WFH Annual Global Survey: New Integrated Electronic Data Collection and Management System

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1) WFH: World Federation of Hemophilia

BACKGROUND & OBJECTIVES

The World Federation of Hemophilia (WFH) works with 122 National Member Organizations (NMOs) to improve and sustain care for people with inherited bleeding disorders. The WFH collects data on people with hemophilia, von Willebrand disease (since 1999), and rare bleeding and inherited platelet disorders (since 2004) in an Annual Global Survey (AGS)[1]. Until 2011, data were collected as text and stored in a unique database each year. This made data validation (DV), data analysis (DA), and longitudinal data comparison difficult. In 2012, WFH implemented an electronic data collection (DC) and management system to enhance AGS quality.

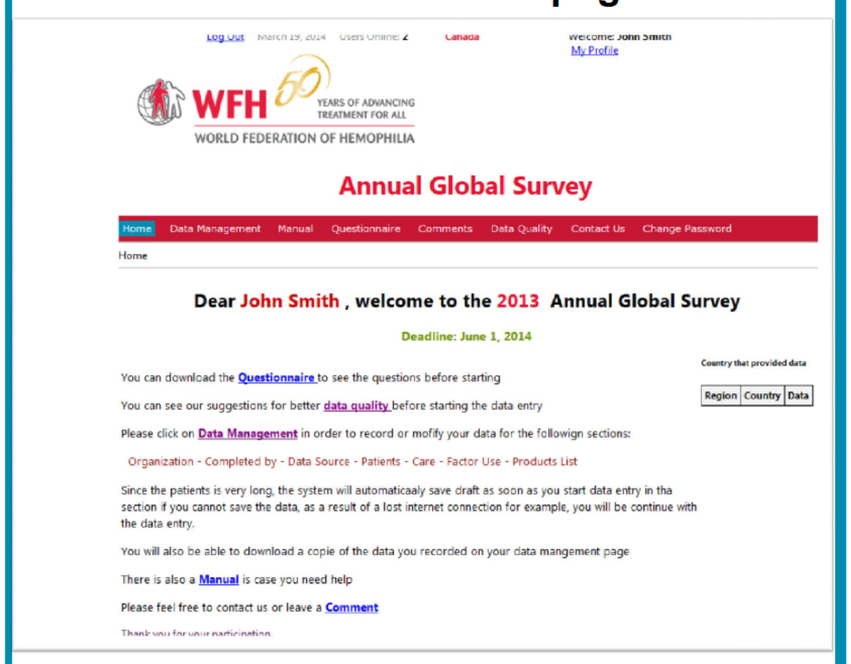
METHODS

AGS data from the first 12 years were merged into a single database and analyzed to identify discrepancies impacting quality. NMOs were surveyed. Feedback from AGS data managers (DM) and the DDC was sought and objectives identified: web-accessibility, ease of data entry, real-time DV and review capability, automated DA, flexible and longitudinal queries (by region, country, GNI, and year) and data tables formatted for the AGS report. A secure web-based DC system was implemented.

