

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/388868813>

PO369: Introduction to the UK PIVOT-vWD Study: A direct to community, cross-sectional study to capture and quantify the impact, voice and outcomes of VWD.

Poster · February 2025

DOI: 10.1111/hae.15148

CITATIONS

0

5 authors, including:



George Morgan

49 PUBLICATIONS 243 CITATIONS

SEE PROFILE



Jo Traunter

University of Hull

8 PUBLICATIONS 40 CITATIONS

SEE PROFILE



Samuel Bristow

DHT.health Limited

9 PUBLICATIONS 0 CITATIONS

SEE PROFILE

Background: There is a **paucity of new evidence/literature** on the clinical outcomes, healthcare resource use (HCRU), cost and the quality-of-life (QoL) **impact on those with von Willebrand Disease (vWD)**. The **PIVOT-vWD study aims to collect patient generated health data** to quantify the impact, voice and outcomes of vWD initially the UK with the **aim to expand across Europe and to the US**.

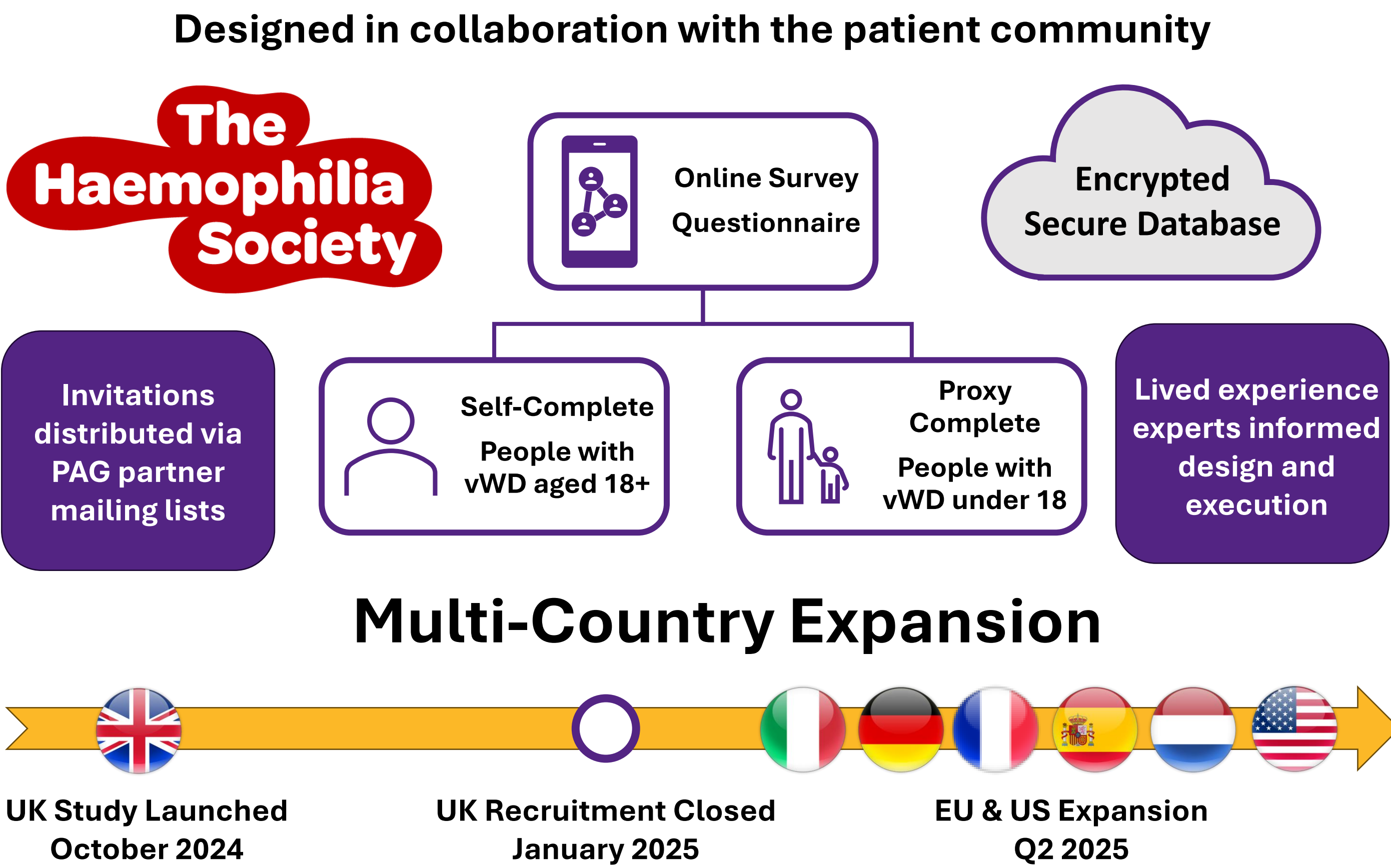
Population Impact Voice Outcomes Together

