UKHCDO
NHD
U.K.H.C.D.O NATIONAL HAEMOPHILIA DATABASE

2026 ANNUAL REPORT

& Bleeding Disorder Statistics for the Financial Year 2025/26

A report from the UKHCDO and NHD

Published by United Kingdom Haemophilia Centre Doctors' Organisation 2026

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ISBN: 978-1-901787-30-6

Table of Contents

1.0 **Chairperson's Report** **9**

Appendix 1 Glossary 13

Appendix 2 Participating Centres 16

2.0 **Comments on the Bleeding Disorder Statistics for 2025/26** **17**

Table 1 People with bleeding disorders by registered diagnosis, 2025/26 20

Table 2 People with bleeding disorders by country of residence, 2025/26 22

2.1 **Congenital haemophilia A** **23**

Table 3 People with congenital haemophilia A and carriers, registered and treated, 2025/26 24

Figure 1 Females with congenital FVIII deficiency and carriers of haemophilia A currently registered and newly registered, by baseline FVIII level, 2025/26 25

Table 4 New registrations of people with congenital haemophilia A and carriers, 2025/26 26

Table 5 New registrations of people with severe congenital haemophilia A aged 2 years and over, and subsequent treatment by year 27

Figure 2 Survival of males with congenital haemophilia A by factor VIII level at birth (IU/dl), actively registered 1969-2026, compared to the general population of males in the UK 28

Figure 3 People with severe congenital haemophilia A by primary treatment, 2016/17 – 2025/26 29

Figure 4 People with moderate severity congenital haemophilia A by primary treatment, 2015/16 – 2025/26 30

Figure 5 Number of people with congenital haemophilia A issued non-trial products, 2016/17 – 2025/26 32

Figure 6 Number of people with severe congenital haemophilia A issued non-trial products, April 2025 – March 2026 33

Figure 7 The proportion of people with severe congenital haemophilia A and no active inhibitor issued treatment by primary treatment, 2018/19 – 2025/26 34

Figure 8 The proportion of people with severe congenital haemophilia A and no active inhibitor issued treatment by primary treatment, April 2025 – March 2026 35

Table 6 People with congenital haemophilia A issued with FVIII and not issued emicizumab by severity, 2016/17 – 2025/26 36

Table 7a Treatment intensity of people with severe congenital haemophilia A without active inhibitors issued with standard half-life FVIII, 2016/17 – 2025/26 37

Table 7b Treatment intensity of people with severe congenital haemophilia A without inhibitors treated with enhanced half-life FVIII, 2017/18-2025/26 38

Table 8a Treatment intensity of people with moderate severity congenital haemophilia A (0.01 - 0.03 IU/ml) treated with standard half-life FVIII, with no inhibitor, 2016/17 – 2025/26 39

Table 8b Treatment intensity of people with moderate congenital haemophilia A (0.01 - 0.03 IU/ml) treated with enhanced half-life FVIII, with no inhibitor, 2017/18 - 2025/26 40

Table 9 Non-trial products issued to treat people with congenital haemophilia A (all severities and including inhibitors), 2024/25 and 2025/26 41

Figure 9 Number of people with congenital haemophilia A (all severities) issued treatment in the UK 2025/26 by non-trial product 42

Table 10 Non-trial Factor VIII and emicizumab treatment issued by UK haemophilia centres by diagnosis, 2025/26 43

Figure 10 The number and proportion of people with severe congenital haemophilia A and no active inhibitor issued emicizumab by comprehensive care centre, 2025/26 44

Figure 11 The number and proportion of people with severe congenital haemophilia A and no active inhibitor issued altuvoct as primary treatment by comprehensive care centre, 2025/26 45

Figure 12 The proportion of previously untreated people (age at registration <= 2 years) with severe congenital haemophilia A by primary treatment 2019/20 – 2025/26 46

Table 11 Haemophilia joint health scores for people with congenital haemophilia A (FVIII <=5 IU/dl) without inhibitors 2015/16 - 2025/26 47

Figure 13 HJHS submission for people with congenital haemophilia A (FVIII <=5 IU/dl) without inhibitors 2015/16 – 2025/26 48

Figure 14 Median evaluable HJHS of people with congenital haemophilia A (FVIII <=5 IU/dl) without inhibitors 2015/16 – 2025/26 49

Table 12 Longitudinal within-person haemophilia joint health scores for people with congenital haemophilia A (FVIII <=5 IU/dl) without inhibitors 2015/16 - 2025/26 50

2.2 Congenital haemophilia B 51

Table 13 People with congenital haemophilia B and carriers, registered and treated, 2025/26 52

Figure 15 Females with congenital FIX deficiency and carriers of haemophilia B currently registered and newly registered, by baseline FIX level, 2025/26 53

Table 14 New registrations of people with congenital haemophilia B and carriers, 2025/26 54

Figure 16 Survival of males with congenital haemophilia B by factor IX level at birth (IU/dl), actively registered 1969-2026, compared to the general population of males in the UK 55

Figure 17 People with severe congenital haemophilia B by primary treatment, 2016/17 – 2025/26 56

Figure 18 People with moderate severity congenital haemophilia B by primary treatment, 2016/17 – 2025/26 57

Figure 19 Number of people with congenital haemophilia B issued product by severity, 2016/17 – 2025/26 59

Table 15 Non-trial products issued to treat people with congenital haemophilia B (all severities and including inhibitors), 2024/25 – 2025/26 60

Table 16 Non-trial Factor IX treatment issued for congenital and acquired haemophilia B by UK haemophilia centres, 2025/26 61

Figure 20 Number of people with congenital haemophilia B (all severities) treated in the UK 2025/26 by non-trial products used 62

Figure 21 The number and proportion of people with severe congenital haemophilia B and no inhibitor issued EHL products by centre 63

Table 17 Haemophilia joint health scores for people with congenital haemophilia B (FIX <=5 IU/dl) without inhibitors 2015/16 – 2025/26 64

Figure 22 HJHS submission for people with congenital haemophilia B (FIX <=5 IU/dl) without inhibitors 2015/16 – 2025/26 65

Figure 23 Median evaluable HJHS of people with congenital haemophilia B (FIX <=5 IU/dl) without inhibitors 2015/16 – 2025/26 66

Table 18 Longitudinal within-person haemophilia joint health scores for people with congenital haemophilia B (FIX <=5 IU/dl) without inhibitors 2015/16 – 2025/26 67

2.3 Gene Therapy 68

Figure 24 Gene therapy trial summary: number of people notified to NHD 69

Figure 25 Gene therapy trial follow-up status 69

Figure 26 Gene therapy trial: treatments received 2025/26 70

2.4 Von Willebrand Disease 72

Table 19 People with von Willebrand disease registered and treated 2025/26 73

Table 20 New registrations of von Willebrand disease between 2025/26, by age at mid-year, severity and gender 75

Table 21 Non-trial products issued to treat people with von Willebrand disease (including inhibitors), 2024/25 and 2025/26 76

Figure 27 Survival of people with von Villebrand disease by type, actively registered 1985-2026, compared to the general population of the UK 77

Figure 28 Units of von Willebrand factor issued by UK haemophilia centres to treat von Willebrand disease 2015/16 – 2025/26 78

Figure 29 People with type 3 von Willebrand disease issued von Willebrand factor by UK haemophilia centres 2016/17 – 2025/26 79

Figure 30 People with non-type 3 von Willebrand disease issued von Willebrand factor by UK haemophilia centres 2016/17 – 2025/26 80

2.5 Congenital and Acquired Factor Inhibitors 81

Table 22 Inhibitors by disease severity – congenital haemophilia A, haemophilia B & von Willebrand disease, 2025-26 82

Figure 31 The incidence of new FVIII inhibitors in people with congenital haemophilia A by year 84

Table 23 Non-trial products issued to treat people with congenital bleeding disorders reported to have a current inhibitor, 2024/25 and 2025/26 85

Table 24 Non-trial products issued to treat people with acquired disorders, 2024/25 and 2025/26 86

Table 25 FEIBA® issues: breakdown by diagnosis, 2023/24 – 2025/26 87

Table 26 NovoSeven® issues: breakdown by diagnosis, 2023/24 – 2025/26 87

Table 27 Emicizumab issues: breakdown by diagnosis, 2023/24 – 2025/26 88

Figure 32 The proportion of people with congenital haemophilia A and an active inhibitor issued treatment products by year 89

Figure 33 The proportion of people with acquired haemophilia A first registered April 2019 – March 2025 issued treatment products by months since registration 90

Figure 34 Survival of people with acquired haemophilia A newly registered April 2021 – March 2026, from date of registration 91

2.6 Other bleeding disorders 92

Table 28 People with other bleeding disorders registered and issued treatment products 2025/26 93

Table 29 People with selected other bleeding disorders registered and treated 2025/26, by factor level 94

Table 30 New registrations of other bleeding disorders 2025/26, by coagulation defect and gender 95

Table 31 Non-trial products issued to treat people with selected other bleeding disorders between 2025/26 96

2.7 Adverse Events 97

2.7.1 Introduction and Adverse Event Assessment Panel 98

Table 32 Adverse Events Reporting by Centre 99

Table 33 Summary of Adverse Events reported between April 2025 & March 2026 100

Table 34 Allergic/ other reactions reported between April 2025 & March 2026 101

Table 35 Infection Events reported between April 2025 & March 2026 101

Table 36 Intracranial haemorrhage (all ages) reported between April 2025 & March 2026 102

Table 37 Inhibitors reported between April 2025 & March 2026 103

Table 38 Malignancy Events reported between April 2025 & March 2026 103

Table 39 Poor Efficacy Events reported between April 2025 & March 2026 104

Table 40 Thrombotic Events reported between April 2025 & March 2026 104

Table 41 Neurological Events reported between April 2025 & 2026 105

Table 42 Other Events reported between April 2025 & March 2026 105

2.8 Mortality 106

Table 43 Causes of death in people with congenital haemophilia A and B between April 2025 & March 2026 107

Table 44 Causes of death in people with other bleeding disorders between April 2025 & March 2026 108

Figure 35 Cumulative incidence of deaths where primary cause of death is reported to be hepatocellular carcinoma or liver failure in people with bleeding disorders in the UK 1969 - 2025 109

Table 45: Deaths where primary cause is reported to be hepatocellular carcinoma or liver failure by HIV/HCV status in people with bleeding disorders in the UK 1969 – 2025 110

3.0 Haemtrack Annual Report for the calendar year 2025 112

3.1 People's Haemtrack Usage Analysis 113

3.1.1 Overall 113

Figure 1 Number of people using Haemtrack and recruitment rate, 2008-2025 114

3.1.2 Haemtrack usage analysis at centre level - people with severe haemophilia 115

Figure 2 Comparison of recruitment to Haemtrack by centre for people with severe haemophilia A/B: Comprehensive Care Centres (CCCs) in 2025 115

Figure 3 Comparison of recruitment to Haemtrack by centre for people with severe haemophilia A/B: Haemophilia Centres (HCs) in 2025 116

4. Data Management Working Party 117
5. Data Analysis Group 120
6. Specialised Blood Disorders NHSE Clinical Reference Group 122
7. Co-Morbidities Working Party 124
8. Genomics Working Party 126
9. Genetic Laboratory Network (UKHCDO-GLN) 127
10. Girls and Women with Bleeding Disorders Working Party 129
11. Inhibitor Working Party 132
12. Laboratory Working Party 133
13. Musculoskeletal Working Party 136
14. Paediatric Working Party 138
15. Peer Review Working Party 140
16. Von Willebrand Working Party 142
17. Dental Task Force 143
18. Emergency Care Guideline Re-write Task Force 144
19. Haemophilia Gene Therapy Hub Panel 145
20. Haemophilia Nurses' Association 148
21. Haemophilia Chartered Physiotherapists' Association 155
22. Haemophilia Psychology Association 159
23. British Society for Haematology Haemostasis & Thrombosis Task Force 161
24. The Haemophilia Society 163
25. Haemophilia Scotland 166
26. National Haemophilia Database - IT Update 168

1.0 Chairperson's Report

Welcome to the 27th Annual General Meeting of UKHCDO. The past year has been one of considerable activity and progress, reflecting the commitment and collective efforts of our members, working parties and colleagues across the four nations. Important developments include the recruitment of clinical leads for the National Haemophilia Database and publication of the revised national service specification. However, as access to increasingly effective therapies expands, it is essential that comprehensive care keeps pace. Services are caring for growing numbers of people with bleeding disorders, while staffing and infrastructure have not expanded commensurately. Ensuring that advances in treatment are matched by adequately resourced multidisciplinary care remains a central priority for UKHCDO.

Implementation of Recommendation 9 of the Infected Blood Inquiry has remained central to our advocacy. Through the Haemophilia and Bleeding Disorder Alliance, we wrote to ministers in March to highlight the lack of progress, longstanding funding disparities and the need for clearer responsibility for implementation. At the All-Party Parliamentary Group meeting on 18 March, we reinforced these concerns, drawing on national peer-review findings to demonstrate the workforce and infrastructure improvements required to protect the future safety of haemophilia care.

An outward-facing national summary of the peer-review programme, covering 32 centres across the UK, has been completed and is undergoing final review ahead of wider circulation following the AGM. The findings highlight persistent deficiencies, particularly in staffing and facilities, which continue to affect the delivery of comprehensive care. Our follow-up gap analysis is nearing completion, but the emerging picture suggests limited progress in addressing these deficiencies, especially where improvements require additional investment. Through the Haemophilia and Bleeding Disorder Alliance, we are working with IQVIA and the Imperial Health Policy Unit to better quantify the funding gaps and strengthen the evidence base for investment in services.

Publication by NHS England of the revised national service specification for haemophilia and related bleeding disorders represents an important milestone. Developed through extensive collaboration involving clinicians, PwBD and other stakeholders, including representatives from all four nations, it provides a clearer framework for comprehensive multidisciplinary care, including psychological support, and strengthens expectations for service delivery and accountability. Consistent implementation will require appropriate local workforce capacity and resources. At a time of uncertainty about the future arrangements for Clinical Reference Groups, we acknowledge the contribution of the entire CRG and particularly thank Dr Susie Shapiro for her leadership as Chair. Preserving specialist clinical input into national commissioning decisions will remain essential. Policy development has also continued, including emicizumab for acquired haemophilia A and vonicog alfa for regular prophylaxis in adults.

Gene therapy has entered routine clinical practice, while the introduction of marstacimab for eligible people with severe haemophilia B without inhibitors has further expanded treatment options. These developments offer greater treatment choice while reinforcing the importance of shared decision-making, appropriate monitoring and national collection of long-term outcomes.

Despite these advances, equitable access to newer therapies remains a significant challenge. Some people with moderate and mild haemophilia A are unable to access newer treatments such as efanesoctocog alfa despite clinically significant bleeding, while those with haemophilia B and inhibitors remain unable to access anti-TFPI therapies through routine commissioning. Access to

specific replacement treatment for ultra-rare disorders, such as plasminogen deficiency, presents similar difficulties. These examples highlight the limitations of existing appraisal and commissioning pathways for small PwBD populations. In August, Dr Mary Mathias wrote on behalf of UKHCDO to Professor James Palmer regarding access to new therapies for people with severe haemophilia B and inhibitors. NHS England acknowledged the substantial unmet need but highlighted the constraints imposed by existing appraisal and commissioning arrangements, offering further discussion. Addressing these gaps and securing equitable access to effective treatments will remain an important priority.

We have continued to seek constructive engagement with the Infected Blood Compensation Authority. Challenges remain in establishing effective communication and working arrangements. Our priorities include clearer processes, accessible points of contact and timely, consistent information for affected individuals, families and the clinical teams supporting them. We will continue to work towards more effective arrangements that meet the needs of all those involved.

Recruitment of clinical leads for the National Haemophilia Database in gene therapy, musculoskeletal health, rare disorders, and women and girls with bleeding disorders represents an important step in strengthening its clinical, scientific and research contribution. The revised consent process for the UK Bleeding Disorders Research Registry has been introduced across all four nations, with centres continuing to seek consent from eligible PwBD. Over the coming year, we will focus on developing investigator-initiated and post-marketing research, supporting centre participation and making fuller use of national data to address clinically important questions. Delivering these ambitions will require sustainable investment, and we will continue to advocate for the additional central funding recommended for the NHD under Recommendation 9f of the Infected Blood Inquiry.

Several elements of the UKHCDO strategy are already being implemented, although the wider strategic review has progressed more slowly than anticipated. We intend to finalise the strategy and accompanying implementation plan early in 2027, with clearly defined priorities, responsibilities and deliverables. We have also re-established the Rare Disorders Working Party, renewing our focus on the needs of people with less common bleeding disorders.

We are particularly grateful to our partners in the Haemophilia and Bleeding Disorder Alliance and to the PwBD organisations whose support has been invaluable in advancing our shared priorities. I also thank my fellow Executive officers, our working-party chairs and members, the NHD and administrative teams, and everyone who contributed to peer review. Across the four nations, the commitment of clinicians, nurses, physiotherapists and other allied health professionals continues to underpin comprehensive care for people with bleeding disorders.

I would particularly like to thank William Horsley, Lead Commissioner for the Specialised Blood Disorders Clinical Reference Group, for his exceptional support over more than a decade. His collaborative approach, openness to clinical perspectives and willingness to work alongside clinicians to find practical solutions have been greatly valued. He has brought a spirit of partnership to complex commissioning discussions, and we are deeply grateful for his sustained commitment to improving care for people with bleeding disorders.

I would also like to thank Kate Burt, Chief Executive of The Haemophilia Society and fellow Co-chair of the Haemophilia and Bleeding Disorder Alliance. Her inclusive approach and commitment to working collaboratively with clinicians and PwBD organisations have strengthened the Alliance and helped us advance our shared priorities. I have greatly valued her partnership and support.

