

## RECAP OF WEBINAR DISCUSSION QUESTIONS AND ANSWERS



**Title:** World Bleeding Disorders Registry Kick-off Webinar

**Date:** Monday, December 12, 2017

**Time:** 9 a.m. – 10 a.m. EST

**WFH Speakers:** Christine Herr, Data & Research Consultant; Mayss Naccache, Data & Research Manager

**Attendees:** HTCs, NMOs, interested parties from around the world

**Background:** The World Federation of Hemophilia (WFH) hosted a webinar for people across the globe including hemophilia treatment centres (HTCs), WFH National Member Organizations (NMOs), people with hemophilia, and those interested in learning more about the WFH's World Bleeding Disorders Registry (WBDR).

### Agenda:

- Background
- Pilot Study
- Global Implementation
  - Program goals
  - Enrollment
  - Privacy
  - Data access
  - Participation processes
- Next steps
- Questions and Feedback

*\* Please refer to available webinar slides and audio recording for full presented content. \**

### Attendee Poll Results:

*Who do you represent?*

Hemophilia Treatment Centre - 50%

Interested stakeholder - 27%

WFH National Member  
Organization - 23%

Person with hemophilia - 0%

*If an HTC, did you participate in the  
WBDR Pilot Study?*

No - 79%

Yes - 21%

*What region of the world are you from?*

Americas - 35%

Africa - 29%

South-East Asia - 23%

Europe - 13%

Eastern Mediterranean - 0%

Western Pacific - 0%

*If an HTC, have you already applied to  
participate in the WBDR?*

Yes - 53%

No - 47%

### Points of Interest from Attendee Q&A:

#### **Database Training**

**Q. Will there be an in-person database training for the WBDR as there was for the pilot?**

A. Yes, there will opportunities for in-person database training at the 2018 WFH World Congress in Scotland. If you cannot attend the Congress yourself, a colleague or team member may attend the training.

**Q. Will there be a database software demonstration?**

A. Yes, there will be several demonstration and training opportunities to ensure participating HTCs are trained and understand the main points of the how to work with the database. In addition to the in-person training at the Congress, additional opportunities will occur via future webinars, handbooks and online videos. The WFH WBDR staff will always be available as well to provide one-on-one support and help where needed.

**Data Management & Access**

**Q. How flexible is the information to include in the database – for example, if a patient is not aware of what tests have been done, or the HTC does not have a certain piece of patient information, does the HTC need to re-do a test or assay in order to include the data?**

A. No, the amount of information to include is flexible. You only need to include the information that is available to you.

**Q. What happens to a patient that is treated at two HTCs?**

A. HTCs will have the ability to transfer patients between HTCs.

**Q. How many people per HTC can do data entry?**

A. Any many as the HTC would like.

**Q. Does each HTC need to enter data for a specific number of patients?**

A. No, the WFH is aware that each HTC sees a different number of patients. The only request is consecutive enrolment – meaning that each participating HTC should aim to enrol all of their eligible patients.

**Database/Registry Linking**

**Q. Is the WBDR open to working with other/existing or future registries?**

A. Please reach out to the WFH WBDR team to discuss data/registry linking on a case-by-case basis.

**Q. Is the WBDR database connected to the United States-based ATHN database?**

A. They are not currently linked, but we hope to work with ATHN to link in the future. Database/ registry linkages will be discussed on a case-by-case basis.

**HTC Process**

**Q. When will the WBDR start?**

A. The WFH's goal is for the database to be available by the end of January and then the first patient data can be entered at that time.

**Q. What is the ethics approval protocol?**

A. The WFH will provide each HTC with a comprehensive ethics toolkit as well as protocol for submission. If more or different information is required, the WFH will work with you to develop it.

**Q. Will the WFH Annual Global Survey continue?**

A. Yes, the WFH Annual Global Survey (AGS) will continue; it includes national aggregate data on inherited bleeding disorders. The WFH has been conducting the AGS since 1999 through the national member organizations. It provides a global overview of the number of patients identified and access to care. The WBDR is collecting real-world patient clinical data, thus building on and complementing Annual Global Survey data. The WBDR aims to collect individual patient data from an international network of treatment centres, which would serve as a platform for directed epidemiological and outcomes research.

**Q. Will there be a way of WFH financially supporting a stipend or similar for HTCs to resource people to conduct data entry?**

A. The WFH is currently discussing and exploring the possibility of this.

**Q. What if a patient refuses to be included?**

A. This is not an issue. HTC's will talk to each of their hemophilia patients about being enrolled into the WBDR and enroll the patients who consent to have their details included in the registry. The patient has the right to decline/not provide consent.

**Q. What type of information will the WFH share in terms of program reporting?**

A. The WFH will be putting together an annual report on the WBDR and looks forward to sharing it. In addition, program status and updates will be shared periodically through e-newsletters, online portal, webinars, World Congress, and other channels.

***NMO Participation***

**Q. What is the role of the NMO?**

A. Everyone can play a part in building this important resource. While HTC's are responsible for inputting patient data into the database, the WFH hopes NMOs will partner with HTC's to promote the program by sharing materials where appropriate and talking about the importance of the program with their local hemophilia community members.

**Q. What data will be available to NMOs?**

A. While only the HTC will be able to input and access their own patients' information in the database, the WFH will share high-level non-identifiable results with NMOs to support country-level advocacy, policy and research efforts.

**THANK YOU**  
**WBDR@WFH.ORG**  
***Please contact us with questions***

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