RESULTS

NMO Access

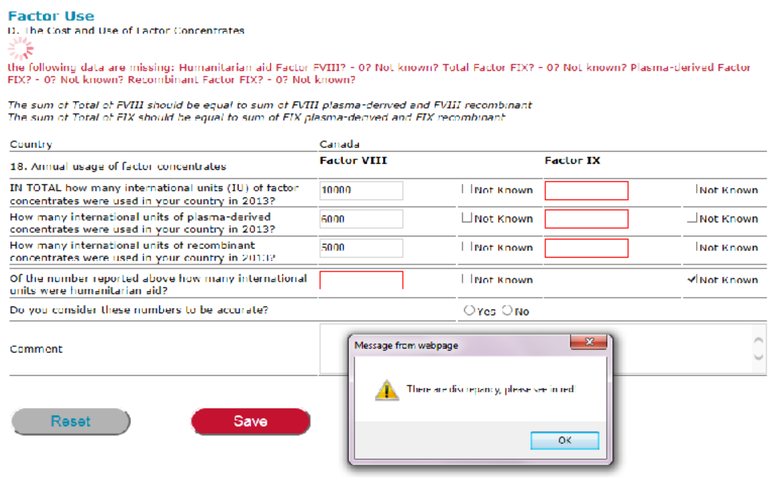
Website Welcome page

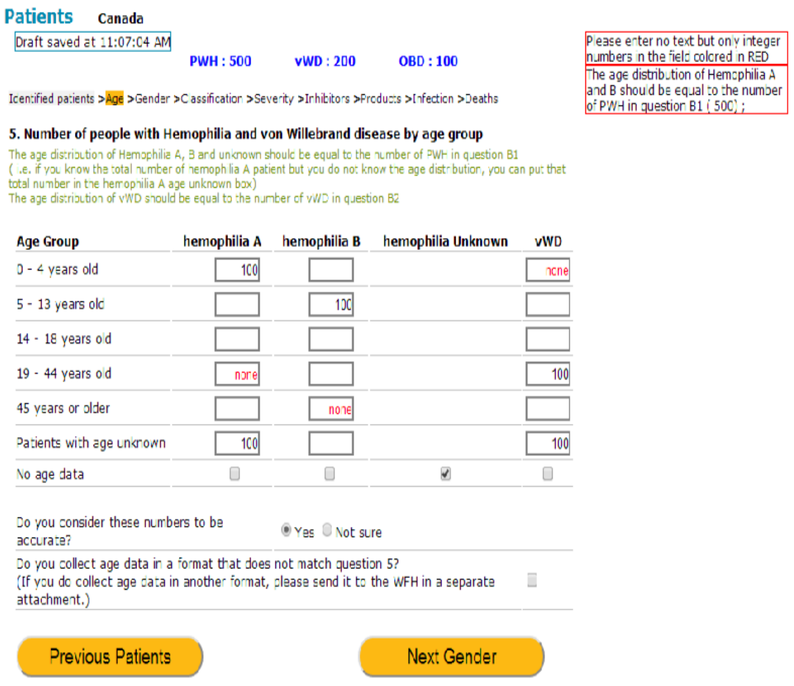


Data Entry & Modification page

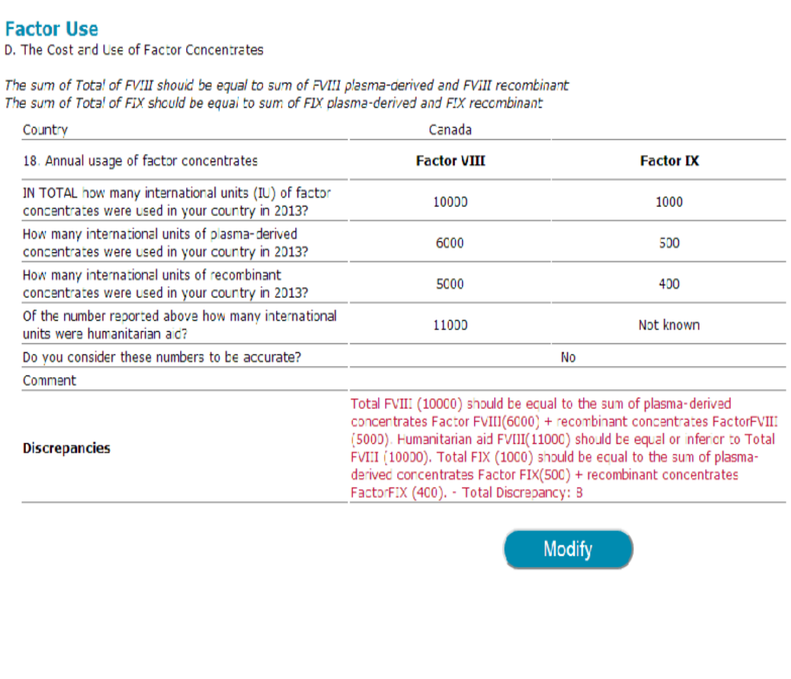
Ongoing Data Validation

Data entry is facilitated with real-time DV (missing data and discrepancy tracking).