In the coming year, our priorities will be to support implementation of the revised service specification, advocate for action on the national peer-review findings, address inequities in treatment access and strengthen the clinical and research contribution of the NHD. We will also focus on securing sustainable investment in comprehensive care and delivering the UKHCDO strategic

work plan. Our overarching aim remains to ensure that advances in treatment are matched by comprehensive, sustainable care for everyone with a bleeding disorder.

On behalf of the UKHCDO Executive

Professor Pratima Chowdary, Chair
Dr Gary Benson, Vice-Chair
Dr Mary Mathias, Secretary
Dr Sarah Mangles, Treasurer

November 2026

Bleeding Disorder Statistics for

April 2025 to March 2026

A report from the UK National Haemophilia Database

November 2026

Appendix 1 Glossary

AE	Adverse Event
AGM	Annual General Meeting
ASH	American Society of Hematology
BCSH	British Committee for Standards in Haematology
BMI	Body mass index
BMS	Biomedical Scientists
BSH	British Society for Haematology
CCC	Comprehensive Care Centre
CEO	Chief executive officer
CMWP	Co-morbidities Working Party
COVID-19	Corona Virus Disease
CPD	Continuing Professional Development
CQUIN	Commissioning for Quality and Innovation
CRG	Clinical Reference Group
DAG	Data Analysis Group
DMWP	Data Management Working Party
EAHAD	European Association for Haemophilia and Allied Disorders
EHL	Enhanced Half-life
EU	European Union
EUHASS	European Haemophilia Safety Surveillance
FEIBA	Factor eight inhibitor bypass agent
FIX	Factor nine
FVII	Factor seven
FVIII	Factor eight
GCP	Good clinical practice
GLH	Genomics Laboratory Hub
GLN	Genetic Laboratory Network
GOSH	Great Ormond Street Hospital
GWBD	Girls and women with bleeding disorders
GWP	Genetics Working Party
HA	Haemophilia A
HB	Haemophilia B
HC	Haemophilia Centre
HCC	Hepatocellular carcinoma

HCIS	Haemophilia Clinical Information System
HCPA	Haemophilia Chartered Physiotherapists' Association
HCV	Hepatitis C virus
HEE	Health Education England
HJHS	Haemophilia Joint Health Score
HNA	Haemophilia Nursing Association
HPA	Haemophilia Psychology Association
ICS	Integrated Clinical Academic
IPSG	International Prophylaxis Study Group
IQR	Interquartile range
ISTH	International Society on Thrombosis and Haemostasis
ITI	Immune tolerance induction
IU	International units
IU/dl	International units per decilitre
IU/kg	International units per kilogram
IWP	Inhibitor Working Party
JRCALC	Joint Royal Colleges Ambulance Liaison Committee
MAHA	Microangiopathic haemolytic anaemia
MDSAS	Medical Data Solutions and Services
MDT	Multidisciplinary team
MTP	Minimally treated people
NEQAS	National External Quality Assessment Service
NHD	National Haemophilia Database
NHF	National Hemophilia Foundation
NHS	National Health Service
NIBSC	National Institute for Biological Standards and Control
NIHR	National Institute for Health Research
PDF	Portable Document Format
pdFIX	Plasma-derived factor nine
pdFVIII	Plasma-derived factor eight
pdVWF	Plasma-derived von Willebrand factor
PPIE	Patient and Public Involvement and Engagement
PUP	Previously untreated person
PwAHA	Person/people with acquired haemophilia A
PwBD	Person/people with a bleeding disorder

PwHA	Person/people with congenital haemophilia A
PwHAi	Person/people with haemophilia A and an inhibitor
PwHB	Person/people with congenital haemophilia B
PwMHA	Person/people with moderate haemophilia A
PwNSHA	Person/people with non-severe haemophilia A
PwNSHB	Person/people with non-severe haemophilia B
PWP	Paediatric Working Party
PwSH	People with severe haemophilia
PwSHA	Person/people with severe haemophilia A
PwSHAi	Person/people with severe haemophilia A and an inhibitor
PwSHB	Person/people with severe haemophilia B
PwVWD	Person/people with von Willebrand disease
RCEM	Royal College of Emergency Medicine
RCPCH	Royal College of Paediatrics and Child Health
RfPB	NIHR Research for Patient Benefit
rFIX	Recombinant factor IX
rFVIII	Recombinant factor VIII
rVWF	Recombinant von Willebrand factor
SAE	Serious Adverse Event
SD	Standard deviation
SHA	Severe Haemophilia A
SHB	Severe Haemophilia B
SHL	Standard Half-life
SOP	Standard operating procedure
TF	Task Force
THS	The Haemophilia Society
UK	United Kingdom
UKHCDO	United Kingdom Haemophilia Centre Doctors' Organisation
UKNEQAS	United Kingdom National External Quality Assessment Service
VWD	Von Willebrand disease
VWF	Von Willebrand factor
WAPPS-Hemo	Web-Accessible Population Pharmacokinetic Service—Hemophilia
WFH	World Federation of Hemophilia
WP	Working party

Appendix 2 Participating Centres

Centre Name	
Aberdeen	Lincoln
Bangor	Liverpool (Children's)
Barnstaple	Liverpool (R.I.)
Belfast - Adult's	Manchester (Children's)
Belfast - Children's	Manchester (R.I.)
Birmingham (Children's)	Newcastle
Birmingham (Queen Elizabeth's)	Newport
Bournemouth/Poole	North Hampshire
Bradford	Norwich
Brighton	Nottingham
Bristol (Infirmary & Children's)	Oxford
Cambridge	Peterborough
Canterbury	Plymouth
Cardiff	Portsmouth
Chichester	Royal Free, London
Coventry	Royal London Hospital
Derby	Salisbury
Dundee	Sheffield (Children's)
Edinburgh	Sheffield (Royal Hallamshire)
Exeter	Shrewsbury
Glasgow (R.H.S.C.)	Southampton
Glasgow (R.I.)	St. George's Hospital, London
Great Ormond Street, London	St. Thomas' and Guy's Hospitals, London
Hammersmith Hospital, London	Staffordshire (Stoke-on-Trent)
Inverness	Swansea
Ipswich	Taunton/Yeovil
Kingston-upon-Hull	Torquay
Leeds	Truro
Leicester	Wolverhampton
Lewisham	York

2.0 Comments on the Bleeding Disorder Statistics for 2025/26

The statistics for the financial year 2025/6 follow. Most of the detailed explanation and commentary will be found with the tables and charts themselves.

Registrations:

Registrations of living people with bleeding disorders has increased markedly in the 23 years since the database was re-established in Manchester from about 16,000 individuals to over 45,000 (Table 1). Some of this increase is accounted for by a gradual increase in the number of people with haemophilia and von Willebrand's disease, although the largest contribution comes from increased registration of people with mild bleeding disorders This increase is also partly attributable to a decrease in management of mild disorders in peripheral hospitals and therefore increased registration and diagnosis of mild disorders by haemophilia centres.

Treatment Trends:

The transfer of people with severe haemophilia A to emicizumab appears to have plateaued.at 64% of PwSHA. In July 2025. Altuvoct (efenasoctocog alfa) was commissioned for severe haemophilia.A only. Since that time, over 400 pwSHA have switched to Altuvoct for prophylaxis and this transfer continues. Most Altuvoct users have switched from SHL or EHL rFVIII with a small group of PwSHA whose response to emicizumab was suboptimal also switching. Altuvoct provides an advantage of less frequent (weekly) administration than SHL and EHL rFVIII for prophylaxis, and, in some cases superior haemostatic efficacy. Preliminary analysis shows excellent bleed outcomes amongst evaluable PwHA. Altuvoct was also used for surgery or intercurrent bleeding in 42 PwSHA. This agent simplifies the haemostatic management of surgery and may permit earlier hospital discharge in some cases. It is unfortunate that Altuvoct has not been commissioned for non-severe haemophilia A. since many PwNSHA require prophylaxis and when undergoing surgery have to stay in hospital longer than people without a bleeding disorder to continue haemostatic treatment. We would anticipate that Altuvoct will largely replace SHL and EHL rFVIII for prophylaxis in SHA. We also anticipate the introduction of Mim8 (Novo) at some stage in 2027, which, will provide some competition with emicizumab.

The trend for PwSHB to switch to EHL rFIX products continues, such that only about 12% of factor IX prophylaxis is conducted using SHL rFIX. SHL rFIX is still used extensively for intercurrent bleeding, surgery and for non-severe haemophilia B.

The number of VW units issued to treat von Willebrand's disease has increased almost three-fold in the past decade. This is partly attributable to the 25% increase in the number of people with type 3 von Willebrand's disease but also to increased use of prophylaxis and an increased proportion of people with type 3 VWD regularly treated (from 58% to 75%). There has been little change in the brands of concentrate used to treat VWD, although the volume of Veyvondi issued has increased by a third over the last year, despite it being commissioned only for surgery and on-demand use in England. Its relatively long half-life would lend itself to prophylactic use, and a commissioning policy

for this is currently being considered by NHSE. Life expectancy for people with type 3 VWD still lags behind that for the general population (80 v 88 years).

Acquired Haemophilia:

An analysis of survival of PwAHA over the past five years shows a one-year all-causes mortality of 33% and a five-year mortality of 56%. Although the median (IQR) age at presentation of these 653 PwAHA was 78.3 (72-84), normal life expectancy would be 8-9 years, depending on sex. The most frequent cause of death was infection followed by bleeding.

Analysis of the haemostatic treatments used for acquired haemophilia shows that FEIBA is the most frequent agent used, followed by Obizur and Novoseven. Treatment is most intense in the first six months after diagnosis, falling to a low level thereafter. 25% require no haemostatic treatment.

Very few PwAHA were issued emicizumab, even though this has become a standard therapeutic approach in mainland Europe, since emicizumab has no product license for this indication. This may change if a much-delayed NHSE acquired haemophilia guideline is finally approved. If this is approved, most PwAHA could be treated with emicizumab from the time of diagnosis and most could be managed as outpatients. One would hope that this will also result in an improvement in survival as well as quality of life. It is also anticipated that it would also be an extremely cost-effective strategy, since PwAHA could be managed outside hospital, would require few other haemostatic agents and would be less likely to suffer infection. Assuming this treatment guideline is adopted, we plan to audit the outcome as a joint activity between the database and the Inhibitor Working Party.

Adverse events:

Survival curves show that survival of people with severe and moderate haemophilia A has improved significantly. Causes of death reported by centres and NHS Digital indicate an increasing proportion dying from dementia and the diseases of old age, largely reflecting causes of death in the general population. More than half of our mortality and cause of death data comes from death certification data from NHS Digital rather than from centre reports. Causes of death may not be known to the centre if the person died at home or in another hospital, especially if they had a mild bleeding disorder. For those people we are dependent on the death certification data from NHS Digital.

Adverse events reports, assessed monthly by the Adverse Event Panel show the usual range of adverse events. All drug-related adverse events are reported back to the manufacturer so that they can satisfy their statutory duty to report adverse events to the regulators. Pharmacovigilance is an important part of the work of the database. Very few adverse events have been reported in relation to emicizumab, partly because drug side effects associated with this agent tend to occur early in the treatment course and most people treated with emicizumab have been using it for several years now.

The report also shows the mean number of adverse event reports per 100 PwBD per year for six anonymised centres selected to show the range of report frequency over the past two years Some centres report far more adverse events per PwBD than others. After last year's AGM, we reported to each centre their reporting statistics, and the group median statistics by way of comparison, to encourage those centres who were not reporting adverse events at all to participate. Comparison of performance for the two years suggests that this has been only partly effective in encouraging more complete adverse event reporting.

Minimisation of numbers:

The tables have not been "minimised" for small numbers. The recommendations of the Royal Statistical Society on data minimisation follow the common-sense principle that if an individual can

be identified from the data presented then the data should be minimised. Following these principles on a case-by-case basis, we concluded that individuals could not be identified from tables as currently presented and, accordingly, the data does not require minimisation.

Acknowledgement:

I would like to take this opportunity to thank the staff of the haemophilia centres for collating and sending in all the data and for helping us with data-cleaning,

We hope that you find the statistics useful and of interest and if you have any suggestions for future issues, please let us know. We hold a report review meeting usually in January, attended by a group of stakeholders including commissioners, PwBD representatives and working party chairs.

Professor Charles RM Hay,

James Chetter, Dennis Glover, Ben Palmer & Dr Hua Xiang

On behalf of the UK National Haemophilia Database

Manchester, November 2026

Table 1 People with bleeding disorders by registered diagnosis, 2025/26

Diagnosis	Number of people registered		
	Male	Female	Total
Haemophilia A	7,050	1,022	8,072
Female with >=40 IU/dl FVIII	0	2,300	2,300
Haemophilia B	1,398	390	1,788
Female with >=40 IU/dl FIX	0	476	476
Factor IX Leyden deficiency	36	8	44
Female with >=40 IU/dl FIX Leyden	0	13	13
Haemophilia A/B with liver transplant	11	0	11
von Willebrand disease	4,756	8,310	13,066
Probable von Willebrand disease	74	193	267
Factor V deficiency	143	250	393
Factor VII deficiency	1,335	1,607	2,942
Factor X deficiency	205	273	478
Factor XI deficiency	2,069	3,112	5,181
Factor XIII deficiency	62	54	116
Prothrombin (factor II) deficiency	15	16	31
Dysfibrinogenemia	380	610	990
Hypofibrinogenemia	163	249	412
Hypodysfibrinogenemia	32	36	68
Afibrinogenemia	11	7	18
Bleeding disorder of unknown cause	345	2,461	2,806
Glanzmann's Thrombasthenia	99	135	234
Bernard-Soulier syndrome	78	94	172
Platelet-type Pseudo von Willebrand Disease	15	29	44
Other platelet disorder	1,213	2,592	3,805
Unknown platelet disorder	306	718	1,024
Combined factors V and VIII deficiencies	18	20	38
Acquired haemophilia A	392	386	778
Acquired von Willebrand disease	137	117	254
Other acquired factor deficiency	31	30	61
Other disorder*	10	13	23
Awaiting confirmation	16	84	100
Total	**20,162**	**25,113**	**45,275**

Sex as registered at birth

*Other reported disorders include:

Thrombomodulin-associated coagulopathy

Type 1 Plasminogen Deficiency

Combined factors II, VII, IX and X deficiencies

Factor X deficiency with liver transplant

Reduced one stage FVIII and normal chromogenic FVIII

Table 1 (previous page): This shows the number of people currently registered with the NHD by diagnosis. Females registered as HA or HB carriers, or with FVIII or FIX deficiency, are reported by their factor level. Otherwise, people are listed by their registered diagnosis. People registered with multiple disorders are reported under each of their individual diagnoses, although they are included only once in the overall totals. It is suspected that liver transplantation is under-reported. Haemophilia B Leyden is also under-reported, as it is sometimes reported as haemophilia B.

Important Note: Throughout the remainder of this report, haemophilia A results include carriers of HA and females with FVIII deficiency. Results for haemophilia B include carriers of HB, females with FIX deficiency, people with FIX Leyden and FIX Leyden carriers. People with multiple disorders are included in results for each of their individual blood disorder diagnoses. Where female or male sex is specified, this refers to sex as registered at birth. Age is calculated at the midpoint of the financial year, i.e. 30th September 2025.

