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Von Willebrand Disease: An international Survey to Inform Priorities for New Guidelines

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Abstract

Background: Von Willebrand disease (VWD) is an inherited bleeding disorder caused by a quantitative or qualitative deficiency of the protein, von Willebrand factor (VWF). There is a lack of clear guidance on best practices to inform the care of people with VWD. **Objectives:** Identify and prioritize the main topics of a collaborative guideline development effort. **Methods:** A scoping survey to prioritize topics to be addressed in a collaborative guideline for VWD was distributed to international stakeholders including patients, caregivers, clinicians, and allied healthcare professionals. The distribution strategy was coordinated by the guideline chairs and representatives of the American Society of Hematology (ASH), the International Society on Thrombosis and Haemostasis (ISTH), the National Hemophilia Foundation (NHF), and the World Federation of Hemophilia (WFH). The survey was conducted in English, French, and Spanish. The survey focused on both diagnosis and management of VWD, using 7-point Likert-scale response options and open ended comments. Descriptive analysis of participants and comparative analysis of results by stakeholder subtype (patients/caregivers versus healthcare providers [HCP]), gender, and income setting was performed. Qualitative conventional content data was analyzed utilizing both deductive and inductive coding processes. **Results:** 601 participants responded to the survey (49% patients/caregivers, and 51% HCPs). The highest priority topics identified were diagnostic criteria/classification, bleeding assessment tools, treatment options for women, and surgical patients. In contrast, screening for anemia and plasma-derived therapy versus recombinant therapies were rated the lowest priority topics (figures 1 – 2). **Conclusion:** The survey results highlighted areas of importance in the diagnosis and management of VWD across diverse groups of stakeholders and will direct future guideline efforts. The large number responses (601) and discrete comments (9,500) attest to the interest and involvement of the VWD community in this effort.