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Data is the new currency: The World Bleeding Disorders Registry Data Quality Accreditation Program

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Quality of Life/Outcomes Research

Abstract

Objective: The World Bleeding Disorders Registry (WBDR) has been designed to collect real world and patient level data from Hemophilia Treatment Centers (HTCs) globally. Data are a powerful tool that can be used to generate evidence for better care and treatment; and to build advocacy initiatives aimed at policy decision makers. While the World Federation of Hemophilia (WFH) encourages patient enrollment, we do not want a silo of poor-quality data. Instead of benefiting from them, we could be drowned in the data pool. Hence, the WFH has implemented the WBDR Data Quality Accreditation (DQA) Program. The objective of the DQA Program is to raise awareness of quality data, and to ensure that the data in the WBDR are of high quality. The term 'quality' is complex but for the WBDR, all data are evaluated on two dimensions, which are 'completeness' where all data fields are completed; and 'accuracy' where data are accurate and valid. By implementing the DQA Program, we also expect 'consistency' in both 'complete' and 'accurate' data. We assessed the impact of the DQA Program on the quality of data at each HTC. **Methodology:** At site level, standardized data collection procedures have been encouraged and employed among the HTCs. They have access to tools (i.e. User Handbook), individual training sessions, and technical assistance in data quality. At the WFH, we conduct a robust data validation process for all patients and all data fields. Regular feedback using data clarification forms is provided to each HTC. Improvement of data quality of each HTC before and after implementing the DQA Program was assessed. HTCs are classified according to the WBDR Data Quality Rating, which consists of Basic (0%-49%); Developed (50%-74%); Intermediate (75%-84%); Advanced (85%-94%); and Leaders (95%-100%) (Figure 1). **Summary:** In 2018, the WFH worked with 29 HTCs that entered data into the WBDR. Prior to implementing the DQA Program, only five (17%) of 29 HTCs were in the 'Leaders' level and one HTC (3%) was considered 'Advanced'. After employing the DQA Program, 24 (83%) of the 29 HTCs achieved the highest level of data quality rating and were classified as 'Leaders'. Three HTCs (10%) achieved the level of 'Advanced' (Figure 2). **Conclusion:** According to World Health Organization, " Sound decisions are based on sound data". The value in good quality data is immense, so awareness in data quality should always be promoted. Compromising on data quality could cause serious consequences that impact the usefulness of the data. The phrase 'Data is the new currency' should be applied in all steps of data management, especially in the medical registries. For the WFH, the DQA Program not only promotes a sense of ownership of quality data but also maintains the overall quality of the WBDR in the long run. The WBDR is supported by our Visionary

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