Table 2 People with bleeding disorders by country of residence, 2025/26

Diagnosis	Number of people registered																	
	England			Northern Ireland			Scotland			Wales			Not known			Total		
	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
Haemophilia A including people with liver transplant	5,909	844	6,753	269	29	298	562	94	656	313	53	366	6	2	8	7,059	1,022	8,081
Female with >=40 IU/dl FVIII	0	1,834	1,834	0	159	159	0	234	234	0	71	71	0	2	2	0	2,300	2,300
Haemophilia B including FIX Leyden deficiency and people with liver transplant	1,184	317	1,501	30	8	38	151	45	196	69	26	95	2	2	4	1,436	398	1,834
Female with >=40 IU/dl FIX including Leyden	0	402	402	0	15	15	0	59	59	0	13	13	0	0	0	0	489	489
von Willebrand disease, including probable VWD	4,052	7,071	11,123	80	97	177	472	948	1,420	220	369	589	6	18	24	4,830	8,503	13,333
Acquired bleeding disorders	477	458	935	9	8	17	36	46	82	36	19	55	2	1	3	560	532	1,092
Other bleeding disorders	5,390	10,152	15,542	57	73	130	703	1,288	1,991	260	532	792	6	18	24	6,416	12,063	18,479
Total	**16,888**	**20,913**	**37,801**	**445**	**387**	**832**	**1,915**	**2,699**	**4,614**	**893**	**1,071**	**1,964**	**21**	**43**	**64**	**20,162**	**25,113**	**45,275**

Sex as registered at birth
Country of residence is marked as 'not known' if postcode is not known, or is not in the ONS postcode directory

2.1 Congenital Haemophilia A

Table 3 People with congenital haemophilia A and carriers, registered and treated, 2025/26

Congenital haemophilia A	Age (years)	Number of people by factor VIII level at birth (IU/dl)																	
		< 1			1 - 5			>5 & <40			≥ 40			People with unknown severity or liver transplant			Total		
		Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
Total Registered	<18	721	3	724	180	4	184	703	179	882	37	233	270	5	4	9	1,646	423	2,069
	>=18	1,694	17	1,711	612	11	623	2,850	808	3,658	233	2,018	2,251	24	45	69	5,413	2,899	8,312
	Total	**2,415**	**20**	**2,435**	**792**	**15**	**807**	**3,553**	**987**	**4,540**	**270**	**2,251**	**2,521**	**29**	**49**	**78**	**7,059**	**3,322**	**10,381**
New Registrations*	<18	31	-	31	9	1	10	62	31	93	5	39	44	3	1	4	110	72	182
	>=18	19	3	22	14	6	20	52	47	99	19	177	196	-	4	4	104	237	341
	Total	**50**	**3**	**53**	**23**	**7**	**30**	**114**	**78**	**192**	**24**	**216**	**240**	**3**	**5**	**8**	**214**	**309**	**523**
Issued concentrate FVIII and/or Emicizumab in year**	<18	701	1	702	138	3	141	173	6	179	8	-	8	1	-	**1**	1,021	10	1,031
	>=18	1,624	6	1,630	381	4	385	600	45	645	33	19	52	4	-	**4**	2,642	74	2,716
	Total	**2,325**	**7**	**2,332**	**519**	**7**	**526**	**773**	**51**	**824**	**41**	**19**	**60**	**5**	**-**	**5**	**3,663**	**84**	**3,747**

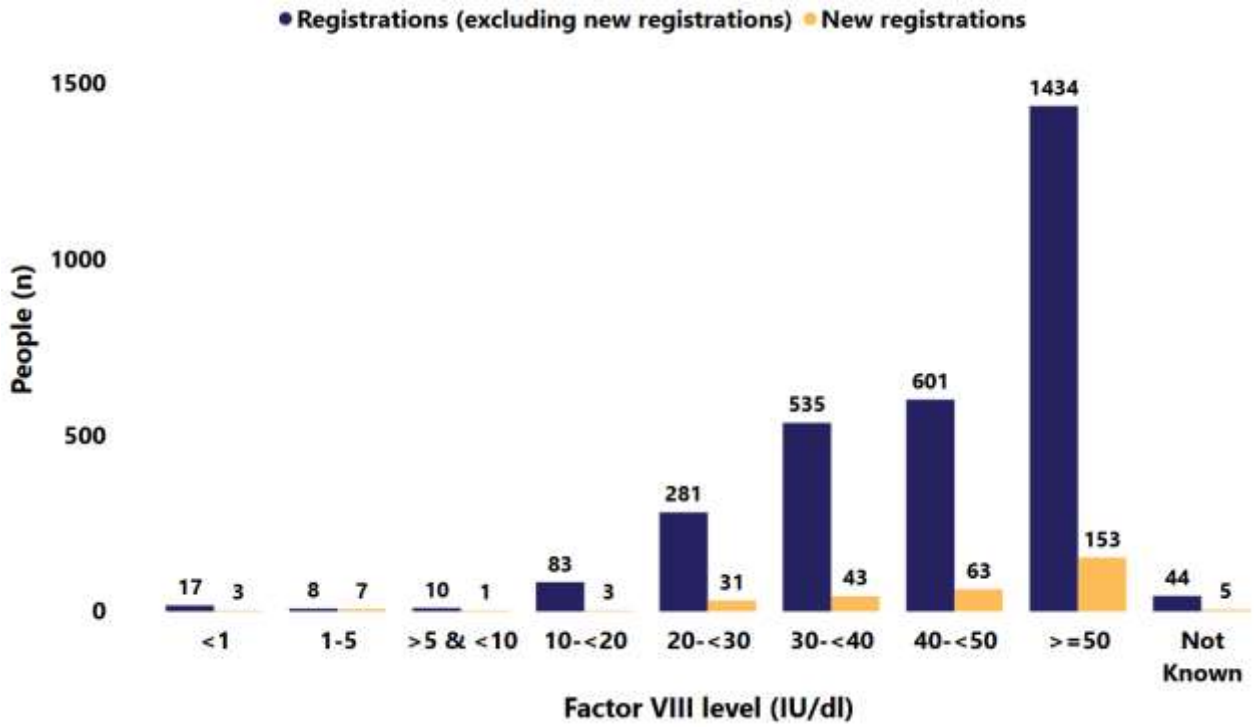
Sex as registered at birth

**New registrations are a subset of the 'In Register' numbers*

***Excluding people only treated with DDAVP and tranexamic acid*

Table 3: This shows the total number of people with haemophilia A (including factor VIII carriers and factor VIII deficient females) registered and/or issued with FVIII concentrate or emicizumab in the UK during 2025/26, by age, sex at birth and disease severity.

Figure 1 Females with congenital FVIII deficiency and carriers of haemophilia A currently registered and newly registered, by baseline FVIII level, 2025/26



N.B: Includes carriers of haemophilia A and females with FVIII deficiency

Diagnosis	Number of people by factor VIII level at birth (IU/dl)									
	<1	1-5	>5 & <10	10-<20	20-<30	30-<40	40-<50	≥50	Not Known	Total
Ongoing registrations (excluding new registrations)	17	8	10	83	281	535	601	1,434	44	3,013
New registrations	3	7	1	3	31	43	63	153	5	309
Total	**20**	**15**	**11**	**86**	**312**	**578**	**664**	**1,587**	**49**	**3,322**

Sex as registered at birth

Figure 1: This shows the number of carriers of haemophilia A currently registered with the NHD by baseline FVIII level. This includes females registered by their centre as having FVIII deficiency or haemophilia A.

Table 4 New registrations of people with congenital haemophilia A and carriers, 2025/26

Age at registration (years)	Number of people by factor VIII level (IU/dl)																	
	< 1			1 - 5			> 5 & < 40			≥ 40			People with unknown severity			Total		
	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
0 - 1	25	-	25	6	-	6	28	6	34	-	2	2	-	-	-	59	8	67
2 - 4	5	-	5	2	-	2	11	8	19	1	7	8	1	-	1	20	15	35
5 - 9	-	-	-	1	-	1	9	8	17	2	10	12	1	-	1	13	18	31
10 - 19	5	-	5	4	3	7	16	11	27	3	27	30	1	1	2	29	42	71
20 - 29	5	2	7	3	1	4	15	13	28	7	39	46	-	1	1	30	56	86
30 - 39	10	-	10	5	2	7	10	10	20	1	50	51	-	1	1	26	63	89
40 - 49	-	-	-	1	-	1	3	6	9	3	35	38	-	-	-	7	41	48
50 - 59	-	-	-	1	-	1	13	11	24	1	16	17	-	-	-	15	27	42
60 - 69	-	-	-	-	-	-	2	2	4	5	16	21	-	2	2	7	20	27
70 and above	-	1	1	-	1	1	7	3	10	1	14	15	-	-	-	8	19	27
Total	**50**	**3**	**53**	**23**	**7**	**30**	**114**	**78**	**192**	**24**	**216**	**240**	**3**	**5**	**8**	**214**	**309**	**523**

Sex as registered at birth

Table 4: This shows the number of new registrations of haemophilia A broken down by reported severity and age at registration. The underlying birth rate of people with severe haemophilia A born in the UK usually runs at 40-45 per year.

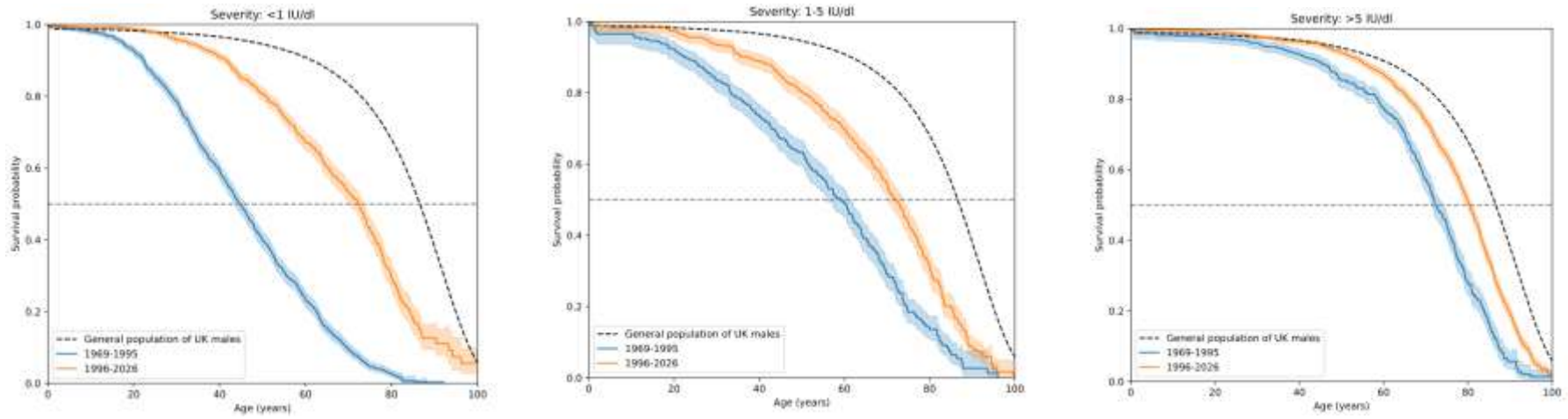
Table 5 New registrations of people with severe congenital haemophilia A aged 2 years and over, and subsequent treatment by year

	Registration year										Total
	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26	2016/2026
New registrations by year	24	21	21	19	13	23	32	23	23	29	228
Issued product by year											
2016/17	22										22
2017/18	22	18									40
2018/19	20	17	16								53
2019/20	19	16	18	18							71
2020/21	17	15	15	13	12						72
2021/22	18	13	11	13	11	20					86
2022/23	16	13	14	11	11	21	30				116
2023/24	16	14	14	11	9	21	30	23			138
2024/25	16	14	15	11	8	20	25	23	20		152
2025/26	16	14	13	10	9	19	26	20	19	23	169
No issue records	1	1	1	0	1	0	1	0	2	6	13

Excludes people resident overseas.

Table 5: This shows the number of people with severe haemophilia A over two years of age when newly registered (and therefore thought potentially to be migrants) each year from 2016/17, excluding those reported to be resident overseas. It also shows the number issued product in each year subsequent to their initial registration. This shows that up to 228 people with severe haemophilia A may have migrated to the UK since 2016/17. This may be an underestimate, since children under two years old are not included in this table. Product was issued to 169/228 of these PwSHA in 2025/26, suggesting that the majority remain but some may be visitors to the country .

Figure 2 **Survival of males with congenital haemophilia A by factor VIII level at birth (IU/dl), actively registered 1969-2026, compared to the general population of males in the UK**



Time period of registration with NHD	Median (interquartile range) survival time for people with haemophilia A by factor VIII level at birth (IU/dl)			
	< 1	1 - 5	>5	General population of UK males
1969-1995	44.6 (31.3-59.0)	59.1 (38.4-72.3)	72.1 (62.1-81.0)	88 (79-95)
1996-2026	72.2 (54.4-81.7)	71.8 (54.9-82.7)	80.3 (69.3-87.7)	

Figure 3 People with severe congenital haemophilia A by primary treatment, 2016/17 – 2025/26

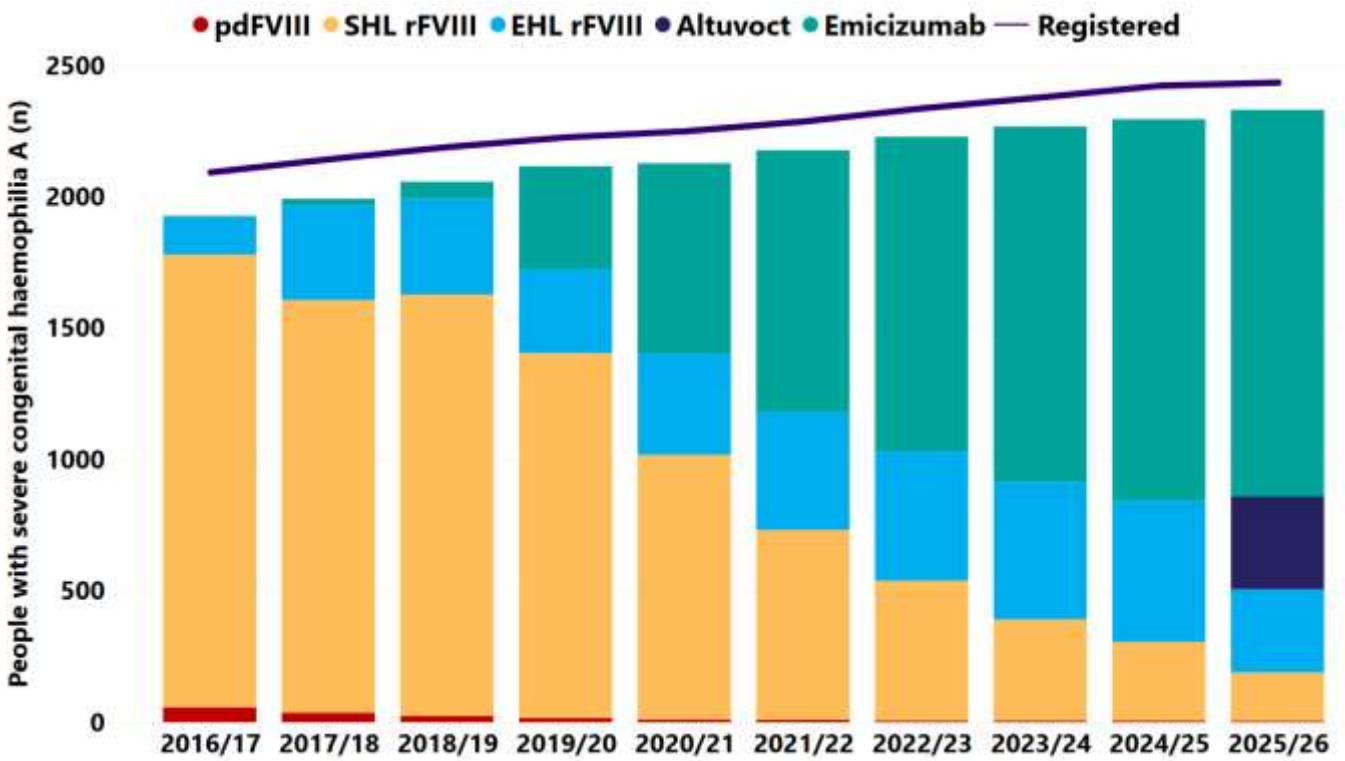


Figure 3: This shows the number of registered PwSHA (baseline FVIII level <1 IU/dl) issued FVIII or emicizumab as primary treatment from 2016/17 to 2025/26, including people with FVIII inhibitors. This chart shows a significant fall off in PwSHA issued FVIII as primary treatment from 2019/20, which is attributable to the introduction of emicizumab prophylaxis from September of 2019. Plasma-derived products have almost completely fallen out of use. The use of SHL-VIII has declined steadily as PwSHA were changed from those products to EHL-VIII and emicizumab. The proportion treated with EHL-VIII has declined rapidly over the past year, replaced by Altuvoct, commissioned on 01/07/2025. So far, only about 5% of PwSHA treated with emicizumab have switched to Altuvoct.

Figure 4 People with moderate severity congenital haemophilia A by primary treatment, 2015/16 – 2025/26

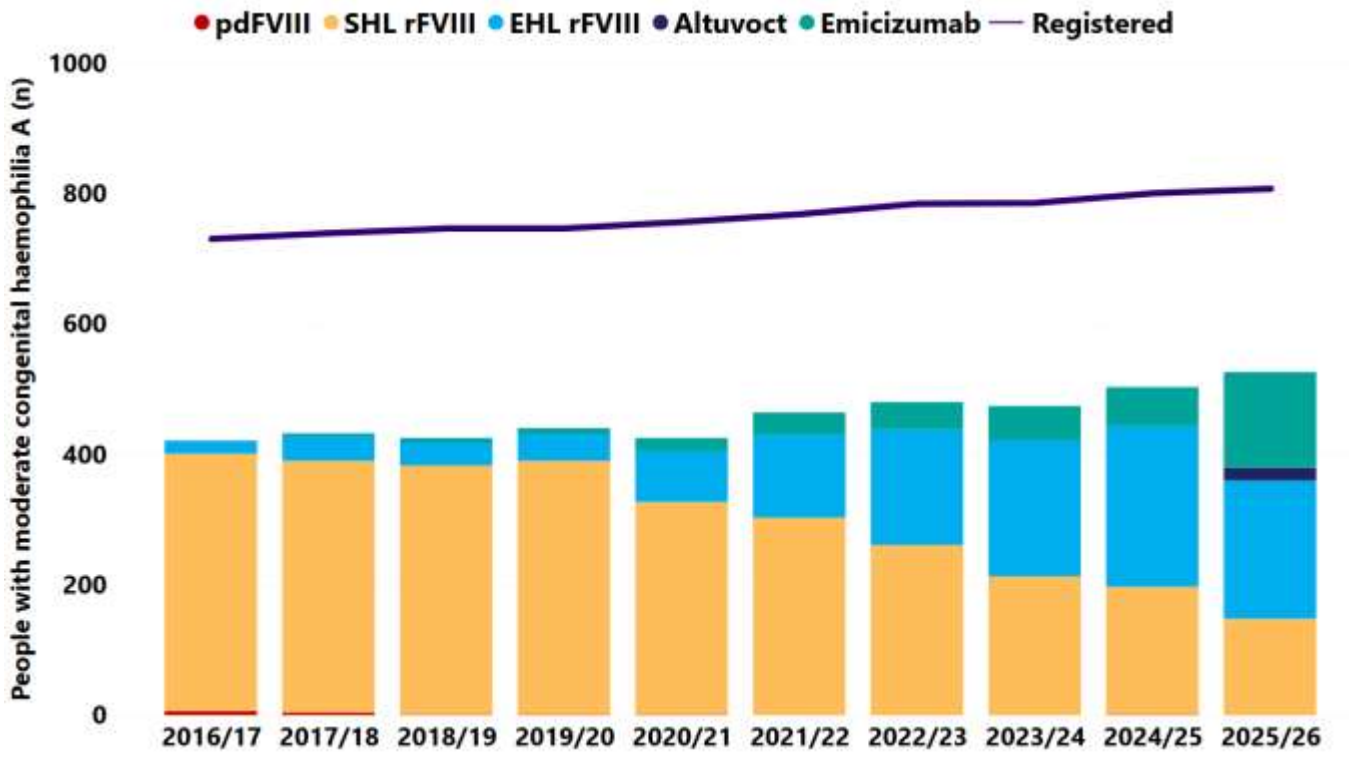


Figure 4: This shows the number of registered PwMHA (baseline FVIII level 1-5 IU/dl) issued FVIII or emicizumab as primary treatment from 2016/17 to 2025/26, including people with FVIII inhibitors. Emicizumab was not commissioned for use in people with moderate haemophilia without inhibitors until 2024. The declining proportion of people issued SHL rFVIII, and increasing proportion of people issued EHL rFVIII or emicizumab as primary treatment can be observed. Although Altuvoct has only been commissioned for severe haemophilia A, it appears to have become the primary treatment for nineteen PwMHA.

