Background

The American Thrombosis and Hemostasis Network (ATHN) is the steward of extensive hemostasis and thrombosis data and analytic resources. The ATHN Affiliate Network consists of over 145 health care entities providing programs and services to individuals impacted by these conditions. Through its partnership with ATHN Affiliates, ATHN routinely collects demographic, clinical, and genetic data for the ATHNDatabase, a de-identified, voluntary data set. The ATHNDatabase is a rich source of data available for clinicians and clinical researchers to identify, explore, and advance knowledge and outcomes that affect the inherited bleeding disorders community within the goal of transforming care. Recently, ATHN received a grant to determine whether data contained in the ATHNDatabase could be utilized in conjunction with other sources of objective clinical intelligence, to predict those people with hemophilia (PwH) who may experience a poor outcome in hemostasis and thrombosis.

Methods

Physicians: A link to a SurveyMonkey® poll was sent via email to all physicians associated with ATHN-affiliated centers in the United States. Physicians were alerted 7 days to complete the survey. Based on the European Hemophilia Safety Surveillance (EHASS) physicians were asked to rank the following outcomes from 1 (least) to 12 (most) severe: cardiovascular event, death, excessive bleeding, hospitalization, inhibitor development, intracranial hemorrhage, inhibitor development, joint development, thrombosis, translation transmitted infection, unexpected poor efficacy, other adverse event possibly related to therapy, and other events.

Subject matter experts (SMEs): In collaboration with staff from the National Hemophilia Foundation (NHF), a five-question survey was developed then sent out to multiple people, asking about the “challenges of living with hemophilia” may not have been familiar with the topics covered in the survey. Finally, we did not get input from other multi-disciplinary hemophilia center team members. Although there were similarities in the themes of the outcomes identified by the two groups, there was overwhelming consensus as to the definition of poor outcome. This approach to the development of a consensus definition of poor outcomes in PwH is novel. Although there were similarities in the themes of the outcomes identified by the two groups, there was overwhelming consensus as to the definition of poor outcome. This approach to the development of a consensus definition of poor outcomes in PwH is novel.

Our approach to arriving at this consensus definition of poor outcome had several limitations. However, the response rate for both physicians and SMEs was low. The physicians were all pediatric providers, potentially affecting the ability to generalize the responses. First, the choices of poor outcomes presented to physicians was limited to those defined by EHASS. For SMEs, the survey was designed to allow free text answers, therefore a qualitative analysis approach was taken to assess the responses. Second, this was the first collaboration between ATHN and NHF in utilizing CVR to directly query SMEs and incorporate the voice of those who experience hemophilia on a daily basis for an ATHN project.

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