

## VERBAL CONSENT SCRIPT

### Australian Bleeding Disorders Registry (ABDR)

Hi, my name is [state your name]. I am the [insert job title] at the [insert name of Haemophilia Treatment Centre]. I'm working on the ABDR project conducted by [insert Director's name]. Do you have a few minutes to discuss the ABDR?

- If yes, continue below.
- If no, but the potential subject is interested in participating, determine a better time to call back to discuss the study.
- If no, thank them for their time.

We are inviting you to register with the Australian Bleeding Disorders Registry (ABDR) because you have been diagnosed with a bleeding disorder. You may already be registered, and if so, we ask you to continue your registration with the ABDR. You would have received some information in the mail recently explaining the ABDR. You may have already read this information, but to summarize the ABDR is a database of your personal and health information that is used only by your healthcare professionals to better treat you and meet your care needs. This information is also important for the National Blood Authority (NBA) to be able to supply your treatment products when you need them. Research is also performed using the data in the ABDR where reports and publications are written and presented.

The information in the ABDR includes your name and address, your diagnoses and treatment plan, and whether you experienced any complications. Please remember that your information is always kept secure and confidential and is never revealed to anyone outside of your healthcare team and authorised people from Haemophilia Foundation Australia (HFA), the NBA, and the Australian Haemophilia Centre Directors' Organisation (AHCDO).

If you decide to register for the ABDR, you will be asked to provide your consent to collect your personal and health information for the database. For research purposes, your information will not be identifiable (that is, your name and personal details will not be disclosed to the researchers).

We are asking all patients with bleeding disorders to register.

There are no risks to you or your family if you choose to register with the ABDR. The potential benefits include enhanced treatment and improved planning for supply and delivery of treatment product. The information would also benefit patients in the future with better treatment and care options.

You will not be paid for participating in the ABDR. There will be no cost to you to participate.

Does this sound like something you'd be willing to participate in?

- If yes, continue below.
- If no, thank them for their time.

Before you agree to participate, there are some additional things you should know about the ABDR.

In order to collect study information, we have to get your permission to use and give out your personal health information. Your permission to use your health information for the ABDR will not expire unless you tell us you want to cancel it. We will keep the information we collect about you indefinitely. If you cancel your permission, you will be removed from the research but your existing information will remain on the registry. You also have the option to use a pseudonym. If this is of interest to you, then please contact a staff member at your HTC.

Your participation in the ABDR is completely voluntary. You are free not to participate or to withdraw at any time, for whatever reason. No matter what decision you make, there will be no penalty or loss of benefit to which you are entitled.

Do you have any questions? Do you agree to register in the ABDR and participate in the research?

- Yes: Document oral consent below. If applicable, inform subject that they will receive an information sheet regarding the ABDR for their records via [mail/email].
- No: Thank them for their time.

Name of Subject:

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**Person Obtaining Consent**

I have read this form to the subject. An explanation of the ABDR was given and questions from the subject were solicited and answered to the subject's satisfaction. In my judgment, the subject has demonstrated comprehension of the information. The subject has provided oral consent to participate in the ABDR.

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Name and Title (Print)

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Signature of Person Obtaining Consent

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Date