Data table for Figure 3: *People with severe congenital haemophilia A by primary treatment, 2016/17 – 2025/26*

Year	PwSHA issued pdFVIII	PwSHA issued SHL rFVIII	PwSHA issued EHL rFVIII	PwSHA issued altuvoct	PwSHA issued emicizumab	PwSHA issued any FVIII, emicizumab or altuvoct	PwSHA registered
	n	n	n	n	n	n	n
2016/17	57	1723	140	-	7	1927	2092
2017/18	37	1570	360	-	25	1992	2142
2018/19	24	1604	366	-	63	2057	2189
2019/20	16	1389	321	-	390	2116	2226
2020/21	11	1007	384	-	725	2127	2249
2021/22	9	723	448	-	997	2177	2286
2022/23	6	533	492	-	1197	2228	2336
2023/24	6	386	522	-	1353	2267	2378
2024/25	6	300	537	-	1452	2295	2422
2025/26	5	185	316	354	1471	2331	2434

Data table for Figure 4: *People with moderate congenital haemophilia A by primary treatment, 2016/17 – 2025/26*

Year	PwMHA issued pdFVIII	PwMHA issued SHL rFVIII	PwMHA issued EHL rFVIII	PwSHA issued altuvoct	PwSHA issued emicizumab	PwMHA issued any FVIII, emicizumab or altuvoct	PwMHA registered
	n	n	n	n	n	n	n
2016/17	6	395	20	-	-	421	730
2017/18	4	386	38	-	4	432	739
2018/19	1	382	35	-	7	425	746
2019/20	1	389	41	-	9	440	746
2020/21	1	326	78	-	20	425	756
2021/22	0	303	128	-	33	464	768
2022/23	0	261	177	-	42	480	784
2023/24	0	213	208	-	53	474	785
2024/25	1	196	246	-	60	503	800
2025/26	0	148	212	19	147	526	807

Figure 5 Number of people with congenital haemophilia A issued non-trial products, 2016/17 – 2025/26

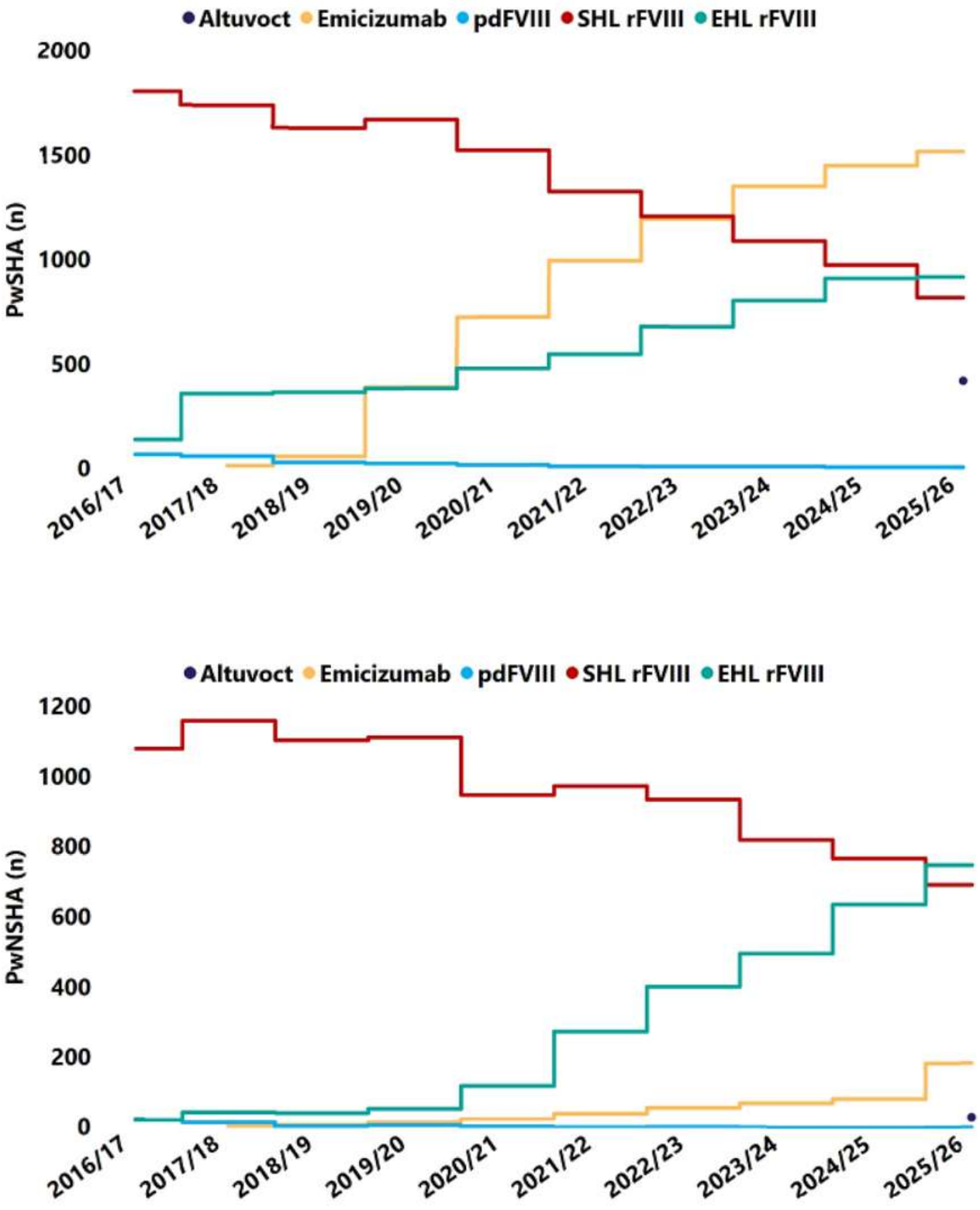


Figure 5: This shows the number of people with haemophilia A (with and without FVIII inhibitors) using different product types, by severity. This shows a gradual introduction of enhanced half-life (EHL) FVIII from 2016. It also shows an overall reduction in the number of people with severe haemophilia A treated with standard half-life (SHL) FVIII as emicizumab was introduced for people

with inhibitors in 2018 and for people with severe haemophilia A without inhibitors in 2019. As people may be issued with more than one product type in any given year, there is some double counting of people between product groups within years. Underlying data tables are available on request.

Figure 6 Number of people with severe congenital haemophilia A issued non-trial products, April 2025 – March 2026

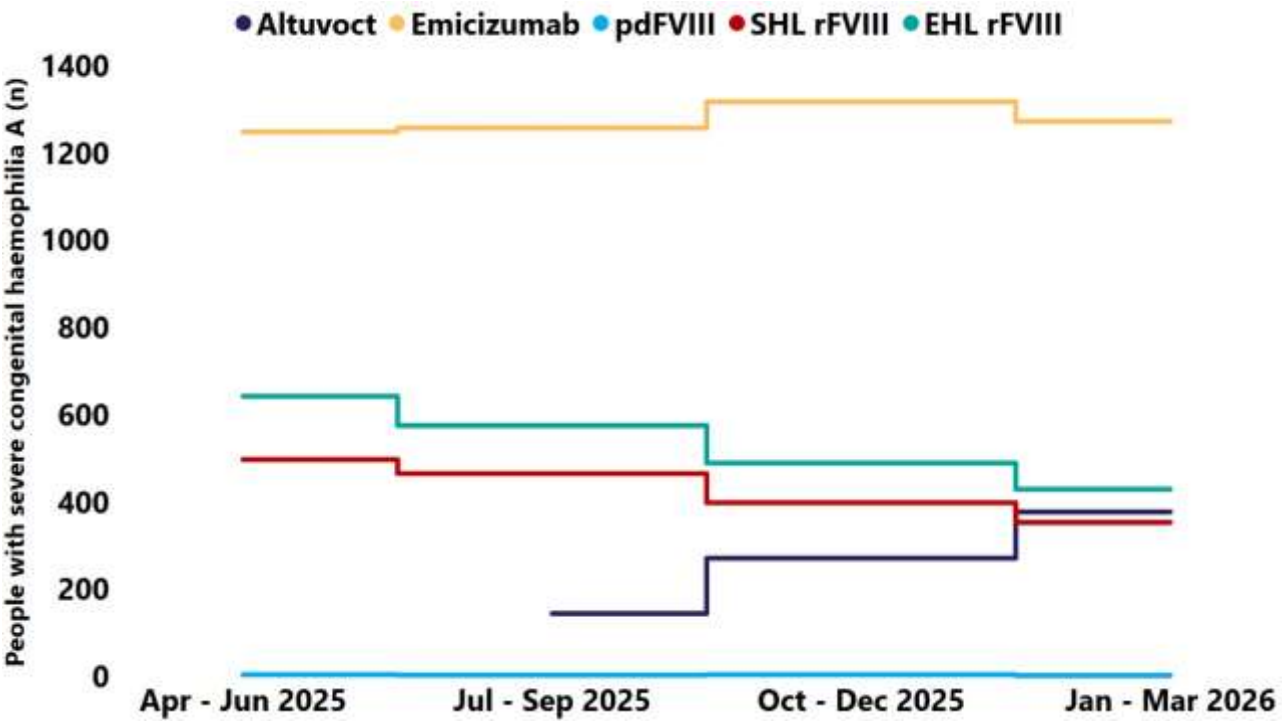


Figure 7 The proportion of people with severe congenital haemophilia A and no active inhibitor issued treatment by primary treatment, 2018/19 – 2025/26

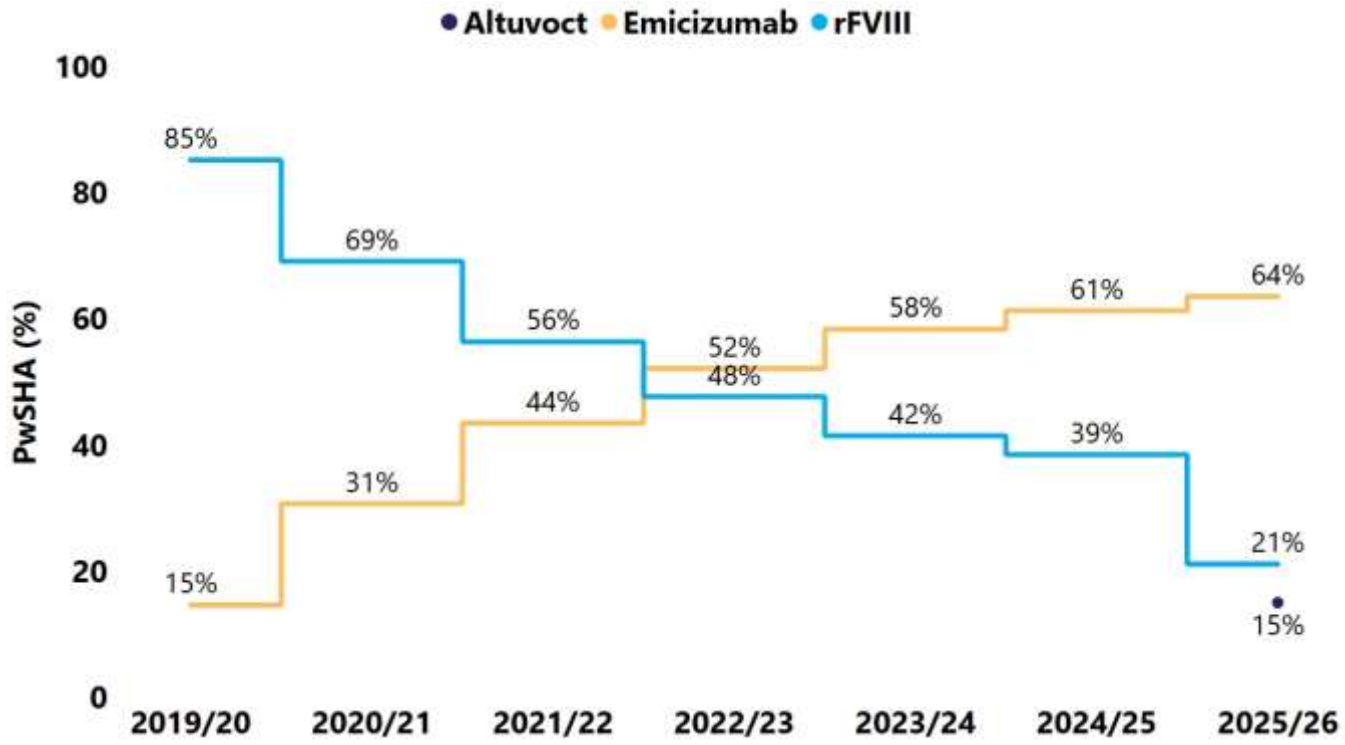


Figure 7: This shows a reduction in the proportion of people with severe haemophilia A, without inhibitors, receiving FVIII as their primary treatment since emicizumab was introduced to this group in 2019/20. People who received neither FVIII nor emicizumab are excluded.

Figure 8 The proportion of people with severe congenital haemophilia A and no active inhibitor issued treatment by primary treatment, April 2025 – March 2026

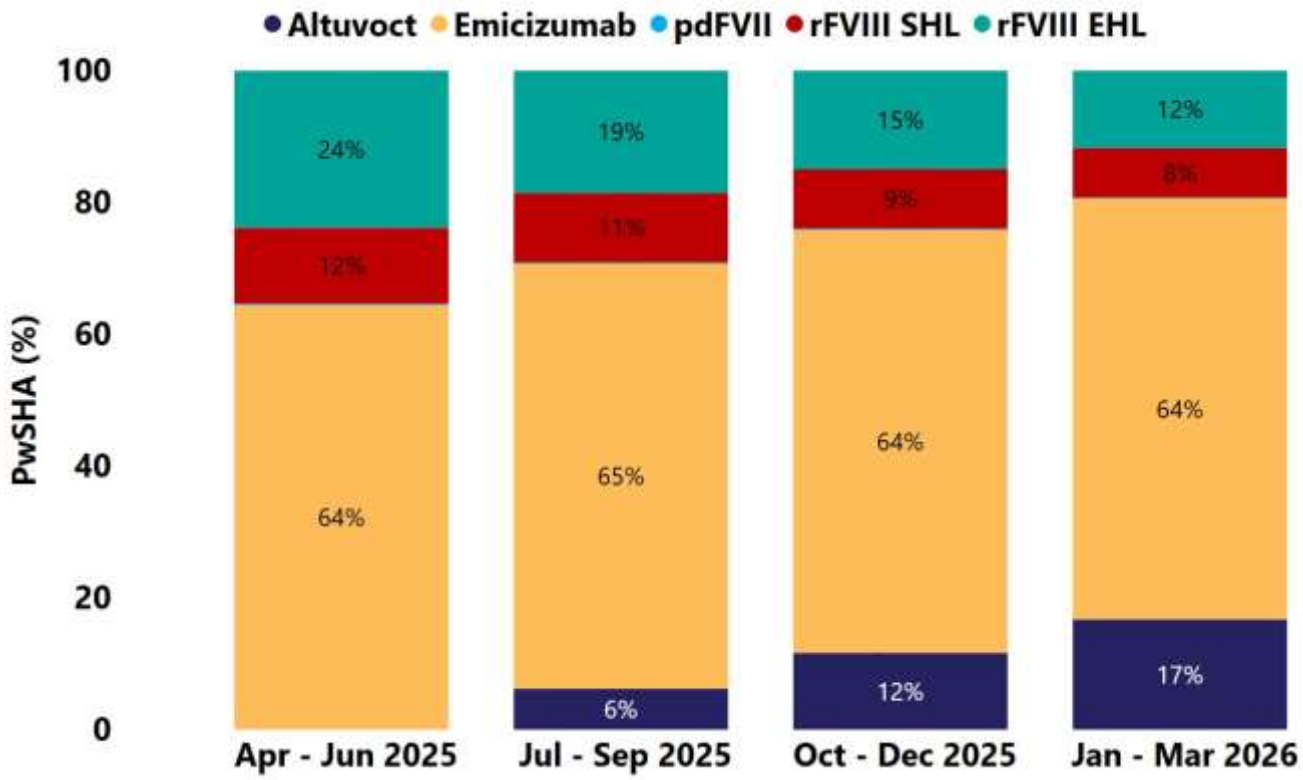


Table 6 People with congenital haemophilia A issued with FVIII and not issued emicizumab by severity, 2016/17 – 2025/26

Year	Number of people with haemophilia A by factor VIII level (IU/dl)											
	<1			1 - 5			>5 & <40			≥ 40, unknown severity or people with a liver transplant		
	Total registered n	Issued FVIII and not issued emicizumab n (%)	% change since 2016/17	Total registered n	Issued FVIII and not issued emicizumab n (%)	% change since 2016/17	Total registered n	Issued FVIII and not issued emicizumab n (%)	% change since 2016/17	Total registered n	Issued FVIII and not issued emicizumab n (%)	% change since 2016/17
2016/17	2092	1986 (94.9)	-	730	437 (59.9)	-	3941	657 (16.7)	-	1790	39 (2.2)	-
2017/18	2142	2018 (94.2)	1.6	739	443 (59.9)	1.4	4020	728 (18.1)	10.8	1904	52 (2.7)	33.3
2018/19	2189	2016 (92.1)	1.5	746	430 (57.6)	-1.6	4112	702 (17.1)	6.8	1995	46 (2.3)	17.9
2019/20	2226	1734 (77.9)	-12.7	746	445 (59.7)	1.8	4177	702 (16.8)	6.8	2092	37 (1.8)	-5.1
2020/21	2249	1410 (62.7)	-29.0	756	416 (55)	-4.8	4218	574 (13.6)	-12.6	2143	32 (1.5)	-17.9
2021/22	2286	1188 (52)	-40.2	768	445 (57.9)	1.8	4268	679 (15.9)	3.3	2224	45 (2)	15.4
2022/23	2336	1041 (44.6)	-47.6	784	449 (57.3)	2.7	4334	762 (17.6)	16.0	2292	53 (2.3)	35.9
2023/24	2378	920 (38.7)	-53.7	785	431 (54.9)	-1.4	4387	767 (17.5)	16.7	2402	52 (2.2)	33.3
2024/25	2422	846 (34.9)	-57.4	800	455 (56.9)	4.1	4479	834 (18.6)	26.9	2525	43 (1.7)	10.3
2025/26	2434	906 (37.2)	-54.4	807	386 (47.8)	-11.7	4535	811 (17.9)	23.4	2597	55 (2.1)	41.0

Table 6: This table shows the number of PwHA issued FVIII in any amount, and not issued emicizumab, during the year, broken down by severity. The number of PwSHA in this group has declined rapidly in recent years. This is attributable to switching to emicizumab. People issued emicizumab who are bleed free may be issued a contingency stock of rFVIII only when their current stock goes out of date.

