EAHAD 2026 DUBLIN, IRELAND 3-6 FEBRUARY 2026

19th ANNUAL CONGRESS OF THE EUROPEAN ASSOCIATION FOR HAEMOPHILIA AND ALLIED DISORDERS

Assessment of joint health and patient-physician alignment on joint damage reports in a cohort of people with haemophilia A: real-world insights from the CHESS III Study

PO058

Matteo Nicola Dario Di Minno[1], Enrico Ferri Grazzi[2,3], Tom Blenkiron[2], Nana Kragh[4], Mahnouch Georget[4], Brian O'Mahony[5,6]

[1]Department of Clinical Medicine and Surgery, Federico II University, Naples, Italy, [2]HCD Economics Ltd, Knutsford, UK, [3]FedEmo (Federazione delle associazioni Emofilici), Rome, Italy, [4]Sobi, Stockholm, Sweden, [5]Irish Haemophilia Society, Dublin, Ireland, [6]Trinity College Dublin, Dublin, Ireland

INTRODUCTION

- Joint health deterioration is a burdensome consequence of haemophilia A (HA), as recurrent joint bleeds can result in gradual joint damage and limitations in physical function [1,2].
- When joint health is not regularly evaluated in clinical settings, misinterpretation of joint symptoms and differing perceptions between people with HA (PwHA) and their health care providers (HCPs) may contribute to mis-identification of issues, as well as suboptimal management.
- Discrepancies between reports of PwHA and their HCPs remain a challenge in this population, and may lead to negative impacts on clinical outcomes, quality of life, and psychosocial well-being.
- This analysis examines joint health within the cohort of PwHA recruited as part of the CHESS III (Cost of Haemophilia: a socioeconomic survey III) study, exploring disagreement between PwHA and HCP reports of problem joints.

METHODS

- The CHESS III study was a burden-of-illness study that enrolled adult male individuals diagnosed with congenital haemophilia A or B of any severity, with or without inhibitors, from France, Germany, Spain, Italy, and the United Kingdom, between 2022-2023.
- The present analysis included the anonymized sample of adult individuals with haemophilia A without inhibitors, from this dataset.
- The CHESS III utilized two linked questionnaires for data collection (each questionnaire completed by a HCP for a PwHA was linked to a questionnaire completed directly by the same PwHA):
  - A case report form (CRF) completed by HCPs, which collected details such as medical history, clinical characteristics, joint status, consultation records, and healthcare resource utilization for each participant.
  - A patient and public involvement and engagement (PPIE) questionnaire completed by PwHA, which gathered information such as clinical characteristics, the impact of haemophilia on daily activities, and health-related quality of life (HRQoL).
- Cross-sectional data including demographic, clinical, and patient-reported outcomes were extracted from the dataset and were analysed descriptively, considering PwHA- and HCP- reports of problem joints (PJ); continuous and categorical variables were reported as mean (SD) or n (%).

Problem Joints (PJ):
Joints with chronic pain and/or limited range of movement due to compromised joint integrity, with or without persistent bleeding [2]

AIM

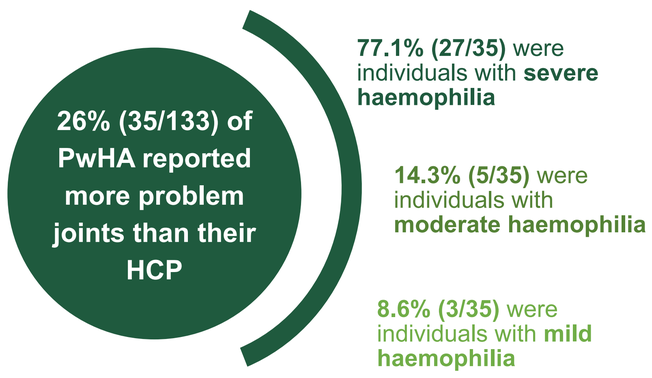
To describe joint health within the cohort of people with haemophilia A recruited as part of the CHESS III study, taking into consideration the level of agreement between PwHA and HCP reports of problem joints.