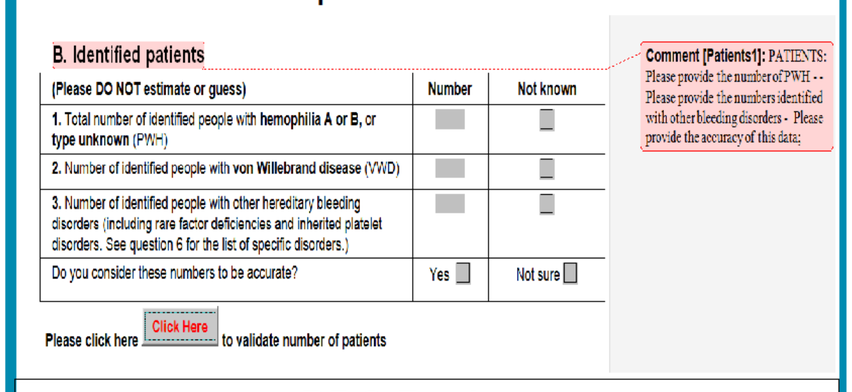




Discrepancies not solved in real-time are flagged and reviewed with NMOs for accuracy, consistency, and completeness.

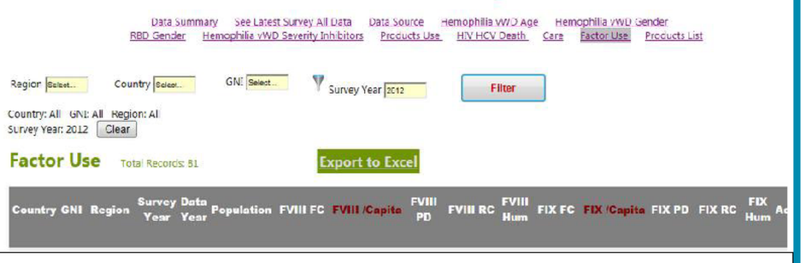


To reduce work involved in follow-up of incomplete data for NMOs using the text form, a suitable form has been developed for the 2013 AGS that will require essential fields to be completed before submission.



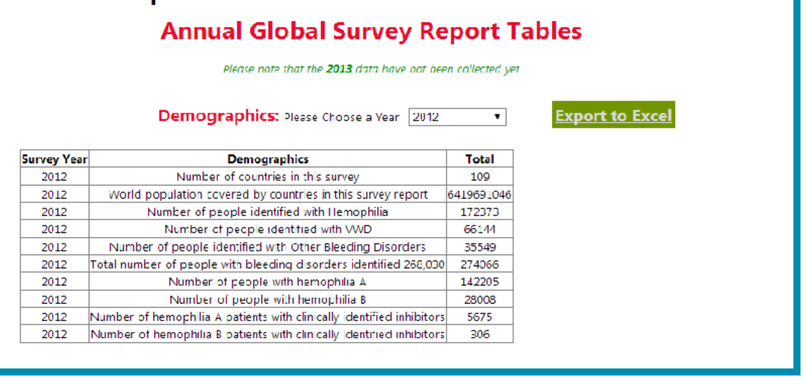
DDC Reviews

The DDC is able to review the data via purpose-built pages. The system will aim to integrate data from WFH research and country-based survey activities



Data Managers

The system generates tables & graphs used by the data mangers to write the AGS annual report.



CONCLUSIONS

The system improves data collection, validation, and analysis, which will have a positive impact on the quality of the data and help WFH achieve its mission. Global internet access for NMO data entry will be possible. Future success of this project requires the participation of the NMOs in providing timely, accurate data.

REFERENCES

1. World Federation of Hemophilia. Data collection: Report on the WFH Annual Global Survey http://www.wfh.org/en/page.aspx?pid=878