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Background & Objectives

Since 2014, PROBE has generated global patient-reported data on haemophilia and controls subjects. But the original framework was designed primarily for men, leaving a major knowledge gap for women with bleeding disorders (WBD).

The WBD module aims to better capture:

- Menstrual bleeding patterns
- Gynaecological complications
- Access to care and ER use
- Reproductive decision-making
- Social and leisure impacts

Why it matters?

- Women with bleeding disorders are frequently **underdiagnosed, misdiagnosed, or experience delayed diagnosis.**
- Comparative quality-of-life data specific to women is limited.
- Menstrual, reproductive, and social participation burdens are not fully reflected in current measures.

Population Insights

The pilot included a diverse population of women with bleeding disorders, including haemophilia carriers, women with haemophilia A or B, women with VWD, individuals with platelet function disorders, and those with rare bleeding disorders.

These early data highlight the heterogeneity of the WBD population and reinforce the need for inclusive data collection approaches that reflect the full spectrum of experiences.

Method

A structured enhancement process was undertaken in 2024 to expand the PROBE questionnaire.

- Targeted literature review
- Conceptual framework exercise
- Gap analysis of domains not sufficiently addressed
- Question development with expert consultation
- Online exploratory pilot launch on International Women's Day 2025

Development Approach

The WBD module was developed to address critical gaps in existing PROBE domains and better capture the lived experiences of women with bleeding disorders.

Evidence Review: Identification of missing domains in women-specific experiences

Conceptual Framework: Inclusion of menstrual health, access to care, reproductive health, and social impact

Expert Collaboration: Input from patients, patient advocates and the WFH, EHC, CoA, NBDF, and CHS

Module Integration: Development and pilot testing of 11 WBD-specific questions

Access to Care & Diagnosis

- ✓ Age at first presentation for abnormal bleeding
- ✓ Age at diagnosis
- ✓ Emergency and urgent care utilisation in the past 12 months
- ✓ Access to specialised and non-specialised healthcare providers

Bleeding Phenotype & Clinical Burden

- ✓ Types of bleeding experienced (e.g., epistaxis, gastrointestinal bleeding, bruising, post-operative bleeding)
- ✓ Presence and impact of heavy menstrual bleeding
- ✓ Iron deficiency and treatment requirements

Menstrual & Reproductive Health

- ✓ Duration of menstrual bleeding and associated symptoms
- ✓ Gynaecological complications including miscarriage, fertility challenges, and postpartum haemorrhage
- ✓ Impact of menopause on bleeding patterns, diagnosis, and access to treatment