RESULTS

- Among the 133 PwHA included in this analysis, the mean (SD) age was 42.2 (16.0) years, and **most individuals were receiving prophylactic treatment** (91/133, 68.4%). The majority of PwHA had **severe haemophilia** (84/133, 63.2%), followed by moderate (31/133, 23.3%) and mild (18/133, 13.5%) – see Table 1.
- The HCP- and the PwHA-reported number of PJs differed in this analysis – the HCPs reported a mean (SD) of 0.89 (1.1) PJ, while PwHA reported 1.15 (1.4) PJ – see **Table 1**.
- Overall, 26.3% (n=35) of PwHA reported **more PJs than their HCP**.

Table 1. Socio-demographic and clinical characteristics

Socio-demographic and clinical characteristics	PwHA sample N=133
Haemophilia severity, n (%)	
Mild	18 (13.5%)
Moderate	31 (23.3%)
Severe	84 (63.2%)
Age, mean (SD)	42.20 (15.99)
Treatment strategy, n (%)	
Prophylaxis (emicizumab)	57 (42.9%)
Prophylaxis (factor products)	34 (25.6%)
On-demand	42 (31.6%)
Problem joint number, mean (SD)	
HCP-reported	0.89 (1.05)
PwHA-reported	1.15 (1.44)



- The most frequently HCP-reported PJ locations were **knees** (31/133, 23.3%), **ankles** (20/133, 15.0%), and **wrists** (14/133, 10.5%), with **PwHA reporting similar PJ locations** – see Figure 1.
- HCP-reported history of joint procedures was noted in 23/133 (17.3%) of PwHA. **Arthrocentesis was the most commonly performed,** with 9/133 (6.8%) reporting this procedure in the past year. Overall, joint procedure locations were **congruent with the reported locations of joint damage** (specifically knees and wrists).
- In terms of the symptoms reported in this cohort, **chronic joint pain** was the most common symptom, highlighted by both HCPs (32%) and PwHA (46%) – see Figure 2. The mean (SD) PwHA-reported pain intensity (on a visual analogue scale of 1–10) was approximately **4.7** (2.0). Importantly, **recurrent bleeding was reported by a higher percentage of HCPs**, compared to PwHA (27/133, 20.3% vs 11/133, 8.3%, respectively).
- In addition, 29/133 (21.8%) of PwHA reported **range of motion (ROM) limitations** due to haemophilia-related joint issues; the severity of the ROM limitations was estimated by PwHA at approximately **4.3** (1.6), **on a scale of 1-10** (with 10 representing the worst outcome).

