

# WFH Shared Decision Making Tool Survey

## Participant Information

The World Federation of Hemophilia (WFH) is conducting a survey to better understand user experiences with the WFH Shared Decision Making (SDM) Tool. The WFH SDM Tool is an interactive decision-support system designed to empower informed and collaborative decision making by facilitating discussions about treatment options between people living with hemophilia A or B and their healthcare team.

### Who can participate?

- Adults living with hemophilia A or B who have used or are willing to use the WFH SDM Tool.
- Adult caregivers and/or family members of people living with hemophilia who have used or are willing to use the WFH SDM Tool.
- Healthcare professionals who manage people living with hemophilia and have used or are willing to use the WFH SDM Tool.

### Participation details

- Participants will be asked to use the WFH SDM Tool and respond to a set of questions about their experience using it. We are also collecting limited demographic information, such as hemophilia type, current treatments, and country of residence.
- Both the WFH SDM Tool and this survey are available in English, French, Spanish, Japanese, German, and Dutch.
- The survey is expected to take approximately 10-30 minutes to complete if you are familiar with the WFH SDM Tool. It may take longer if you are unfamiliar with the tool, or if you would like to spend more time with it.

### Voluntary participation and e-consent

- Participants will be asked to provide electronic consent (e-consent) before starting the survey.
- Participation is voluntary and you may withdraw your consent or discontinue participation at any point by exiting the survey or closing your browser.
- Your choice to participate or withdraw at any time will not impact your relationship with the WFH or your healthcare team.

### Why participate?

- By participating you will contribute to important research aimed at improving resources for people living with hemophilia and their healthcare teams.

- You may also gain valuable insights into your own decision-making processes and how you engage with your healthcare team or, if applicable, your patients.
- Anonymous survey data will be summarized and used to inform WFH future project planning (e.g., updates and improvements to the WFH SDM Tool). Summarized results will be shared publicly (e.g., on the WFH website, at conferences or community meetings, or through peer-reviewed publications).

### **Data management and security**

- Survey responses are anonymous and securely collected using Zoho Survey.
- To ensure the highest level of security, Zoho Survey follows several internationally recognized and respected standards, including ISO/IEC 27001, GDPR (General Data Protection Regulation), and HIPAA.
- For more information, we invite you to visit the Zoho compliance page here: [Zoho Compliance](#).
- Additional security features built into the survey software, such as end-to-end encryption, Secure Sockets Layer (SSL), and CAPTCHA, have also been optimized.

*If you have questions about this survey or the WFH SDM Tool, please contact [SDM@wfh.org](mailto:SDM@wfh.org)*

*Please note that this survey is not intended to collect information regarding adverse events or reactions to treatment. If you have experienced an adverse event or have medical concerns, please contact your healthcare provider or report them through the appropriate regulatory channels.*

Thank you for your participation and for contributing to the advancement of hemophilia care.