**Appendix 3: Patient Information Page**

**Version 2.0 02.06.2024**



Thank you for your interest in taking part in this survey.

This survey has been designed for people who have personal experience of being treated for severe haemophilia A. You have been invited as you are currently a severe haemophilia A patient who is being treated in the UK.

If this is not the case, please click exit to leave the survey.

We (the research team) will be asking you about how you would choose between different treatment options for people with haemophilia A, with a specific focus on gene therapy.

Gene therapy is a medical approach that treats or prevents disease by correcting the underlying genetic problem.

This survey is part of a PhD study called HAEM-PROSPECT which seeks to understand how patients make choices with regard to gene therapy in haemophilia. Your participation will therefore help researchers further understand how patients make these choices.

There are no right or wrong answers; we are just interested in hearing about your views. We do not envisage any disadvantages/risks to you in taking part and links to further information on gene therapy will be provided at the end of the survey.

This survey is split into three parts and should take no longer than 20 minutes to complete.

* Part 1: Your views on healthcare
* Part 2: Making treatment choices - video and survey questions
* Part 3: You and your haemophilia

This survey is being led by John Spoors, who is a researcher at the London School of Hygiene and Tropical Medicine (LSHTM).

If you have any further questions about the survey, then please contact:-

Email : john.spoors@lshtm.ac.uk

Phone : 07825559570

If you remain unhappy and wish to complain formally, you can do this by contacting the study sponsor: The LSHTM Research Governance and Integrity Office at <rgio@lshtm.ac.uk or +44 (0) 20 7927 2626>. The LSHTM, as study sponsor, holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

LSHTM is the sponsor for the research and they have full responsibility for the project including the collection, storage and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly. Personal data collected for both UK and EU studies must be done so in accordance with the General Data Protection Regulation (GDPR).

In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

At the end of the study we will save some of the data in case we need to check it. We will make sure no-one can work out who you are from the reports we write.

This information will include your name, contact details, age, education, ethnicity, employment status and haemophilia status. 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.

We will keep all information about you safe and secure. Data will be stored securely for a maximum of 10 years and in-line with the LSHTM data management plan for research students.

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.

Results from the study will be disseminated at conferences, peer-reviewed manuscripts and submitted as part of a PhD Thesis.

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 can find out more about how we use your information by:-

* Visting - [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
* Visiting - https://www.lshtm.ac.uk/files/research-participant-privacy-notice.pdf
* Asking the lead researcher (John Spoors) or the sponsor (LSHTM) on the contact details listed above.
* by sending an email to the LSHTM data controller: DPO@lshtm.ac.uk

All research involving human participants 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 favourable opinion by the LSHTM Research Ethics Committee (Ref: 30882), The NHS HRA Ethics Committee (Cambridge South REC) (Ref: 343332) has also reviewed the study and have agreed that it is okay for us to ask people to take part.

Thank you for taking time to read this information sheet. If you think you will take part in the study please click continue or alternatively click exit to leave.