of this research study?

The results are likely going to be published towards the end of 2026, we will keep you updated through the SMA UK Website.

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers
Version 1.5
Date 17/03/26
Corresponding protocol version and date 1.3 27/02/26
IRAS ID 349476

Trial Information Sheet



46703

When the study has finished, we will present our findings to other researchers, and we will put the results in medical magazines and websites that researchers read. We would also like to put a brief summary on the hospital research website so that you will be able to read about our results too. This will be available at the end of the study, on www.sheffieldchildrens.nhs.uk/research-and-innovation.htm. We will also share the summary with SMA UK for their website. They will be anonymous, which means that you will not be able to be identified from them.

Your information will only be used for the purpose of health and care research and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

9. Who can I contact if I have a complaint?

Complaints about Data Handling

If you are not happy after that, you can contact the Data Protection Officer for Sheffield Children's Hospital.

Name: Mark Talbot

Contact: scn-tr.dataprotection@nhs.net

If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

Complaints about your treatment on the research study:

If you have a concern about your participation on this study, you should ask to speak to the researchers who will do their best to answer your questions.

Name: Emma Kimpton

Title: Mrs

Hospital/Department: Sheffield Children's Hospital

Tel: 0114 271 7000

If you remain unhappy and wish to complain formally, you can do this by contacting:

Sarah Fraser

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers

Version 1.5

Date 17/03/26

Corresponding protocol version and date 1.3 27/02/26

IRAS ID 349476



46703

Trial Information Sheet

Patient Advice & Liaison Co-ordinator

Sheffield Children's NHS Foundation Trust

Tel: 0114 271 7594

Harm

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation, but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

10. How can I find out more about research here at Sheffield Children's Hospital?

If you would like to find out more about Research here at Sheffield Children's Hospital, follow the below link to our video resources:

www.sheffieldchildrens.nhs.uk/research-and-innovation.htm



Or Contact:

Tel: 0114 3053478

Email: research.sheffchild@nhs.net

If you would like to know more specific information about this research project, please contact the project co-ordinator:

Name: Emma Kimpton

Title: Mrs

Hospital/Department: Sheffield Children's Hospital

Tel: 0114 271 7000

If you would like advice as to whether you should participate you could contact the project team, or one of your child's health care professionals.

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers

Version 1.5

Date 17/03/26

Corresponding protocol version and date 1.3 27/02/26

IRAS ID 349476

Trial Information Sheet



46703

If you decide to take part in this study, you will be given this information sheet and signed consent and assent forms to keep.

Thank you for taking the time to read this information sheet.

Full title of study: Priorities, information sharing and decisions in care for SMA patients, carers, and healthcare professionals in the UK: PRISM SMA

Participant Information Sheet: Parents and Carers

Version 1.5

Date 17/03/26

Corresponding protocol version and date 1.3 27/02/26

IRAS ID 349476