Study Objectives

- Characterize the impact of vWD on patients, caregivers, healthcare systems, and society.
- Elicit the preferences and opinions regarding the treatment and management of vWD.
- Quantify outcomes for individuals with vWD, including quality of life, ABR, HCRU etc.
- Integrate all relevant data into a comprehensive dataset that can be analysed as one.

A direct-to-community, cross-sectional study to capture and quantify the impact, voice and outcomes of VWD.

Study Design



Study Content

- CHARACTERISTICS**

 - Demographics
 - Haemophilia Treatment Centre
 - Disease Characteristics (vWD Type Disease Severity and others)
 - Comorbidities (Iron Deficiency Anaemia and others)
- IMPACT**

 - Bleeding episodes (ABR, SABR)
 - Joint Damage
 - Healthcare Resource Use
 - Treatment use and Regimen (By type, product & adherence)
 - Caregiver Assistance
- OUTCOMES**

EQ-5D-5L: Self-Complete (18 + or Caregiver) Proxy (Under 18)

AQoL-4D: Self-Complete (18 +) Proxy (Under 18)

WPAI: Self-Complete (18 + or Caregiver) Proxy (Under 18)
- VOICE**

Diagnostic Experience

Healthcare Satisfaction

Treatment Satisfaction

Preference Treatments

Opinion on QoL Tools

Attribute Ranking
- The content of the survey will also allow us to generate direct medical, direct non-medical and indirect cost of vWD.

