

DATA QUALITY FRAMEWORK

AN OVERVIEW

WORLD BLEEDING DISORDERS REGISTRY
Data Quality Accreditation Program



Background

The World Bleeding Disorders Registry (WBDR) is designed to collect real-world patient-level data from hemophilia treatment centers (HTCs) around the world. Quality data serve as a powerful tool for evidence-based research and advocacy, as well as patient treatment, and care. They constitute the cornerstone of any database, especially in healthcare. To uphold the WBDR's data quality to the highest standards, the World Federation of Hemophilia (WFH) has introduced the WBDR Data Quality Accreditation (DQA) Program.

What is the WBDR Data Quality Accreditation Program?

The WBDR DQA Program is a combination of tools and techniques provided by the WFH to all HTCs that participate in the WBDR. It consists of database and data-entry training, data quality training, mentoring and coaching, technical assistance, and a set of internal data quality assessment tools. The WBDR DQA Program aims to emphasize the importance of high-quality data and equip HTCs with the essential tools for achieving it in the WBDR. This program enables the WFH and its partnering HTCs to continuously assess and enhance data quality within the WBDR. It facilitates proactive management of data quality issues and identifies areas for improvement. Through the DQA Program, the WFH seeks to enhance the registry's effectiveness, efficiency, and long-term viability.

How does the WBDR DQA Program work?

To create a supportive environment for positive outcomes and for the sustainability of the WBDR, the WBDR DQA Program focuses on six key elements (Figure 1). To sustain positive impact, the WBDR team builds *partnerships*

and works closely with all HTCs to develop a common understanding of the importance of high quality data. The WFH also adopts *inclusivity* in the data-quality management process, which includes robust data validation of all patient records and all data fields, along with aggregated data analysis and reporting. For the WBDR, all data are verified on two dimensions, which are “completeness” (all data fields are completed), and “accuracy” (all data are accurate and valid). By implementing the DQA Program, we expect consistency in both “complete” and “accurate” data.

If any discrepancies are found in the database, the WFH is *responsive*, and provides timely feedback to the HTC on data quality using simple language. All HTCs are classified according to the WBDR Data Quality Rating scale (Figure 2). The data quality assessment baseline score serves as a benchmark for measuring the progression of data quality for each HTC. For *transparency* purposes, the data quality scores are shared with each HTC, ensuring *accountability* for each HTC on their performance, which in turn creates a sense of *ownership* of quality data. All in all, we believe that these six key elements—partnership, inclusivity, responsiveness, transparency, accountability and ownership—are the key to the sustainability of the WBDR.



Figure 1: Foundation of the WBDR DQA Program

“More complete and accurate information allows us to improve future care and research. Data from the WBDR can be a powerful tool to help change the policy of care for people with hemophilia.”

– Rungrote Natesirinilkul, MD, Faculty of Medicine, Chiang Mai University

Why measure data quality performance?

Every year, the WBDR team evaluates the outcome of the DQA Program based on the quality of WBDR data. The WBDR Data Quality Rating scale (Figure 2) allows the WFH to compare results globally and monitor trends in data quality. It also enables the WFH to adapt its approach to maximize the impact of both the DQA Program and the WBDR.

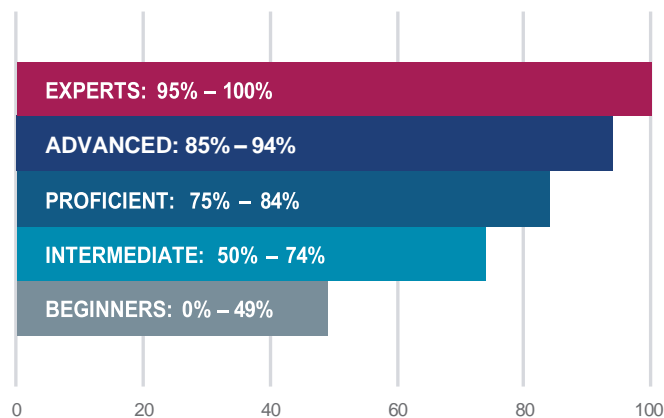


Figure 2: WBDR Data Quality Rating scale

WBDR DQA Program in action

The WBDR was launched in 2018 and by the end of the year, the WFH worked with 29 HTC that entered data into the database. At the first data quality assessment—prior to implementing the WBDR DQA Program—five (17%) of 29 HTCs were classified as “Experts” and one (3%) was considered “Advanced”. After establishing the WBDR DQA Program, 24 (83%) of the 29 HTCs achieved the highest level of data quality rating and were classified as “Experts”. Three HTCs (10%) achieved the level of “Advanced” (Figure 3).

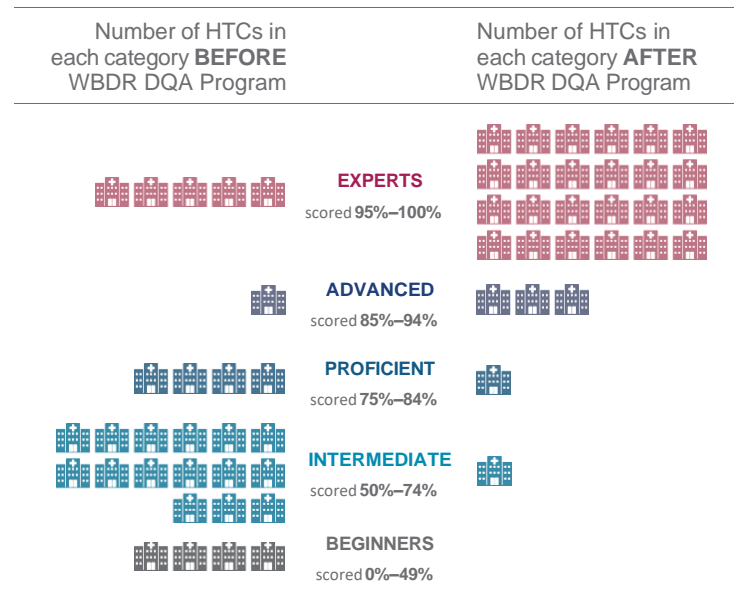


Figure 3: Results of the WBDR DQA Program in 2018

To date, the WBDR DQA Program has been implemented in 31 countries by 59 HTCs, and over 4,500 patient records have been verified (Figure 4). Annually, the WFH provides **Certificates of Data Excellence** to the HTCs that reach the “Experts” level, where the data quality score is above 95%. The WBDR team continues to work closely with each HTC to ensure data quality in the WBDR remains high. This close collaboration with the WBDR team also helps increase the DQA Program’s usefulness as a tool for evidence-based research and advocacy to better support treatment and care for all patients.

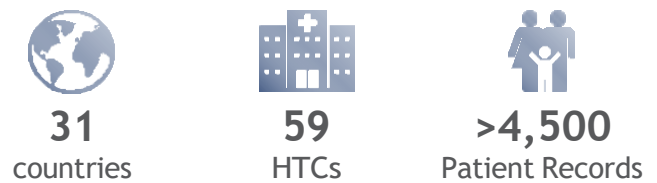


Figure 4: WBDR DQA Program in action

For further information please contact wbd@wfh.org