Table 7a Treatment intensity of people with severe congenital haemophilia A without active inhibitors issued with standard half-life FVIII, 2016/17 – 2025/26

Year	People (n)		Treatment Intensity (Units/kilogram/person/year)		Change in treatment intensity year on year (%)	
	<18 Years	≥18 years	<18 Years	≥18 years	<18 Years	≥18 years
2016/17	456	1,013	6,092	3,436	-	-
2017/18	398	952	6,336	3,322	4.0	-3.3
2018/19	413	974	6,204	3,626	-2.1	9.2
2019/20	345	854	6,433	3,579	3.7	-1.3
2020/21	242	629	6,629	3,278	3.0	-8.4
2021/22	184	427	7,120	3,257	7.4	-0.6
2022/23	121	326	8,167	3,197	14.7	-1.8
2023/24	75	243	9,068	3,319	11.0	3.8
2024/25	49	204	9,395	3,452	3.6	4.0
2025/26	14	137	6,791	3,844	-27.7	11.4

Table 7a: This shows that the number of PwSHA without active inhibitors whose primary treatment is SHL rFVIII has reduced dramatically over the last ten years. For those who continue to use SHL rFVIII, treatment intensity was increasing to a greater extent in children compared to adults up until 2024/25, corresponding with a gradual increase in the intensity of prophylaxis and improved bleed outcomes during that period. This trend has reversed in the last year, although only 14 people aged under 18 years are issued only SHL rFVIII. The proportion of these PwSHA aged under 18 years with a past history of an inhibitor was 21% in the last year, whilst in those aged 18 years and above it was 16%. Missing weight data are imputed. A sub-analysis of PwSHA with known weight data by year yielded similar results.

NOTE - exclusions from this analysis: People issued with altuvoct, people issued with emicizumab, people issued with both EHL- and SHL-FVIII, people using gene therapy, people resident overseas, people not registered for full treatment period, people for whom inhibitors are reported within the treatment period

Table 7b Treatment intensity of people with severe congenital haemophilia A without inhibitors treated with enhanced half-life FVIII, 2017/18- 2025/26

Year	People (n)		Treatment Intensity (Units/kilogram/person/year)		Change in treatment intensity year on year (%)	
	<18 Years	≥18 years	<18 Years	≥18 years	<18 Years	≥18 years
2017/18	68	72	5,396	3,442	-	-
2018/19	112	172	5,498	3,652	1.9	6.1
2019/20	110	138	5,561	3,605	1.1	-1.3
2020/21	89	134	5,972	3,413	7.4	-5.3
2021/22	89	214	6,218	4,102	4.1	20.2
2022/23	87	248	5,776	3,823	-7.1	-6.8
2023/24	93	281	7,657	3,775	32.6	-1.3
2024/25	109	302	8,462	3,766	10.5	-0.2
2025/26	39	201	6,362	3,590	-24.8	-4.7

Table 7b: This shows a fluctuating trend in the treatment of EHL rFVIII for severe haemophilia A. In 2021/22, the increase in the number of adult PwSHA issued EHL, and the increased treatment intensity correspond with the widespread uptake of Esperoct. The proportion of people aged under 18 years with inhibitor histories has increased from 12 to 23% over this period, whilst in those aged 18 years and above it has increased from 17 to 23%. The recent decline in use of EHL rFVIII is attributable to PwSHA changing to emicizumab and then Altuvoct (both excluded from this table).

NOTE - exclusions from this analysis:

People issued with altuvoct, people issued with emicizumab, people issued with both EHL and SHL FVIII, people using gene therapy, people resident overseas, people not registered for full treatment period, people for whom inhibitors are reported within the treatment period.

Table 8a Treatment intensity of people with moderate severity congenital haemophilia A (0.01 - 0.03 IU/ml) treated with standard half-life FVIII, with no inhibitor, 2016/17 – 2025/26

Year	People (n)		Treatment Intensity (Units/kilogram/person/year)		Change in treatment intensity year on year (%)	
	<18 Years	≥18 years	<18 Years	≥18 years	<18 Years	≥18 years
2016/17	60	163	3,644	1,725	-	-
2017/18	67	149	2,769	1,429	-24.0	-17.2
2018/19	53	152	3,122	1,653	12.7	15.7
2019/20	52	151	3,736	1,736	19.7	5.0
2020/21	40	134	3,372	1,640	-9.7	-5.5
2021/22	33	114	2,959	1,591	-12.2	-3.0
2022/23	30	103	2,528	1,741	-14.6	9.4
2023/24	29	76	2,011	1,731	-20.5	-0.6
2024/25	27	67	2,389	1,578	18.8	-8.8
2025/26	16	50	4,534	1,726	89.8	9.4

Table 8a: This table shows the trend in treatment intensity in people with haemophilia A and factor level between 0.01 - 0.03 IU/ml issued SHL over the last ten years. Only people treated during this time are included. However, the range of baseline FVIII levels and bleeding phenotypes included in this data ranges from those on regular prophylaxis to those requiring only occasional treatment. This renders the data more difficult to interpret and impossible to compare directly with the relatively more homogeneous group of people with severe haemophilia A. Emicizumab was not commissioned for moderate severity haemophilia A at that time. This shows that treatment intensity fluctuates over time in both age groups. However, these changes may reflect PwHA selection more than anything else. “Heavy users” with a relatively high annualised bleed rate are more likely to be chosen to switch to an alternative EHL rFVIII treatment. The number of both adults and children issued product has reduced over recent years, as people have been switched to EHL rFVIII. The proportion of people aged under 18 years with inhibitor histories has decreased from 10 to 0% over this period, whilst in those aged 18 years and above, the proportion was the same over the last year as it was ten years ago (6%)..

NOTE - exclusions from this analysis: People issued with altuvoct, people issued with emicizumab, people issued with both EHL and SHL FVIII, people using gene therapy, people resident overseas, people not registered for full treatment period, people for whom inhibitors are reported within the treatment period

Table 8b Treatment intensity of people with moderate congenital haemophilia A (0.01 - 0.03 IU/ml) treated with enhanced half-life FVIII, with no inhibitor, 2017/18 - 2025/26

Year	People (n)		Treatment Intensity (Units/kilogram/person/year)		Change in treatment intensity year on year (%)	
	<18 Years	≥18 years	<18 Years	≥18 years	<18 Years	≥18 years
2017/18	4	8	3,110	3,147	-	-
2018/19	8	18	3,803	3,331	22.3	5.8
2019/20	8	21	4,469	2,576	17.5	-22.7
2020/21	6	19	2,808	3,341	-37.2	29.7
2021/22	15	38	2,681	3,121	-4.5	-6.6
2022/23	23	57	3,072	2,900	14.6	-7.1
2023/24	25	72	5,883	2,843	91.5	-2.0
2024/25	27	91	4,730	2,569	-19.6	-9.6
2025/26	16	78	2,935	2,197	-37.9	-14.5

Table 8b: This illustrates the introduction of EHL FVIII to a relatively small group of people with haemophilia A and a factor level between 0.01 - 0.03 IU/ml between April 2017 and March 2026. The proportion of people with inhibitor histories has increased from 0 to 6% in people aged under 18 years, and from 0 to 1% in those aged 18 years and above.

NOTE - exclusions from this analysis:

People issued with altuvoct, people issued with emicizumab, people issued with both EHL and SHL FVIII, people using gene therapy, people resident overseas, people not registered for full treatment period, people for whom inhibitors are reported within the treatment period,

Table 9 Non-trial products issued to treat people with congenital haemophilia A (all severities and including inhibitors), 2024/25 and 2025/26

Product Type	Manufacturer	Product	2024/25		2025/26	
			Units (IU)	People (n)	Units (IU)	People (n)
Non-factor	Roche	Emicizumab (mg)	6,438,392	1,533	7,195,865	1,702
Recombinant	LFB	Cevenfacta	369	3	1,460	8
	Novo Nordisk	Refixia	-	-	2,000	1
		NovoSeven (mg)	10,335	119	9,597	94
		Esperoct	108,403,060	797	93,903,000	750
		NovoEight	12,122,300	139	468,000	9
	Octapharma	Nuwiq	6,787,000	101	4,276,000	80
	Pfizer	ReFacto AF	43,251,500	503	35,487,264	422
	SOBI	Altuvoct	-	-	34,818,702	456
		Elocta	98,177,350	783	85,967,908	943
	Takeda	Advate	76,156,890	1,065	66,186,876	1,018
		Obizur	98,000	1	193,500	5
		Adynovi	6,172,000	22	-	-
Plasma-derived	BPL	BPL FVIII 8Y	373,890	1	131,765	1
	CSL Behring	Riastap	2	1	-	-
		Voncento	202,500	3	255,000	1
	Grifols	Haemoctin	368,000	1	364,000	1
	Octapharma	Fibryga	-	-	4	1
		Octanate	2,012,000	5	1,832,000	6
		Octaplex	-	-	5,000	1
	Takeda	FEIBA	2,431,000	19	768,000	11
	National blood transfusion	Platelets	-	-	2	1

Units in IU unless otherwise stated
Products which include VWF and FVIII are reported in FVIII units
Excludes issues of investigational products

Table 9: This shows a breakdown of product volumes, listed by supplier, issued to treat people with congenital haemophilia A during 2024/25 and 2025/26, including those with inhibitors. People may be issued multiple products. The data reflects the reduction in FVIII issues in recent years, as emicizumab was introduced to treat people with severe haemophilia A with and without inhibitors. The declining issues of some products, including Novoeight, Octanate and Adynovi, relates to their

reduced availability rather than a lack of confidence in the product. Reduced usage of EHL products as a group, is also attributable to people with severe haemophilia switching to Altuvoct.

These figures have been cross-checked against manufacturers' sales figures, where available. Whilst one would not expect a perfect match, there is generally a high level of correlation. These sales figures are not reported, by agreement with suppliers, for reasons of commercial sensitivity.

By and large, the plasma-derived products listed were used for immune tolerance induction. ITI is also being used less frequently when inhibitors arise or relapse. In general, there is a very steep decline in the use of plasma-derived factor VIII for prophylaxis, which has largely fallen out of use altogether.

Investigational products are not reported due to confidentiality agreements and commercial sensitivities. Their use has declined steeply in recent years as clinical trials have come to an end.

Centres were approached to confirm apparently anomalous issues of Refixia, Riastap, Voncento, Fibyga and Octaplex. Some of these relate to products issued in error.

Figure 9 Number of people with congenital haemophilia A (all severities) issued treatment in the UK 2025/26 by non-trial product

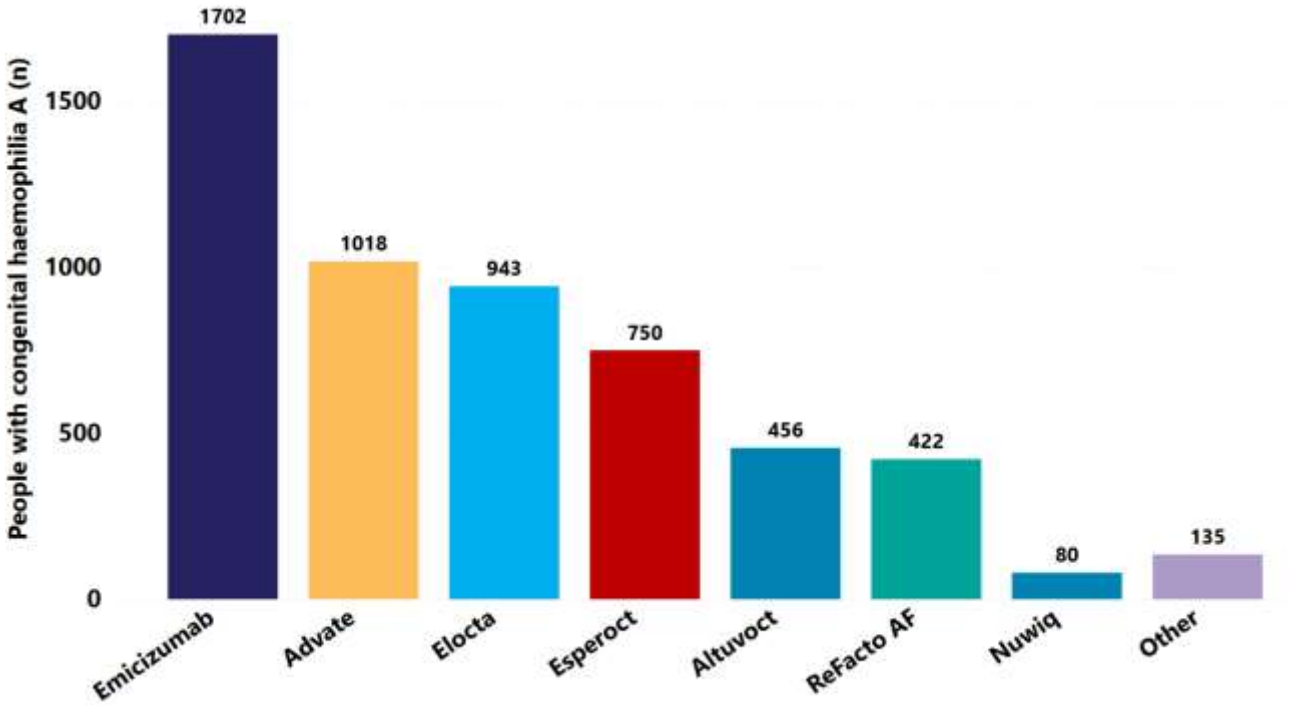


Figure 9: This shows the number of people with haemophilia A issued each product during the year, including those issued to people with an inhibitor. The data that informs this graph can be found in Table 9. People issued multiple products in the year are included in the numbers for each product, so there is some double counting. There were 3,768 individual people with haemophilia A issued these products during the year. Adynovi and Octanate have been withdrawn from the UK market.

Table 10 Non-trial Factor VIII and emicizumab treatment issued by UK haemophilia centres by diagnosis, 2025/26

Bleeding disorder	Factor VIII (IU)						Emicizumab		Total
	People (n)	Plasma-derived	Standard half-life recombinant	Enhanced half-life recombinant	Altuvoct	Total	People (n)	mg	People (n)
Haemophilia A	3,116	2,586,765	106,611,640	179,870,908	34,818,702	323,888,015	1,702	7,195,865	3,747
von Willebrand disease	587	27,720,267	472,900	1,303,000	-	29,496,167	2	2,160	588
Acquired haemophilia A	60	7,200	4,349,000	2,000	-	4,358,200	4	9,105	62
Acquired von Willebrand disease	42	781,050	28,000	4,000	-	813,050	1	3,600	43
Combined factors V and VIII deficiencies	5	-	14,500	29,000	-	43,500	-	-	5
Miscellaneous	2	39,000	-	-	-	39,000	-	-	2
Haemophilia B	1	-	2,000	-	-	2,000	-	-	1
Factor V deficiency	1	-	1,500	-	-	1,500	-	-	1
Heritable platelet disorder	1	3,000	-	-	-	3,000	-	-	1
Total	**3,815**	**31,137,282**	**111,479,540**	**181,208,908**	**34,818,702**	**358,644,432**	**1,709**	**7,210,730**	**4,450**

Excludes issues of investigational products

Table 10: This table shows FVIII and emicizumab issues by diagnosis, including any apparently anomalous reported use. Products used to treat VWD which include VWF and FVIII are reported in FVIII units. Issues of these products to treat VWD is provided in Table 21. Please note people issued with both FVIII and emicizumab are counted only once in the final column. Issues of emicizumab for acquired haemophilia A are presumed to be related to individual funding requests, as these indications are unlicensed and not yet subject to NHSE policy. Centres were contacted to query apparently anomalous issues of FVIII to PwHB, factor V deficiency and heritable platelet disorder. All were confirmed. FVIII was issued to one PwHB in error.

