UK Bleeding Disorder Research Registry
(UK-BDRR)

PARTICIPANT INFORMATION SHEET FOR YOUNG PEOPLE (11-15 YEARS)

Please read this leaflet and talk to your mum, dad, or the person who looks after you. You can also ask your doctor or nurse if you have any questions. This leaflet explains why we are asking you to help and what it will involve for you. Thank you for reading this.

Why am I being asked?

You have a bleeding disorder that makes your blood thinner than other people. It means you are more likely to bleed. If you do bleed, you get treatment to stop it. Some people also have treatment to prevent bleeds from happening in the first place.

We are asking everyone in the UK who has a bleeding disorder, no matter how old they are, whether they want to take part in this study.

What is the purpose of the UK Bleeding Disorder Research Registry (UK-BDRR)?

Bleeding disorders are rare, so we need to gather information from lots of people across the UK over a long time to understand them better. By combining information from many people, doctors and researchers can learn more about these disorders and how to treat them.

This study will help us understand bleeding disorders better and improve the care for people who have them. We want to find out more about what causes bleeding disorders, how they affect your life, and what the best treatments are.

What is the National Haemophilia Database (NHD)?

Your Haemophilia Centre sends information about your bleeds and treatment to the NHD. The NHD has information about all patients in the UK who have a bleeding disorder. This information helps manage your condition. By combining it with information from other people, the NHS can understand how much treatment is needed for everyone with a bleeding disorder now and in the future. The NHD also looks into how treatments work and if they cause any problems. It does not change your treatment; it only researches at what happens to you during your usual care. If you use Haemtrack to record your bleeds and treatment at home, this information can also be used for research if you agree.

What is the link between the UK-BDRR and the NHD?

The UK-BDRR collects data from several places. Most of the information comes from the NHD and other hospital records.

What happens to the results of the research?

The results may be published in medical journals or presented at meetings to help doctors and nurses worldwide understand bleeding disorders better. Reports are also shared with companies that make treatments for bleeding disorders. No one will be able to identify you from these reports.

Do I have to take part?

No, taking part is your choice. It's okay if you don't want to take part. If you decide not to, it won't affect the care you receive now or in the future. We won't ask you to do anything extra, most of the time, but we might ask you to fill out questionnaires about your health and bleeding disorder.

What are the possible benefits of taking part?

This research might not help you directly, but it could help improve treatment for people with bleeding disorders in the future.

Will anyone else know I'm taking part?

Your family, doctors, nurses at your Haemophilia Centre, and people working at the NHD will know you're taking part. All your information will be kept safe. Your name won't be used, so no one will be able to identify you from the research.

What if I don't want to take part anymore?

If you decide to join but later change your mind, that's okay. You can stop at any time without saying why. Just tell one of the nurses or doctors, or ask your mum, dad, or carer to let us know. Stopping won't affect your treatment in any way, and you can still see the doctors and nurses as usual.

What will I be asked to do if I take part?

You will need to sign a form to give us permission to use your information for research. You won't have to do anything else, and your treatment won't change.

Thank you for reading this - please ask any questions if you need to.

UK Bleeding Disorder Research Registry (UK-BDRR)
Assent Form – Child (11-15 years)

Participant details

Patient Full Name:
Date of Birth:
Hospital Number:

	Initials
1. I confirm that I have read and understood the patient information sheet, version 2.0, for the UK Bleeding Disorder Registry.	☐
2. I give consent for my clinical data from any hospital that I attend to be provided to the UK-BDRR by my haemophilia centre or other researchers who have access to relevant information.	☐
3. I give permission for UK NHD to share my personal identifiers (name, H & C number and Date of Birth) with the Business Services Organisation (Health and Social Care NI) to allow BSO to trace patients using the supplied identifiers to match mortality data in respect of deceased patients hence ensuring accurate mortality data and thereby contributing to UK wide research regarding bleeding disorders.	☐
4. I understand that my participation is voluntary and that I can withdraw at any time without giving a reason and without my medical care or legal rights being affected.	☐
5. I consent to my anonymised and pseudonymised data being transferred between the collaborating research institutions and/or industrial partners for research, including safety surveillance in the UK and abroad.	☐
6. I understand that my medical information may be looked at by authorised individuals from regulatory authorities or by the ethics committee where it is relevant to my participation in this study. All my medical information will be treated as confidential.	☐

Name of Patient **Signature** **Date**

Name of Parent/Guardian **Signature** **Date**

Name of person taking consent **Signature** **Date**