

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

Annual Global Survey

Dear John Smith, welcome to the 2013 Annual Global Survey
Deadline: June 1, 2014

Data Entry & Modification page

2013 Data Management

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

Patients Canada
Draft saved at 11:07:04 AM
PWH: 500 VWD: 200 OBD: 100

Identified patients > Gender > Classification > Severity > Inhibitors > Products > Infection > Deaths

5. Number of people with Hemophilia and von Willebrand disease by age group

Age Group	hemophilia A	hemophilia B	hemophilia Unknown	vWD
0 - 4 years old	100			100
5 - 13 years old		100		
14 - 18 years old				
19 - 44 years old	not a			100
45 years or older		not a		
Patients with age unknown	100			100
No age data				

Do you consider these numbers to be accurate? Yes No

Do you collect age data in a format that does not match question 5? (If you do collect age data in another format, please send it to the WFH in a separate attachment.)

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

Factor Use
D. The Cost and Use of Factor Concentrates

The sum of Total of FVIII should be equal to sum of FVIII plasma-derived and FVIII recombinant
The sum of Total of FIX should be equal to sum of FIX plasma-derived and FIX recombinant

Country	Factor VIII	Factor IX
Canada	10000	1000

18. Annual usage of factor concentrates

IN TOTAL how many international units (IU) of factor concentrates were used in your country in 2013?

How many international units of plasma-derived concentrates were used in your country in 2013? 6000

How many international units of recombinant concentrates were used in your country in 2013? 5000

Of the number reported above how many international units were humanitarian aid? 11000

Do you consider these numbers to be accurate? No

Discrepancies

Total FVIII (10000) should be equal to the sum of plasma-derived concentrates Factor FVIII(6000) + recombinant concentrates Factor FVIII (5000). Humanitarian aid FVIII(11000) should be equal or inferior to Total FVIII (10000). Total FIX (1000) should be equal to the sum of plasma-derived concentrates Factor FIX(500) + recombinant concentrates Factor FIX (400). - Total Discrepancy: 3

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.

B. Identified patients

(Please DO NOT estimate or guess)	Number	Not known
1. Total number of identified people with hemophilia A or B, or type unknown (PWH)		
2. Number of identified people with von Willebrand disease (VWD)		
3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders. See question 6 for the list of specific disorders.)		

Do you consider these numbers to be accurate? Yes Not sure

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 managers to write the AGS annual report.

Annual Global Survey Report Tables

Survey Year	Demographics	Total
2012	Number of countries in this survey	109
2012	World population covered by countries in this survey report	641969,046
2012	Number of people identified with Hemophilia	172373
2012	Number of people identified with VWD	66241
2012	Number of people identified with other Bleeding Disorders	35549
2012	Total number of people with bleeding disorders identified	274266
2012	Number of people with hemophilia A	142205
2012	Number of people with hemophilia B	28008
2012	Number of hemophilia A patients with clinically identified inhibitors	5675
2012	Number of hemophilia B patients with clinically identified inhibitors	306

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>