Figure 10 The number and proportion of people with severe congenital haemophilia A and no active inhibitor issued emicizumab by comprehensive care centre, 2025/26

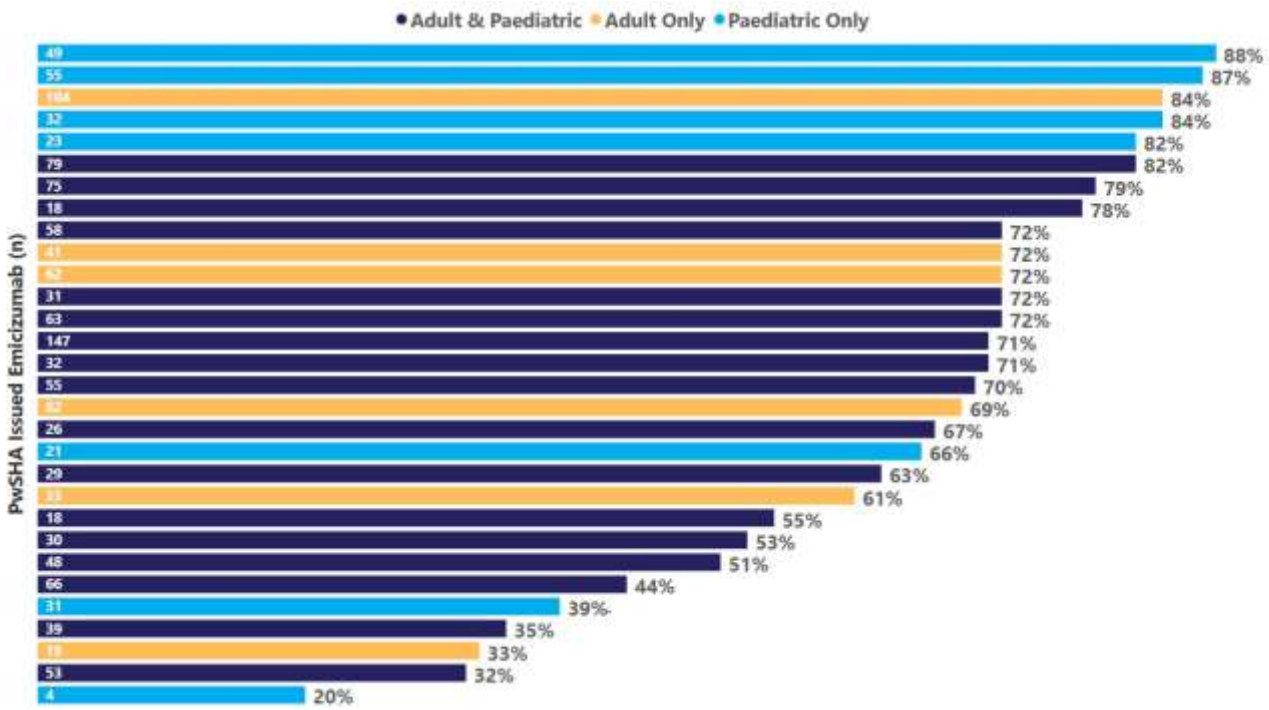


Figure 10: This shows the ranked proportion of people with severe congenital haemophilia A without an inhibitor who were issued emicizumab, by comprehensive care centre, in 2025/26. This shows considerable centre-to-centre variation (median 71%, IQR 53-78%), which reflects diversity of clinical opinion. As emicizumab is issued via CCCs, HCs are not included.

Figure 11 The number and proportion of people with severe congenital haemophilia A and no active inhibitor issued altuvoct as primary treatment by comprehensive care centre, 2025/26

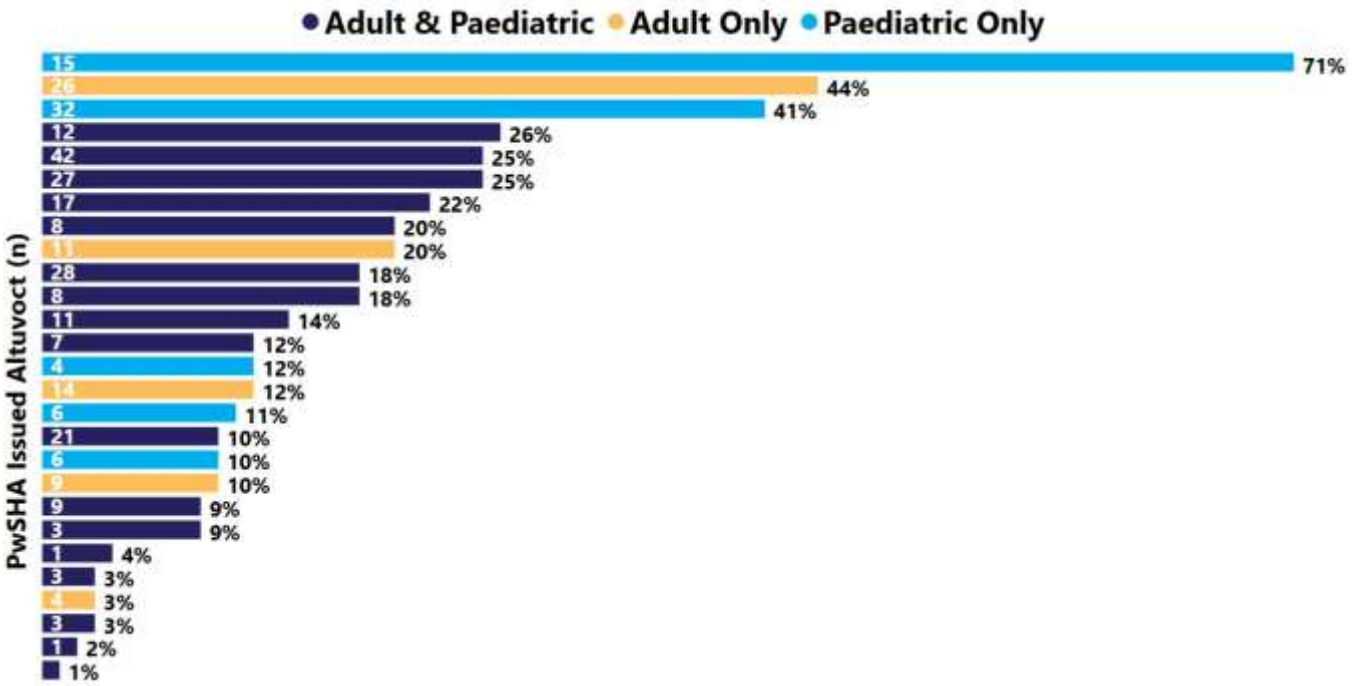
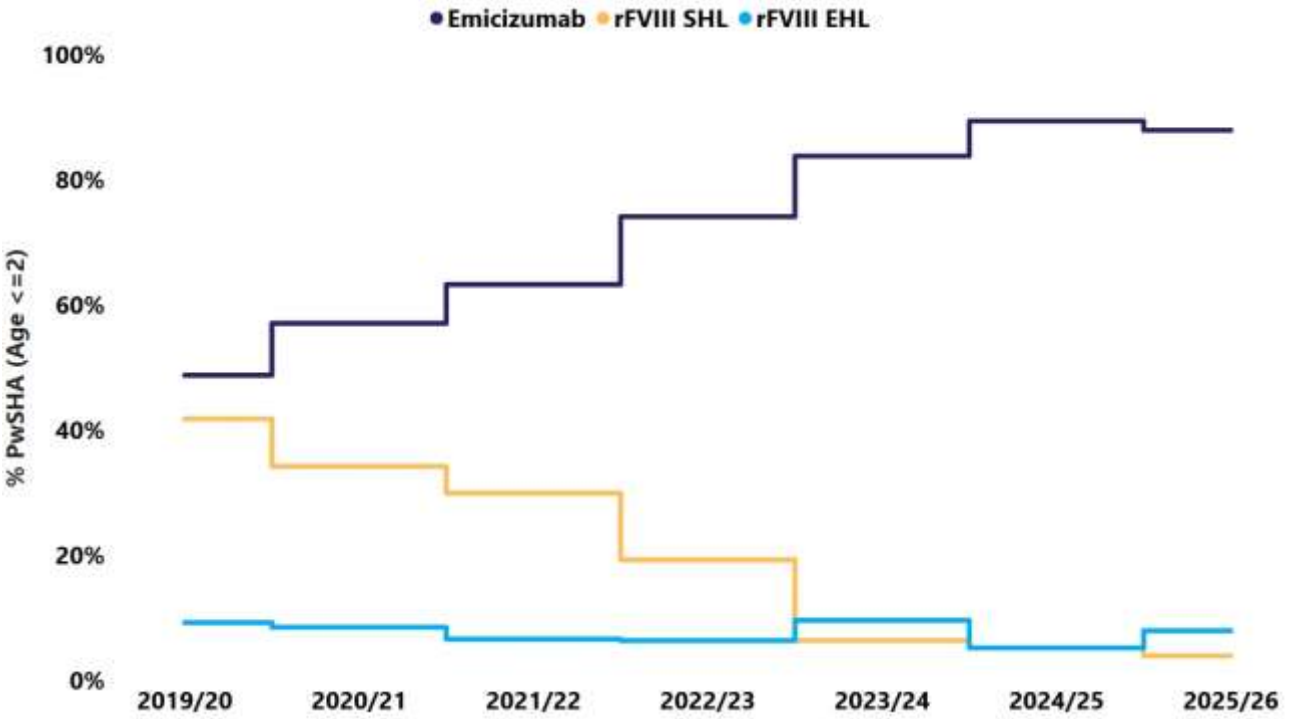


Figure 11: This shows the ranked proportion of people with severe congenital haemophilia A without an inhibitor who were issued altuvoct as primary treatment, by comprehensive care centre, in 2025/26 (median 12%, IQR 9-22%). This shows very marked centre to centre variation. Most of the people switched to Altuvoct were previously treated with SHL rFVIII and EHL rFVIII, so the variation in uptake of Altuvoct is largely a reflection of the centre's historic use of those products.

Figure 12 The proportion of previously untreated people (age at registration <= 2 years) with severe congenital haemophilia A by primary treatment 2019/20 – 2025/26



Treatment group	Previously untreated people with congenital severe haemophilia A aged <= 2 years n (%)						
	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
SHL rFVIII	18 (41.9%)	12 (34.3%)	9 (30.0%)	6 (19.4%)	2 (6.5%)	2 (5.3%)	1 (4.0%)
EHL rFVIII	4 (9.3%)	3 (8.6%)	2 (6.7%)	2 (6.5%)	3 (9.7%)	2 (5.3%)	2 (8.0%)
Emicizumab	21 (48.8%)	20 (57.1%)	19 (63.3%)	23 (74.2%)	26 (83.9%)	34 (89.5%)	22 (88.0%)

Figure 12: This shows a marked treatment trend since 2019/20, with fewer previously untreated PwSHA aged under two years starting on SHL rFVIII, and the vast majority now receiving emicizumab as their first treatment. Some centres start all PUPwSHA on emicizumab, although the trend appears to have levelled off in the last two years. It is suspected that although the reduction in issues of rFVIII will continue, a proportion of PUPwSHA will start on Altuvoct. This may become apparent in the next year, now this product has been commissioned for SHA.

Table 11 Haemophilia joint health scores for people with congenital haemophilia A (FVIII <=5 IU/dl) without inhibitors 2015/16 - 2025/26

FVIII level	Age (years)	Year	Registered, n	HJHS submitted, n (% of registered)	HJHS evaluable, n (% of submitted)	HJHS = 0, n (% of submitted)	Median (iqr) evaluable HJHS
<1 IU/dl	4-9	2015/16	209	84 (40.2)	83 (98.8)	60 (71.4)	0.0 (0.0 -1.0)
		2020/21	232	74 (31.9)	73 (98.6)	48 (64.9)	0.0 (0.0 -1.3)
		2025/26	219	66 (30.1)	64 (97.0)	46 (69.7)	0.0 (0.0 -0.9)
	10-17	2015/16	273	116 (42.5)	109 (94.0)	61 (52.6)	0.0 (0.0 -3.0)
		2020/21	294	108 (36.7)	105 (97.2)	59 (54.6)	0.0 (0.0 -2.0)
		2025/26	303	85 (28.1)	84 (98.8)	39 (45.9)	0.5 (0.0 -2.4)
	18-49	2015/16	1,009	315 (31.2)	278 (88.3)	30 (9.5)	11.0 (4.0 -26.0)
		2020/21	1,098	248 (22.6)	231 (93.1)	32 (12.9)	13.0 (4.0 -26.0)
		2025/26	1,244	308 (24.8)	287 (93.2)	49 (15.9)	9.5 (2.0 -23.0)
	50-64	2015/16	180	48 (26.7)	34 (70.8)	0 (0.0)	39.5 (27.9 -55.3)
		2020/21	235	65 (27.7)	61 (93.8)	0 (0.0)	39.0 (30.3 -48.5)
		2025/26	261	61 (23.4)	52 (85.2)	0 (0.0)	37.0 (26.0 -42.8)
	65 and above	2015/16	60	13 (21.7)	10 (76.9)	0 (0.0)	46.8 (33.8 -62.3)
		2020/21	82	8 (9.8)	4 (50.0)	0 (0.0)	50.5 (19.0 -78.3)
		2025/26	107	20 (18.7)	14 (70.0)	0 (0.0)	38.5 (24.0 -53.0)
1-5 IU/dl	4-9	2015/16	71	23 (32.4)	22 (95.7)	12 (52.2)	0.0 (0.0 -2.1)
		2020/21	60	9 (15.0)	9 (100.0)	5 (55.6)	0.0 (0.0 -1.5)
		2025/26	64	11 (17.2)	11 (100.0)	5 (45.5)	1.0 (0.0 -3.0)
	10-17	2015/16	77	23 (29.9)	23 (100.0)	13 (56.5)	0.0 (0.0 -5.0)
		2020/21	89	14 (15.7)	13 (92.9)	5 (35.7)	1.0 (0.0 -5.8)
		2025/26	84	18 (21.4)	18 (100.0)	9 (50.0)	0.5 (0.0 -2.4)
	18-49	2015/16	332	53 (16.0)	48 (90.6)	20 (37.7)	2.0 (0.0 -14.8)
		2020/21	341	25 (7.3)	25 (100.0)	4 (16.0)	7.0 (1.0 -20.8)
		2025/26	373	42 (11.3)	42 (100.0)	12 (28.6)	3.5 (0.0 -12.3)
	50-64	2015/16	128	15 (11.7)	10 (66.7)	1 (6.7)	8.0 (2.0 -16.8)
		2020/21	133	5 (3.8)	5 (100.0)	0 (0.0)	31.0 (3.5 -39.5)
		2025/26	140	16 (11.4)	15 (93.8)	2 (12.5)	18.0 (8.0 -37.0)
	65 and above	2015/16	65	10 (15.4)	9 (90.0)	1 (10.0)	26.0 (6.5 -42.5)
		2020/21	70	1 (1.4)	1 (100.0)	0 (0.0)	41.0 (41.0 -41.0)
		2025/26	82	7 (8.5)	5 (71.4)	0 (0.0)	25.0 (14.5 -43.5)

Table 11 (previous page) and Figure 14 (overleaf): These show HJHS for PwHA without inhibitors over the last ten years. It is hoped that the low submission of HJHS data for PwSHA and PwMHA can be improved. However, submission rates appear to be in decline **(Figure 13)**. Whilst reporting lag may be a factor, this is thought to reflect the limited resources available to transcribe local electronic medical records into HCIS. **Figure 14** shows that reported HJHS scores for children have been stable and close to zero for the 10-year period shown. It would appear that joint scores for PwSHA aged 65 years and above have improved over the last decade. This may be a response to increasing factor VIII treatment intensity, as it antedates the introduction of emicizumab. It is notable that HJHS in PwMHA aged 50 to 64 years have increased dramatically (although not to the levels observed in PwSHA in this age group). This may reflect this group's poorer access to prophylaxis when younger. However, their low HJHS submission rate suggests that these results should be interpreted with caution.

