

# UK Bleeding Disorder Research Registry (UK-BDRR)

## PARTICIPANT INFORMATION SHEET FOR CHILDREN (6 -10 YEARS)

Please read this carefully. If there are any words you don't understand, ask your doctor, nurse, or parents for help. Thank you for reading this.

### Why am I being asked?

You have a condition that makes your blood thinner than other children, which means you might bleed more easily. You get treatment at your Haemophilia Centre to help stop any bleeds or to stop you from getting them in the first place.

We collect information about your medicine and any bleeds you have to help your Centre make your treatment the best it can be. We want to use this information to learn more about how your condition affects you and how well the treatments work. We will combine your information with that of others in the UK who have bleeding disorders. This will help us find ways to make treatments even better. We need to ask if you're happy for us to do this.

### Why me?

We are asking everyone in the UK who has a bleeding disorder if they want to take part. Your condition might need regular treatment, or it might not.

### What will I have to do?

You don't have to do anything different or extra. There will be no extra blood tests.

### Do I have to join in?

No, it's up to you. It's okay if you don't want to join in; you will still get your usual treatment.



### Where will the study take place?

We will collect information about your treatment both at home and at your Haemophilia Centre.

### Will anyone else know I'm doing this?

Only your family, doctors, and nurses will know you're taking part. All the information about you will be kept safe on a computer both within and outside the hospital.



### What if I don't want to join anymore?

It's okay if you decide to join and then change your mind. You can stop at any time, and you don't have to say why. You will still see the doctors and nurses at the Centre as usual.



### If I say 'yes,' what happens next?

If you say 'yes,' you will need to sign a form. Your mum or dad will also need to sign a form to give their permission for you to take part.



THANK YOU FOR READING THIS - PLEASE ASK ANY QUESTIONS IF YOU NEED TO.

# UK Bleeding Disorder Research Registry (UK-BDRR)

## UK Bleeding Disorder Research Registry (UK-BDRR) Assent Form – Child (6-10 years)

### Participant details

---

**Patient Full Name:**  
**Date of Birth:**  
**Hospital Number:**

	<b>Initials</b>
1. I have read, or had read to me about this study	<input type="text"/>
2. I give permission for my information to be provided for this registry	<input type="text"/>
3. I give permission for this registry to share my information with Business Services Organisation (Health and Social Care NI) so that correct information is used for this study	<input type="text"/>
4. I understand that I can decide to come off the study at any time without it affecting my treatment	<input type="text"/>
5. I understand that my information may be seen by others who will check that the study is being done the right way	<input type="text"/>
6. I do not want my information to be part of this research	<input type="text"/>

\_\_\_\_\_  
**Name of Participant**

\_\_\_\_\_  
**Signature**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Name of Parent / Guardian**

\_\_\_\_\_  
**Signature  
(If consented at centre)**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Name of Person taking consent**

\_\_\_\_\_  
**Signature**

\_\_\_\_\_  
**Date**