Figure 1. HCP- and PwHA-reported PJ locations

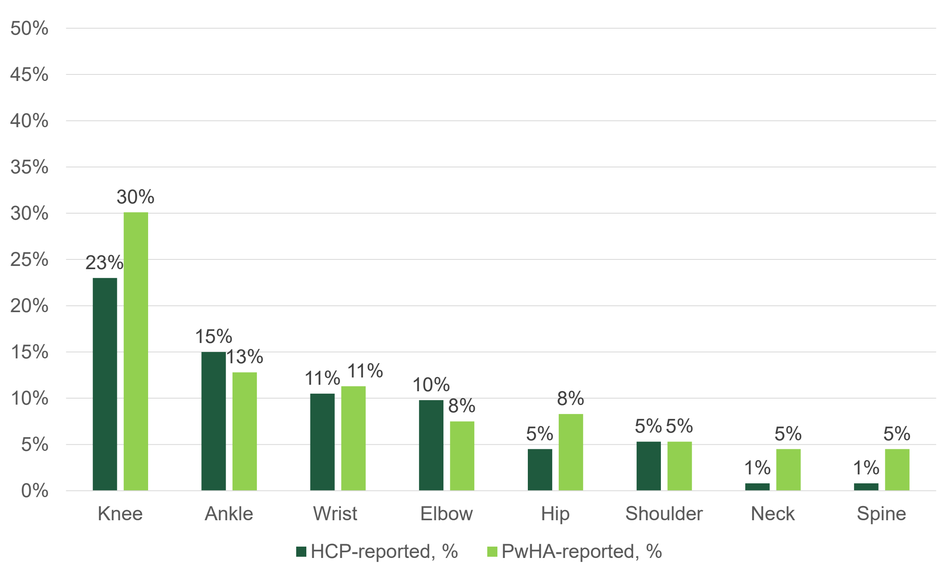
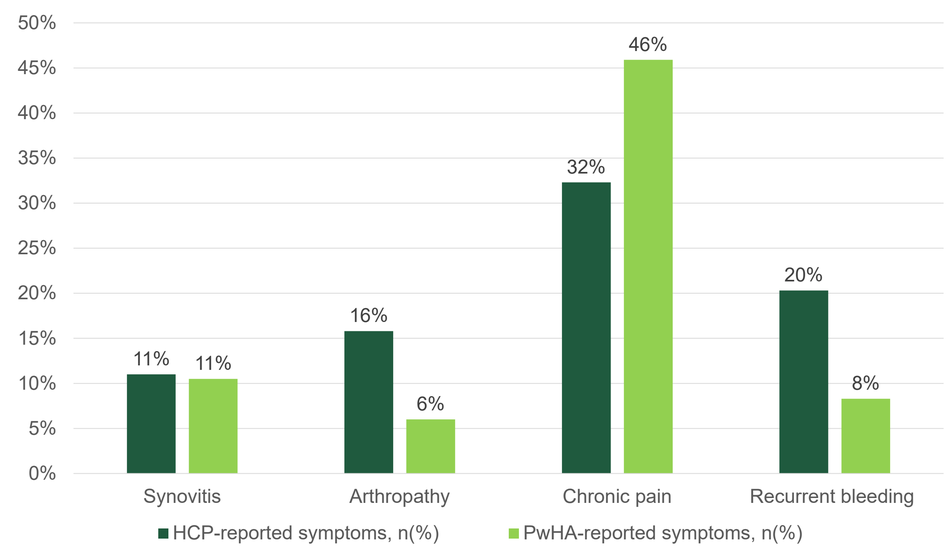


Figure 2. HCP- and PwHA-reported symptoms



CONCLUSIONS

- **A quarter of PwHA reported more problem joints than their HCPs**, indicating a meaningful gap in symptom recognition and potential underestimation of joint assessment in routine care.
- **Chronic pain** emerged as the **most commonly-reported issue across participants**, underscoring its persistent burden and influence on overall quality of life; in addition, **range of motion limitations** posed substantial challenges for PwHA.
- These findings highlight the **need for improved joint health assessment and management strategies**, as well as **greater alignment between patient- and clinician-reported outcomes**. Further research is warranted to clarify how such discrepancies affect joint disease progression, symptom management, and everyday functioning of people with haemophilia A.

REFERENCES

1. McLaughlin, P., De la Corte-Rodriguez, H., Burke, T., et al. 2025. An assessment of burden associated with problem joints in children and adults with moderate or severe haemophilia A: analysis of the CHESS-Paediatrics and CHESS II cross-sectional studies. Orphanet Journal of Rare Diseases, 20(1), p.18.
2. Burke T, Rodriguez-Santana I, Chowdary P, et al. 2023. Humanistic burden of problem joints for children and adults with haemophilia. Haemophilia. 29(2):608-618. doi: 10.1111/hae.14731.

ACKNOWLEDGEMENT

The authors acknowledge Nick Fulcher, PhD, CMPP, from Sobi, for publication coordination. Sobi and Sanofi reviewed and provided feedback on the poster. The authors had full editorial control of the poster and provided their final approval of all content.

Funding for this study was provided by Sobi.

CONTACT

Nana Kragh
Swedish Orphan Biovitrum AB,
SE-112 76 Stockholm, Sweden
nana.kragh@sobi.com