Figure 13 HJHS submission for people with congenital haemophilia A (FVIII <=5 IU/dl) without inhibitors 2015/16 – 2025/26



Figure 14 Median evaluable HJHS of people with congenital haemophilia A (FVIII <=5 IU/dl) without inhibitors 2015/16 – 2025/26

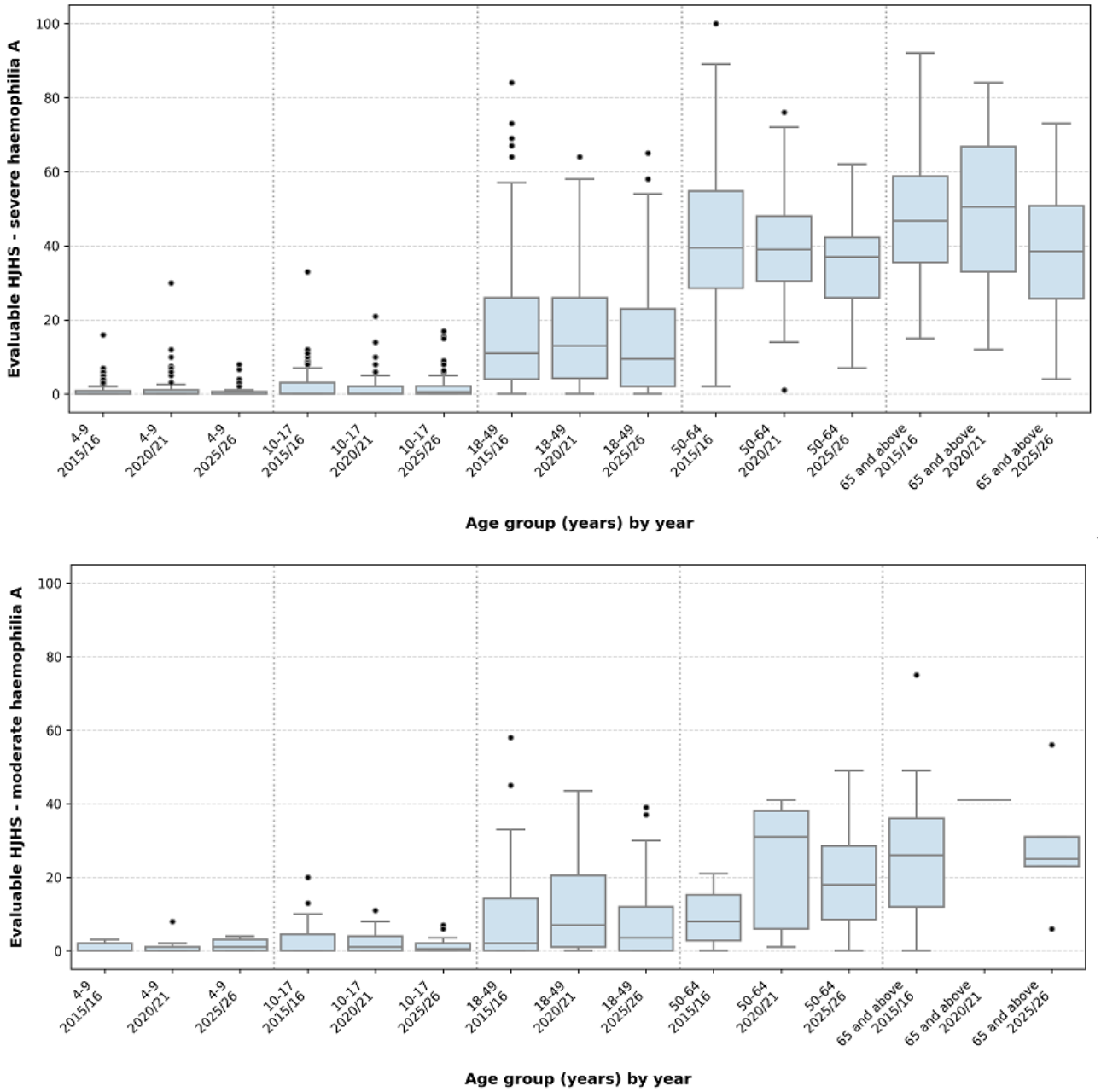


Table 12 Longitudinal within-person haemophilia joint health scores for people with congenital haemophilia A (FVIII <=5 IU/dl) without inhibitors 2015/16 - 2025/26

FVIII level (IU/dl)	Age (years) 2015/16	Registered 2015/16 (n)	HJHS evaluable 2015/16 (n)	HJHS evaluable 2015/16 and 2025/26	Median (iqr) evaluable HJHS		
					2015/16	2020/21	2025/26
<1	4-9	209	83	33	0 (0-2)	1.3 (0-3.8)	1 (0-4)
	10-17	273	109	31	0 (0-2)	1 (0-5.3)	3 (0-7)
	18-49	1009	278	79	12 (4-27)	16 (9.5-33)	17 (8-31)
	50 and above	240	44	6	34.5 (23.6-46.3)	61 (50-72)	41.3 (33-49.5)
1-5	4-9	71	22	3	0 (0-1)	1 (1-1)	0 (0-1)
	10-17	77	23	7	0 (0-5)	2 (1-11.3)	0 (0-2)
	18-49	332	48	11	11 (0-15)	2 (2-2)	10 (6-12)
	50 and above	193	19	0	-	-	-

Table 12: This shows longitudinal within-person HJHS for PwHA with HJHS assessed in 2015/16 and 2025/26. It can be observed that joint health in children with SHA as of 2015/16 is generally maintained over the subsequent decade. The joint health of younger adults with SHA in 2015/16 appears to deteriorate, and that of older adults fluctuates over the same period. However, longitudinal HJHS data is available only for a minority of PwHA, and variability in 2020/21 scores may reflect fewer 'in-person' appointments (and therefore assessments) due to the COVID pandemic, particularly in those with fewer joint problems. Arthropathy, once established, is likely to deteriorate progressively, even in the absence of ongoing bleeding.

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2.2 Congenital Haemophilia B

Table 13 People with congenital haemophilia B and carriers, registered and treated, 2025/26

Congenital haemophilia B	Age (years)	Number of people by factor IX level at birth (IU/dl)																	
		< 1			1 - 5			>5 & <40			≥ 40			People with unknown severity or liver transplant			Total*		
		Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
Total Registered	<18	136	1	137	79	0	79	112	100	212	8	55	63	3	2	5	338	158	496
	>=18	271	0	271	271	6	277	491	290	781	56	426	482	9	7	16	1,098	729	1,827
	Total	**407**	**1**	**408**	**350**	**6**	**356**	**603**	**390**	**993**	**64**	**481**	**545**	**12**	**9**	**21**	**1,436**	**887**	**2,323**
New Registrations **	<18	11	0	11	2	0	2	10	13	23	0	6	6	0	1	1	23	20	43
	>=18	3	0	3	7	0	7	5	17	22	5	36	41	1	1	2	21	54	75
	Total	**14**	**0**	**14**	**9**	**0**	**9**	**15**	**30**	**45**	**5**	**42**	**47**	**1**	**2**	**3**	**44**	**74**	**118**
Issued concentrate FIX in year***	<18	129	0	129	42	0	42	45	3	48	3	0	3	0	0	**0**	219	3	222
	>=18	241	0	241	148	1	149	130	36	166	7	12	19	1	0	**1**	527	49	576
	Total	**370**	**0**	**370**	**190**	**1**	**191**	**175**	**39**	**214**	**10**	**12**	**22**	**1**	**0**	**1**	**746**	**52**	**798**

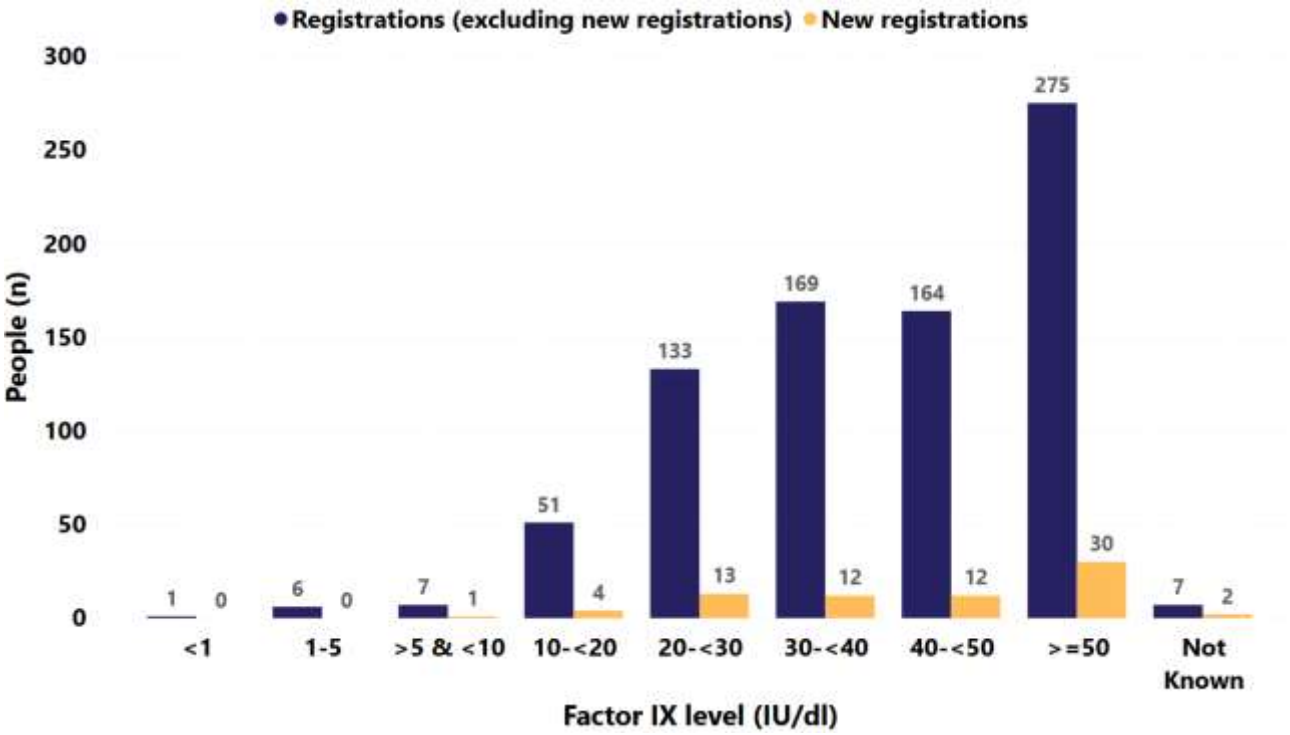
Sex as registered at birth

***New registrations are a subset of the 'In Register' numbers*

****Excluding people only treated with DDAVP and tranexamic acid*

Table 13: This shows the number of people with haemophilia B (including FIX Leyden, carriers and females with factor IX deficiency), broken down by severity, sex at birth and age. The number of new registrations is also shown, as are the numbers issued FIX concentrate.

Figure 15 Females with congenital FIX deficiency and carriers of haemophilia B currently registered and newly registered, by baseline FIX level, 2025/26



N.B: Includes carriers of haemophilia B and females with FIX deficiency

Diagnosis	Number of people by factor IX level at birth (IU/dl)									
	<1	1-5	>5 & <10	10-<20	20-<30	30-<40	40-<50	≥50	Not Known	Total
Ongoing registrations (excluding new registrations)	1	6	7	51	133	169	164	275	7	813
New registrations	0	0	1	4	13	12	12	30	2	74
Total	**1**	**6**	**8**	**55**	**146**	**181**	**176**	**305**	**9**	**887**

Figure 15: This shows the distribution of reported FIX levels amongst registered carriers of haemophilia B in the UK. All carriers should be registered.

It is interesting that there is a relatively large number of very low-level carriers. These mostly have an extreme degree of lyonisation, although some are homozygous daughters from consanguineous unions.

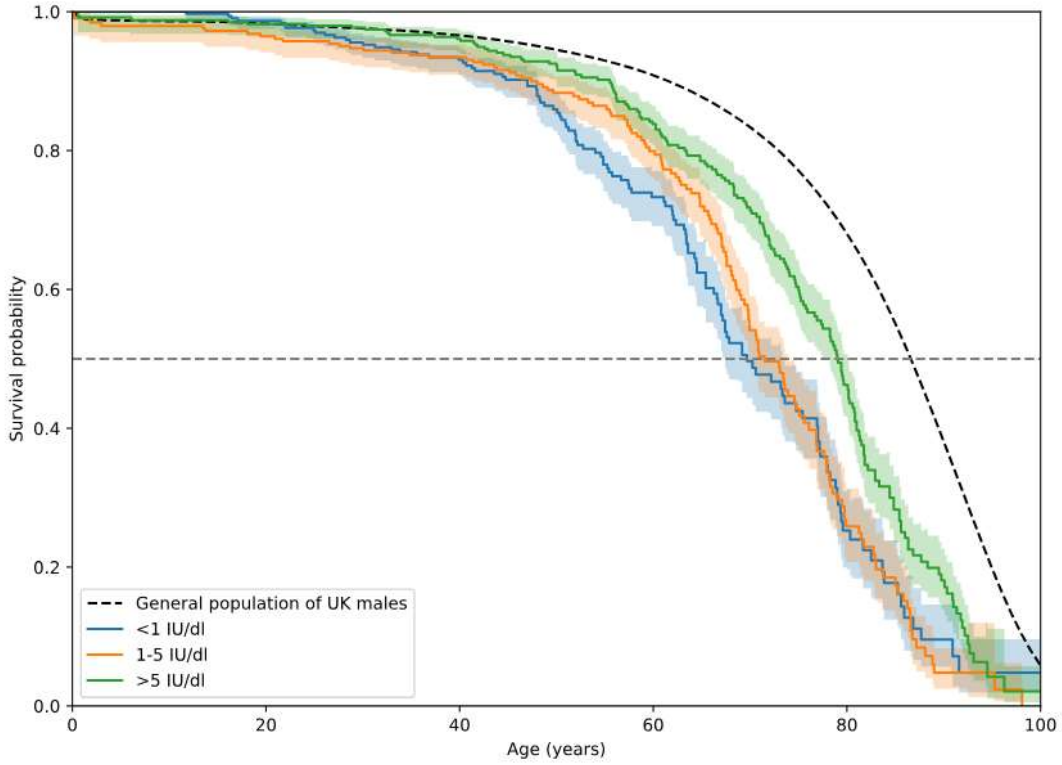
Table 14 New registrations of people with congenital haemophilia B and carriers, 2025/26

Age at registration (years)	Number of people by factor IX level (IU/dl)																	
	< 1			1 - 5			> 5 & < 40			≥ 40			People with unknown severity			Total		
	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
0 - 1	8	0	8	0	0	0	3	3	6	0	0	0	0	0	0	11	3	14
2 - 19	3	0	3	3	0	3	8	11	19	0	9	9	0	1	1	14	21	35
20 and above	3	0	3	6	0	6	4	16	20	5	33	38	1	1	2	19	50	69
Total	**14**	**0**	**14**	**9**	**0**	**9**	**15**	**30**	**45**	**5**	**42**	**47**	**1**	**2**	**3**	**44**	**74**	**118**

**Sex as registered at birth*

Table 14: This shows new registrations of haemophilia B broken down by reported severity and age at registration. Less severe disease will often present at a later age and the proportion of that group not native to the UK has not been investigated. It is presumed that most of those with severe haemophilia registered at aged two years or above have migrated or are visitors to the UK.

Figure 16 Survival of males with congenital haemophilia B by factor IX level at birth (IU/dl), actively registered 1969-2026, compared to the general population of males in the UK



Median (iqr) survival time (years) for people with haemophilia B: <1 IU/dl: 69 (57-79) , 1-5 IU/dl: 71 (62-81), >5 IU/dl: 79 (68-85)

Figure 16: This shows survival of people with congenital haemophilia B broken down by severity from 1969 to 2026 with 95% confidence intervals. . Survival will have improved since 1969, but the number of PwHB is too low to break the figure down into shorter periods of follow-up.

Figure 17 People with severe congenital haemophilia B by primary treatment, 2016/17 – 2025/26

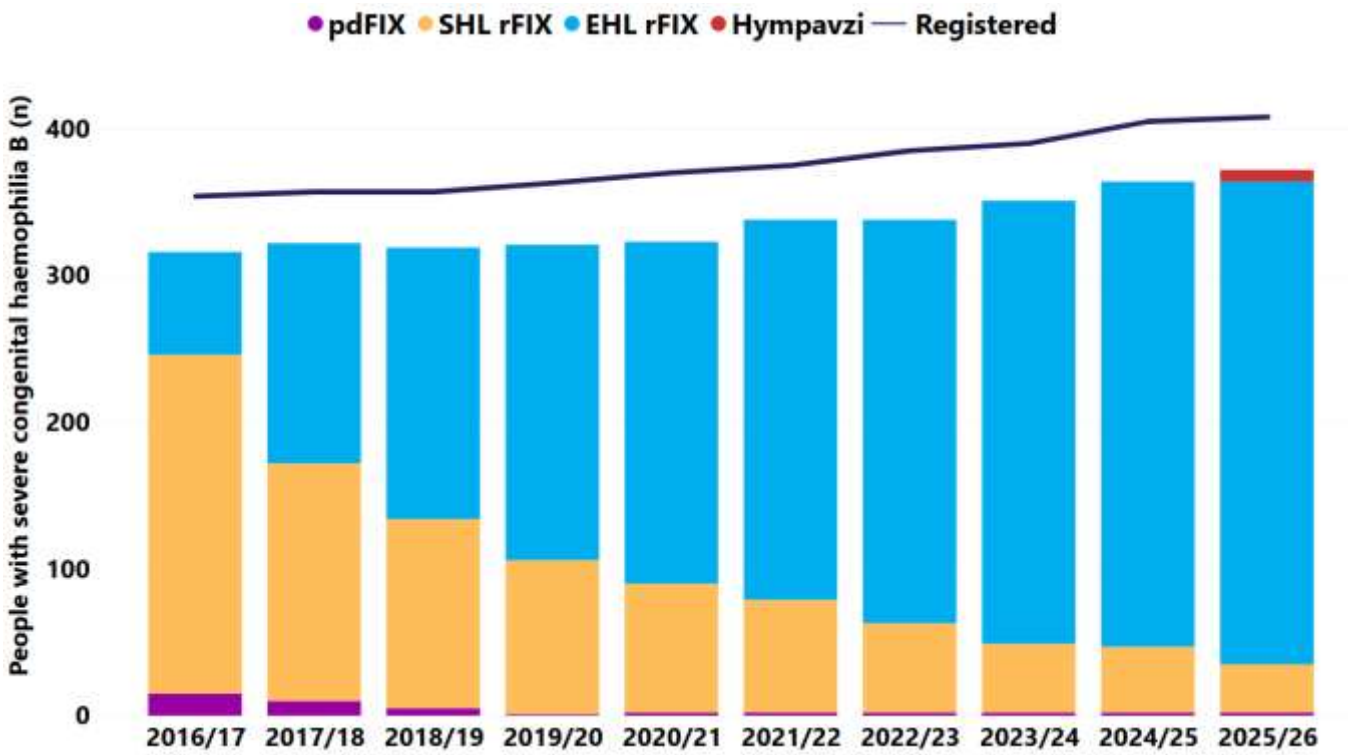


Figure 17: This shows the number of registered PwSHB issued FIX by primary treatment type from 2016/17 to 2025/26. The number of people reported to have been issued FIX shows a gradual increase. This shows that people continue to switch from standard half-life to extended half-life products, and plasma-derived factor IX concentrate is now used by relatively few people with severe haemophilia B. Gene therapy is also reducing the numbers requiring FIX to some degree but is not a marked trend.