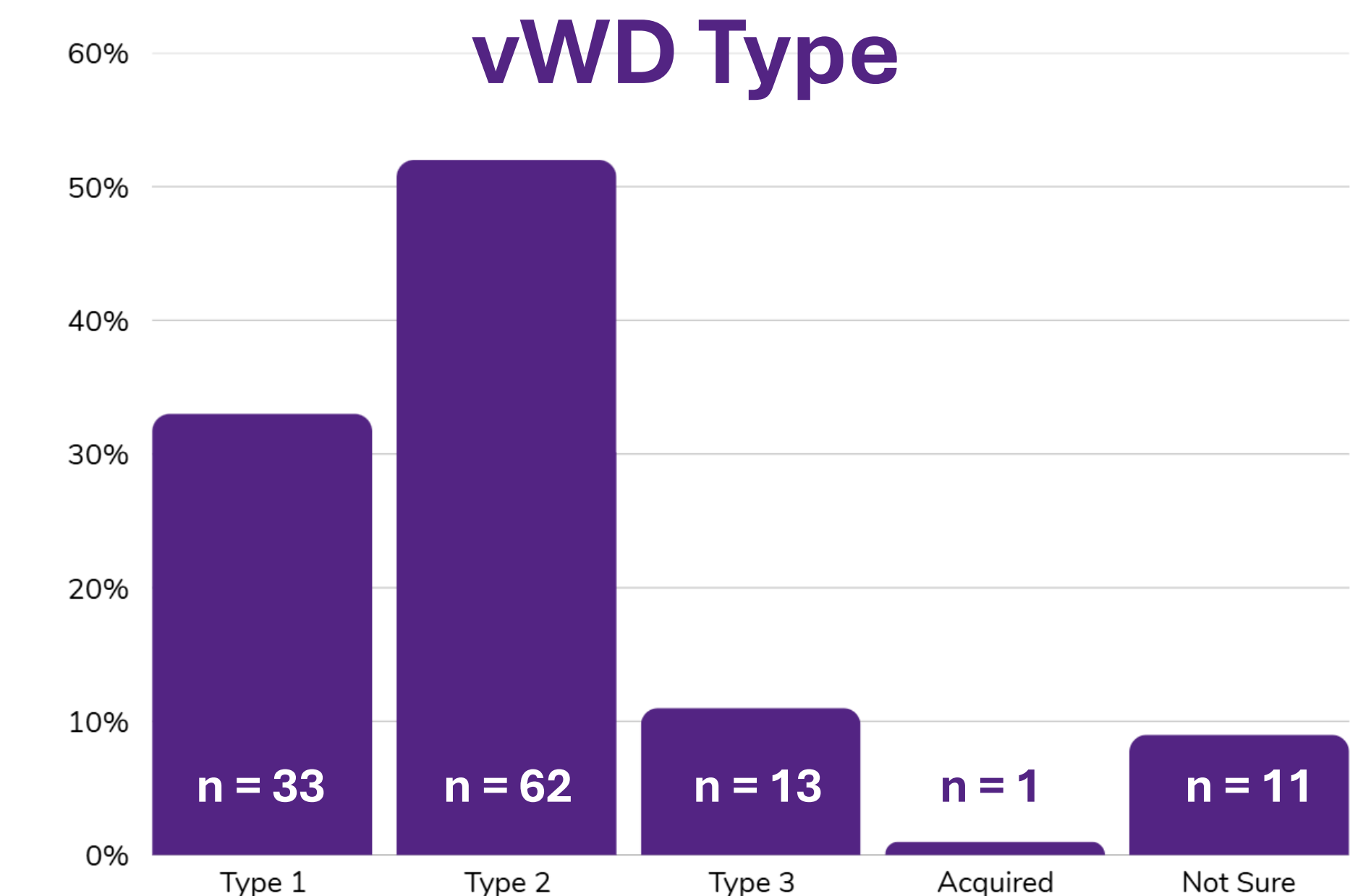
PIVOT-vWD delivers a unified dataset enabling multi-variate analysis of the impact, voice, and outcomes of vWD

Survey Metrics

- Number of Completes
N = 120
- Median Completion Time
28 minutes
- Completion Rate
73%
- Sample opted in for recontact
81%

Study Sample Characteristics

- Average Age
Self-Complete: 49 yrs. Proxy: 9 yrs
- Completer Type
Self-Complete n = 100
Caregiver n = 20
- Gender Split
Female n=80
Male n=40



Conclusion: Capturing the **clinical & quality of life impact** upon individuals with VWD is **critical to supporting new and emerging therapies**. **Gathering the voice** of the community leads to **greater understanding of the priorities of the community**, leading to **more informed decision making and relevant treatments**. The **PIVOT-vWD study demonstrates** that the **PIVOT methodology** can be **applied** not only in von Willebrand Disease but also **in other disease areas with unmet evidence needs**, providing a comprehensive dataset **to address key research questions** while **minimising participant repetition & burden**.



George Morgan^{1,2}, Jo Traunter^{3,4}, Debra Morgan⁴, Hannah Yarnall⁴, Sam Bristow^{1,2}
¹DHT.health, North West, United Kingdom; ²Lancaster University, Health Innovation Campus, Lancaster, United Kingdom; ³The University of Hull, Hull, United Kingdom; ⁴The Haemophilia Society, London, United Kingdom;

