

QOL 64

Combining Data from Hemophilia Registries with the World Bleeding Disorders Registry: A Proof of Concept Study with the Czech National Haemophilia Programme Registry

Naccache, Mayss Naccache; Engren, Johan; Blatny, Jan; Ovesna, Petra; Pierce, Glenn F; Coffin, Donna

Submission Group

Quality of Life/Outcomes Research

Abstract

Objective: Registries, with international collaboration between countries, are the best way to pool sufficient data to increase knowledge and evidence in rare disorders. The World Federation of Hemophilia (WFH) World Bleeding Disorders Registry (WBDR) provides a platform for a network of hemophilia treatment centers (HTCs) around the world to collect uniform and standardized patient data and guide clinical practice. As a global organization with access to a network of 140 national member organizations (NMO), more than 1,000 HTCs, and numerous patients in countries with varying levels of access to care, the WFH is uniquely positioned to develop such a registry. In an effort to combine resources from existing hemophilia registries, and maximize the utility of data that currently exist, the development of the WBDR includes an international data integration component with the aim of facilitating data transfer from existing patient registries to the WBDR. **Methods:** As part of a proof-of-concept study, de-identified data from the 2018 Czech National Haemophilia Programme Registry (CNHPR) is being imported into the WBDR. This import is based on a minimal set of data common to both registries. Data fields in both registries were examined to assess their interoperability. Common data elements were further analyzed for data compatibility and standardization of terms, before being mapped from the CNHPR to the WBDR (Figure 1). In addition to the procedural step required, legal, regulatory and technical issues, will also inform a standard protocol which will be developed to import data from other existing patient registries into the WBDR. **Summary of results:** Data on 775 patients are being imported from the CNHPR to the WBDR. The data reported in the CNHPR represent 100% of identified patients in the Czech Republic. Further results will be communicated in a manuscript in 2019. **Conclusions** A protocol to import data from other existing patient registries into the WBDR is currently in development, based on the proof-of-concept study. The program is available to interested countries who want to set up an import process to combine their national data with the WBDR. Interested individuals are encouraged to contact the WFH at wbd@wfh.org. The WBDR is supported by our Visionary Partners: SOBI and Takeda; and our Collaborating Partners: Bayer, CSL Behring, Grifols, Pfizer, and Roche.