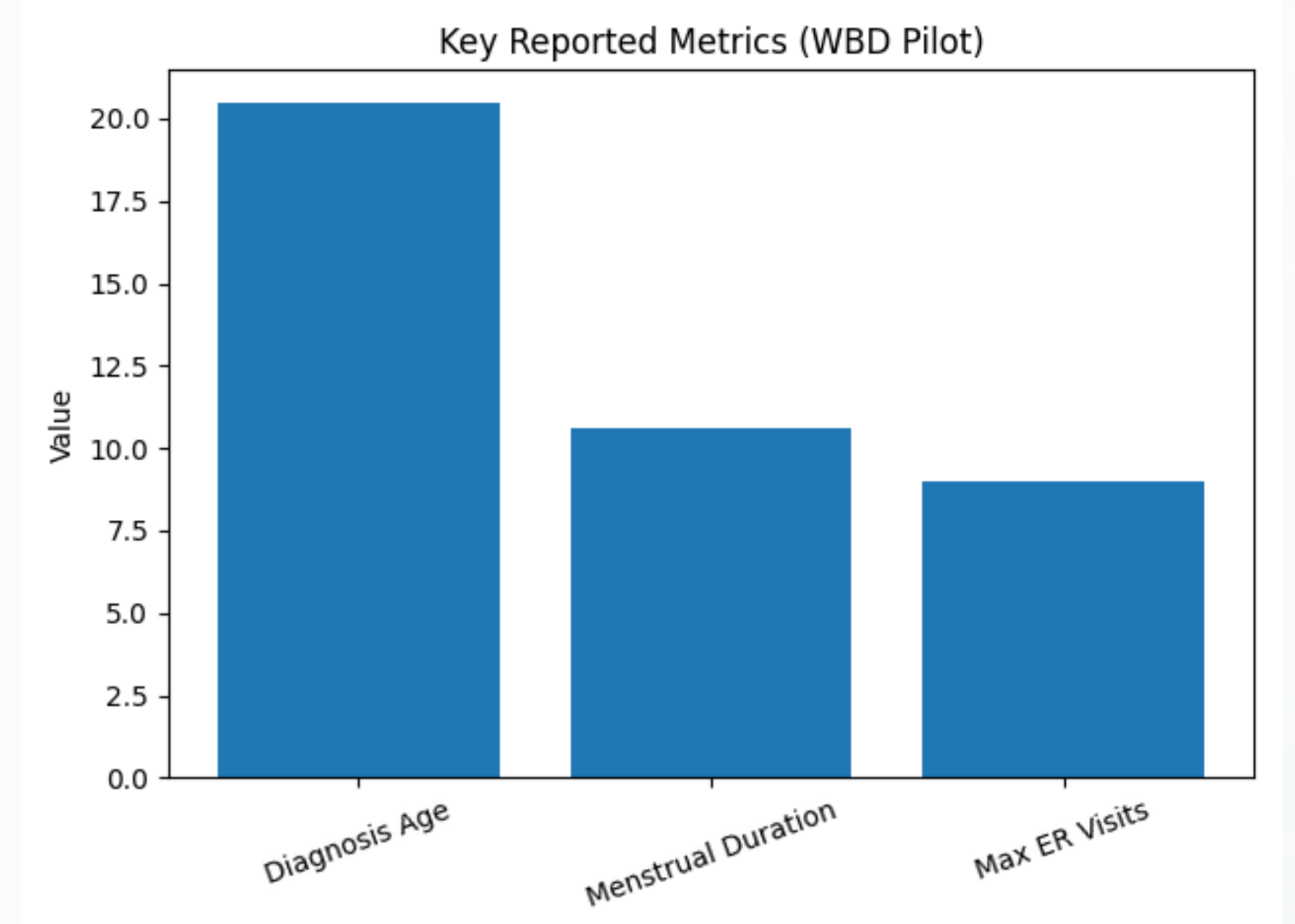
Daily Life Impact & Decision - Making

- ✓ Influence of bleeding disorder on decisions regarding family planning
- ✓ Impact on social and leisure activities

Together, these questions enable a more comprehensive and gender-responsive assessment of health outcomes, capturing both clinical burden and the broader psychosocial impact of bleeding disorders in women.

Key Findings

Preliminary findings reveal substantial unmet needs among women with bleeding disorders:



Three headline observations:

20.45 years
mean age of diagnosis

10.6 days
average menstrual period length

up to 9 ER visits
in the previous 12 months

Pilot participation

64 total pilot participants
33% completed the WBD module

module uptake

33%

Implications & Conclusions

These early insights demonstrate the critical importance of integrating a dedicated WBD module into the core PROBE study. Expanding data collection in this way will enable a more accurate and comprehensive understanding of health outcomes in women with bleeding disorders.

Ultimately, this work will support more targeted advocacy, improved clinical management, and the development of policies and care models that better address the needs of this historically underserved population.

Note: In this poster, 'women with bleeding disorders' encompasses girls and individuals with the biological capacity to menstruate.

Take-home message

Early insights from the WBD module reinforce the necessity of integrating a dedicated WBD component into the core PROBE study.

Enhanced, inclusive data collection will support more accurate understanding and inform targeted advocacy, research, management, and treatment strategies for this underserved population.

We would like to sincerely thank our global partner organisations, including the World Federation of Hemophilia (WFH), European Haemophilia Consortium (EHC), Coalition of Americas (CoA), National Bleeding Disorders Foundation (NBDF), and Canada Hemophilia Society (CHS) for their collaboration and support, and all participants for their invaluable contributions to the survey.

Better data can inform stronger advocacy, research, management, and treatment strategies for an underserved population.

Advocacy
more visibility

Research
better evidence

Care
more responsive care

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