

# The Development of the World Bleeding Disorder Registry Pilot Phase

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## Introduction and Objective

- Management of hemophilia has benefited from country specific and national registries, however many countries do not have a standardized data collection system.
- The World Federation of Hemophilia (WFH) is seeking to develop an international World Bleeding Disorder Registry (WBDR).
- This will help hemophilia treatment centres in assessing patients over time and may improve hemophilia care.
- Prior to implementing the WBDR, a pilot phase is being conducted to assess the feasibility of the project.

## Materials and Methods

- HTC of varying levels of economic development (emerging, mid-level and established) were invited to participate in the pilot phase.
- Each HTC is expected to enrol approximately 10 patients with hemophilia.
- A Universal Case Report Form (U-CRF) was developed based on published recommendations and consensus of world experts in hemophilia.



WORLD FEDERATION OF HEMOPHILIA  
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## Results

Participating Hemophilia Treatment Centers  
40 HTCs invited, 31 participating = **78% Participation Rate**

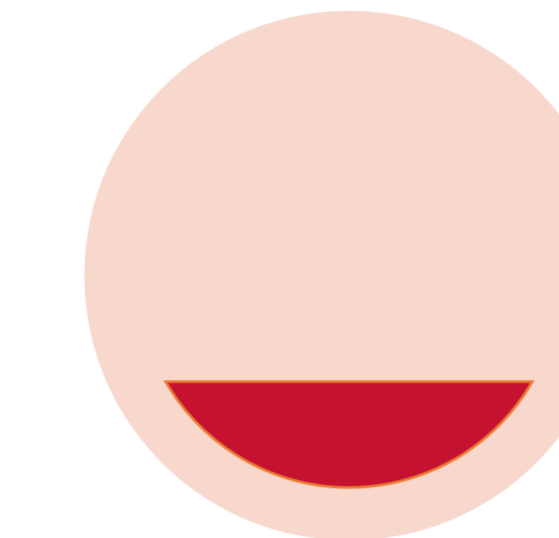


**Participating HTCs:** Algeria, Argentina, Australia, Belgium, Brazil, Cameroon, Canada, Egypt, Estonia, Ethiopia, India, India, Indonesia, Jamaica, Kenya, Kyrgyzstan, Mali, Morocco, Philippines, Senegal, Slovenia, Sri Lanka, Switzerland, Thailand, Uganda, United Kingdom, United States of America, Uzbekistan, Venezuela, Vietnam, Zimbabwe

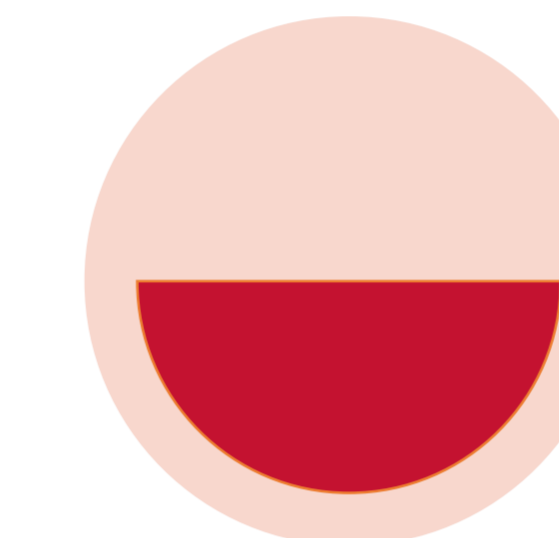
## Conclusions

- The results of the pilot phase of the WBDR will be reported in Q1 of 2017.
- Engagement from the HTCs has been encouraging, with 78% of invited HTCs having agreed to participate.
- The feasibility of implementing a larger scale WBDR for use by HTCs worldwide will be based on performance indicators and will be assessed in December 2016.

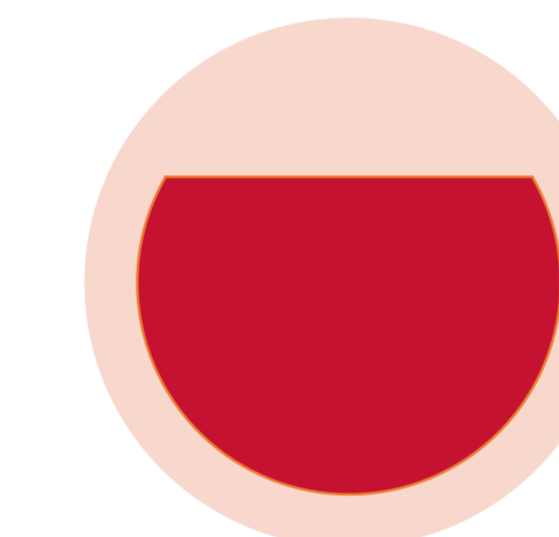
## Performance Indicators of Pilot Phase



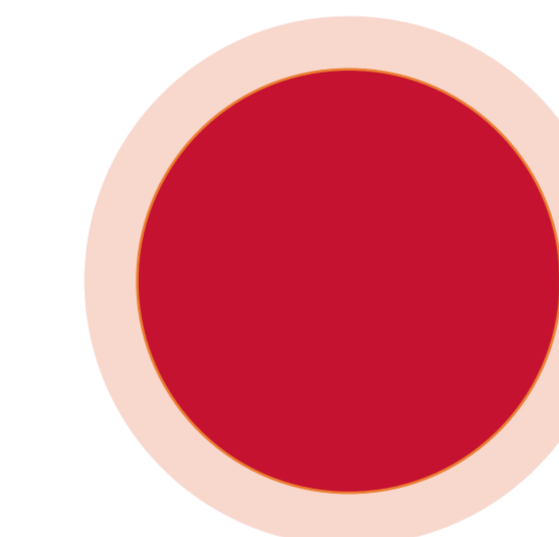
Proportion of HTCs invited who participate;



Proportion of participating HTCs who successfully obtain regulatory approval;



Proportion of patients approached who consent to participate;



Proportion of enrolled patients on which data collection and database entry is successful.

## Universal Case Report Form (U-CRF)

- The U-CRF is available at <http://www.wfh.org/en/u-crf> for use by the hemophilia community, with the aim of encouraging a standardized approach to documentation of clinical care on patients with hemophilia around the world.

## Acknowledgements

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Data and Demographics  
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