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World Federation of Hemophilia Annual Global Survey 2017 – 19 years of reporting

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Abstract

Objective: Over the past 20 years, the Annual Global Survey (AGS) has provided an international snapshot of the progress in hemophilia patient identification and access to care. This survey was designed to give the national member organizations (NMOs) affiliated with World Federation of Hemophilia (WFH), healthcare providers and policy makers an overview of the patterns and trends in treatment, and to determine the gaps and areas where improvements are necessary. The annual report monitors hemophilia care using demographic information on patients as well as information on the level of care. **Methods:** The Report on the Annual Global Survey is an annual cross-sectional survey. Each year in April the questionnaire is sent out to NMOs to complete the survey. The questions are organized in different sections including Data Source, Identified Patients, Hemophilia Care and Factor Use. The survey includes patients with hemophilia A, B, type unknown, and those with von Willebrand disease and other bleeding disorders. Surveys can be filled out online or on paper in English, Spanish or French. Between May and October data is received and reviewed. The review process includes individual follow up with the NMOs. Once the review process is complete, the Report on the Annual Global Survey is published. In 2018, the survey was sent to 140 NMOs. **Summary:** **Response Rate:** In 2018, a record of 116 countries responded to the survey, a significant increase since the report first started 19 years ago when only 77 countries were included in the report. The countries included in the 2018 report were representative of 91% of the entire world population (Figure 1). **Patient identification** Since the start of the survey there has been an increase of 184% in reported number of identified patients. In its first year, the AGS identified 111,203 and has since increased to 315,423 (Figure 1). This can be attributed to progress through the WFH Comprehensive Development Model including improvements in the WFH data collection efforts. **Factor use** Looking at the World Bank's gross national income per capita categories, there is a vast difference between the factor usage of the lower income and higher income countries. Since 2002, the increase in factor use in high income countries has been more significant than the increase in low income countries (Figure 2). **Conclusions:** The findings of the AGS offer insight into hemophilia care management. On the verge of its 20 th anniversary, the AGS report has shown continuous improvement with support of the NMOs. Improved data collection, and analysis of this data has allowed for better advocacy and healthcare planning, to further diagnose patients with bleeding disorders and to continue to work towards the WFH mission of treatment for all.