Figure 18 People with moderate severity congenital haemophilia B by primary treatment, 2016/17 – 2025/26

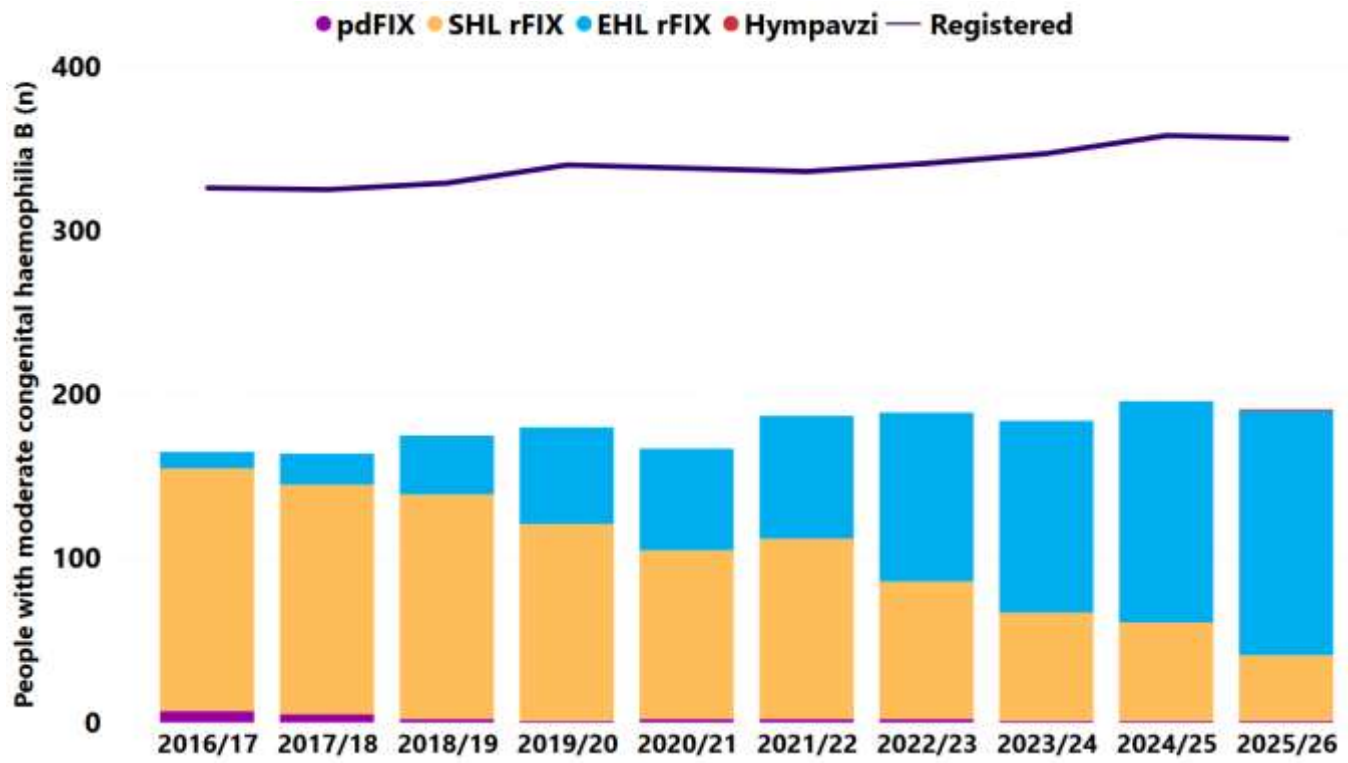


Figure 18: This shows the number of registered people with moderate haemophilia B issued FIX by primary treatment type from 2016/17 to 2025/26. The declining proportion of people issued SHL rFIX, and increasing proportion of people issued EHL rFIX can be observed.

Data table for Figure 17: *People with severe congenital haemophilia B by primary treatment, 2016/17 – 2025/26*

Year	PwSHB issued pdFIX		PwSHB issued SHL rFIX		PwSHB issued EHL rFIX		PwSHB issued Hympavzi		PwSHB issued any FIX or Hympavzi		PwSHB registered
	n	% difference since 2016/17	n	% difference since 2016/17	n	% difference since 2016/17	n	% difference since 2025/26	n	% difference since 2016/17	n
2016/17	15	-	231	-	70	-	-	-	316	-	354
2017/18	10	-33.3	162	-29.9	150	114.3	-	-	322	1.9	357
2018/19	5	-66.7	129	-44.2	185	164.3	-	-	319	0.9	357
2019/20	1	-93.3	105	-54.5	215	207.1	-	-	321	1.6	363
2020/21	2	-86.7	88	-61.9	233	232.9	-	-	323	2.2	370
2021/22	2	-86.7	77	-66.7	259	270	-	-	338	7	375
2022/23	2	-86.7	61	-73.6	275	292.9	-	-	338	7	385
2023/24	2	-86.7	47	-79.7	302	331.4	-	-	351	11.1	390
2024/25	2	-86.7	45	-80.5	317	352.9	-	-	364	15.2	405
2025/26	2	-86.7	33	-85.7	329	370	8	-	372	17.7	408

Data table for Figure 18: *People with moderate congenital haemophilia B by primary treatment, 2016/17 – 2025/26*

Year	PwSHB issued pdFIX		PwSHB issued SHL rFIX		PwSHB issued EHL rFIX		PwSHB issued Hympavzi		PwSHB issued any FIX or Hympavzi		PwSHB registered
	n	% difference since 2016/17	n	% difference since 2016/17	n	% difference since 2016/17	n	% difference since 2025/26	n	% difference since 2016/17	n
2016/17	7	-	148	-	10	-	-	-	165	-	326
2017/18	5	-28.6	140	-5.4	19	90	-	-	164	-0.6	325
2018/19	2	-71.4	137	-7.4	36	260	-	-	175	6.1	329
2019/20	1	-85.7	120	-18.9	59	490	-	-	180	9.1	340
2020/21	2	-71.4	103	-30.4	62	520	-	-	167	1.2	338
2021/22	2	-71.4	110	-25.7	75	650	-	-	187	13.3	336
2022/23	2	-71.4	84	-43.2	103	930	-	-	189	14.5	341
2023/24	1	-85.7	66	-55.4	117	1070	-	-	184	11.5	347
2024/25	1	-85.7	60	-59.5	135	1250	-	-	196	18.8	358
2025/26	1	-85.7	40	-73	149	1390	1	-	191	15.8	356

Figure 19 Number of people with congenital haemophilia B issued product by severity, 2016/17 – 2025/26

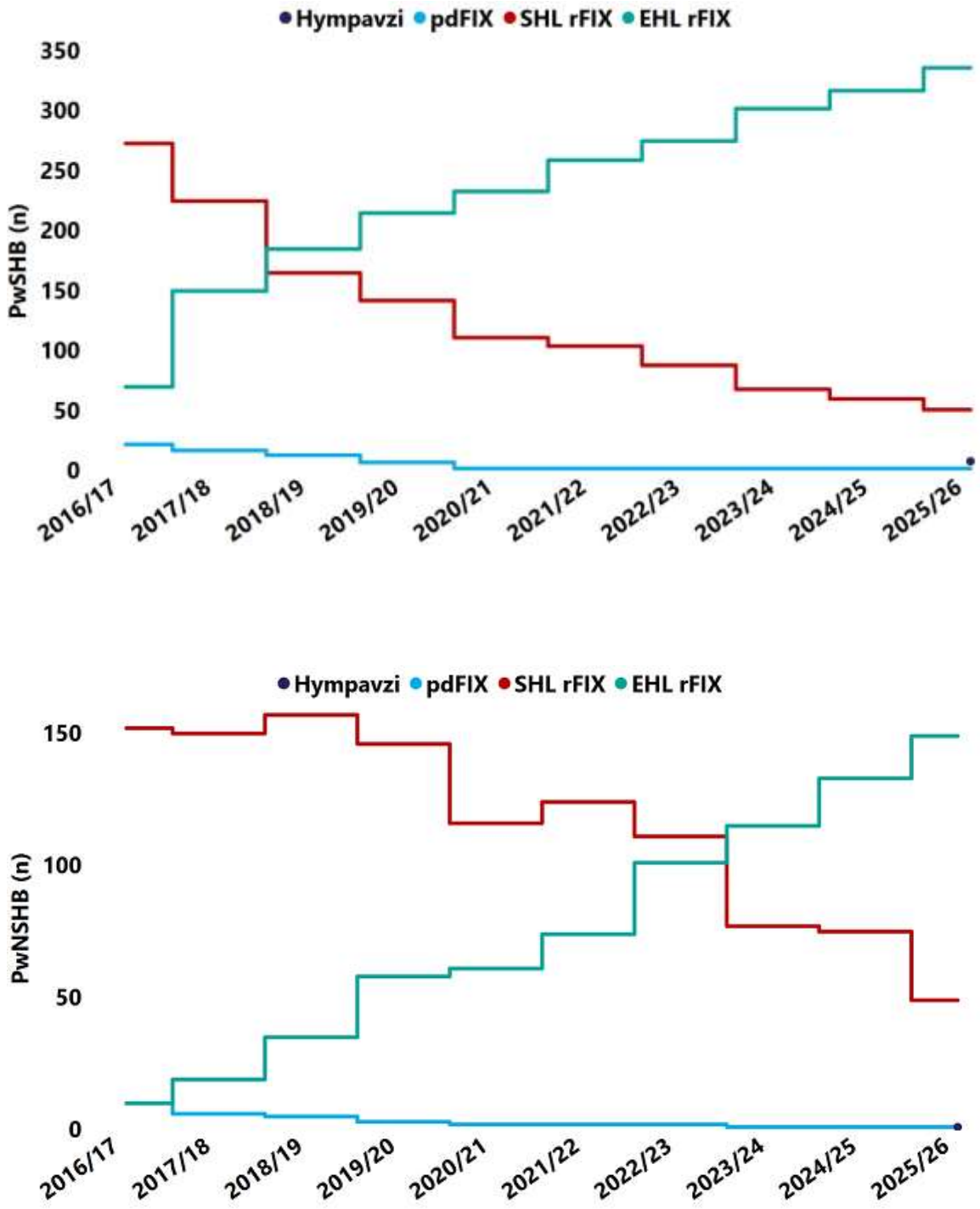


Figure 19: This shows a decline in the number of people with severe haemophilia B issued SHL rFIX, caused by the increasing use of EHL rFIX. Plasma-derived IX issues have also declined to a very low level and have almost fallen out of use.

Table 15 Non-trial products issued to treat people with congenital haemophilia B (all severities and including inhibitors), 2024/25 – 2025/26

Product Type	Manufacturer	Product	2024/25		2025/26	
			Units (IU)	People (n)	Units (IU)	People (n)
Non-factor	Pfizer	Hympavzi	-	-	18,300	9
Recombinant	CSL Behring	IDELVION	10,753,720	117	11,371,750	112
	LFB	Cevenfacta	712	2	2,126	3
	Novo Nordisk	Refixia	9,546,500	103	9,850,500	98
		NovoSeven (mg)	8,564	8	6,892	9
	Pfizer	Benefix	23,447,000	259	20,673,000	202
		ReFacto AF	-	-	2,000	1
	SOBI/Biogen	ALPROLIX	45,925,450	368	53,538,753	426
	Takeda	RIXUBIS	507,000	2	612,000	2
Plasma-derived	BPL	BPL Replenine	820,000	3	1,003,000	4
	Takeda	FEIBA	45,000	1	78,100	2

Units in IU unless otherwise stated
Excludes issues of investigational products

Table 15: This gives a breakdown of the products issued to treat people with haemophilia B in the UK in 2024/25 and 2025/26, presented by supplier. These figures have been cross-checked against manufacturers' sales figures, where available. Whilst one would not expect a perfect match, there is a high level of correlation. These sales figures are not reported, by agreement with suppliers, for reasons of commercial sensitivity. The use of EHL FIX continues to increase. Refacto AF was issued and administered to a PwHB in error. The use of investigational FIX has largely ceased due to clinical trials coming to an end. *It is advised that data on trial products be reported to the NHD, anonymising the product, and at a local level with commissioners so that they have a realistic estimate of future product consumption and avoid any inadvertent reduction in future budget.*

Table 16 Non-trial Factor IX treatment issued for congenital and acquired haemophilia B by UK haemophilia centres, 2025/26

Bleeding disorder	Factor IX (IU)					Hympavzi		Total
	People (n)	Plasma-derived	Standard half-life recombinant	Enhanced half-life recombinant	Total	People (n)	mg	People (n)
Haemophilia B	801	1,003,000	21,285,000	74,761,003	97,049,003	9	18,300	802
Haemophilia A	1	-	-	2,000	2,000	-	-	1
Total	802	1,003,000	21,285,000	74,763,003	97,051,003	9	18,300	803

Excludes issues of investigational products

Table 16: This shows FIX and Hympavzi issues reported to the NHD in 2025/26, broken down by product type and diagnosis. FIX was administered to one PwHA in error.

Figure 20 Number of people with congenital haemophilia B (all severities) treated in the UK 2025/26 by non-trial products used

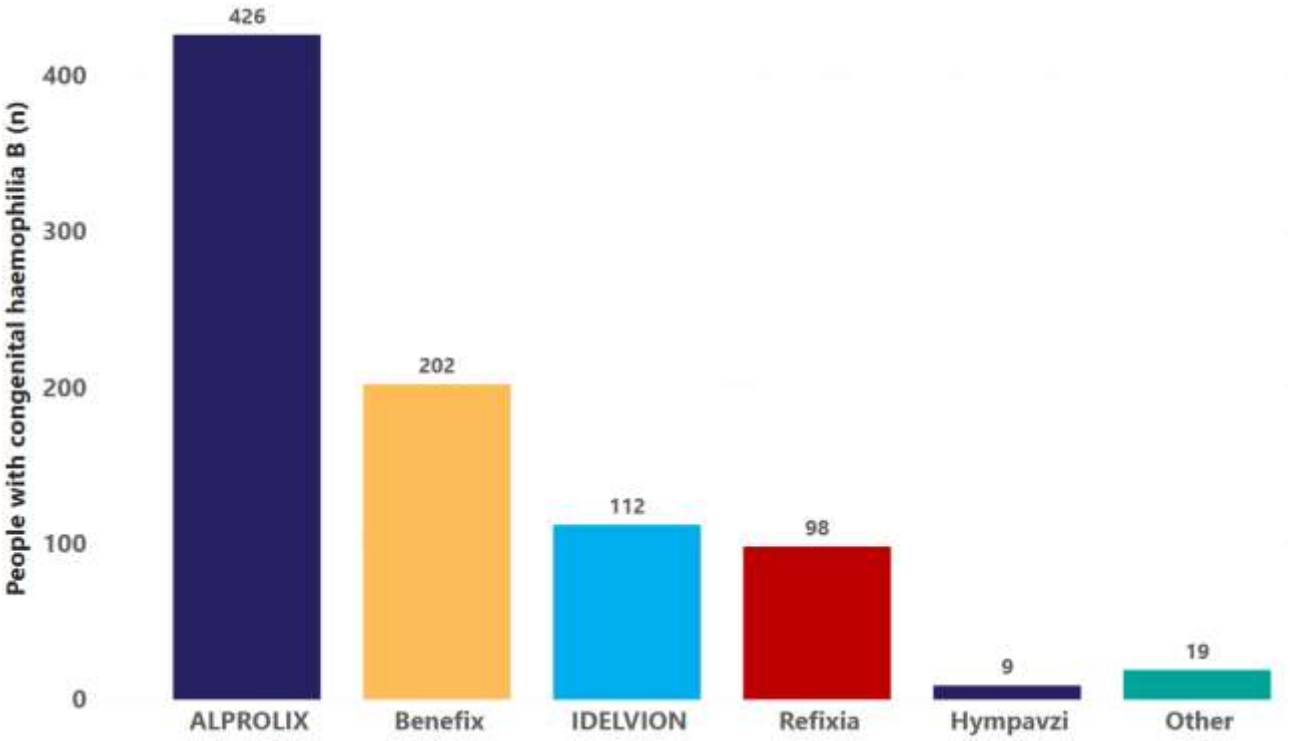


Figure 20: This shows the number of people with haemophilia B treated by product, including those issued to people with an inhibitor. The data that informs this graph can be found in Table 15. People issued multiple products within the year are included in the numbers for each product, resulting in some double counting. There were 811 individual people with haemophilia B issued these products during the year. The large number of people issued Benefix reflects episodic use for non-severe haemophilia B, episodic use for surgery or intercurrent bleeding, and continued use as prophylaxis for a declining proportion of people with severe haemophilia B.

Figure 21 The number and proportion of people with severe congenital haemophilia B and no inhibitor issued EHL products by centre

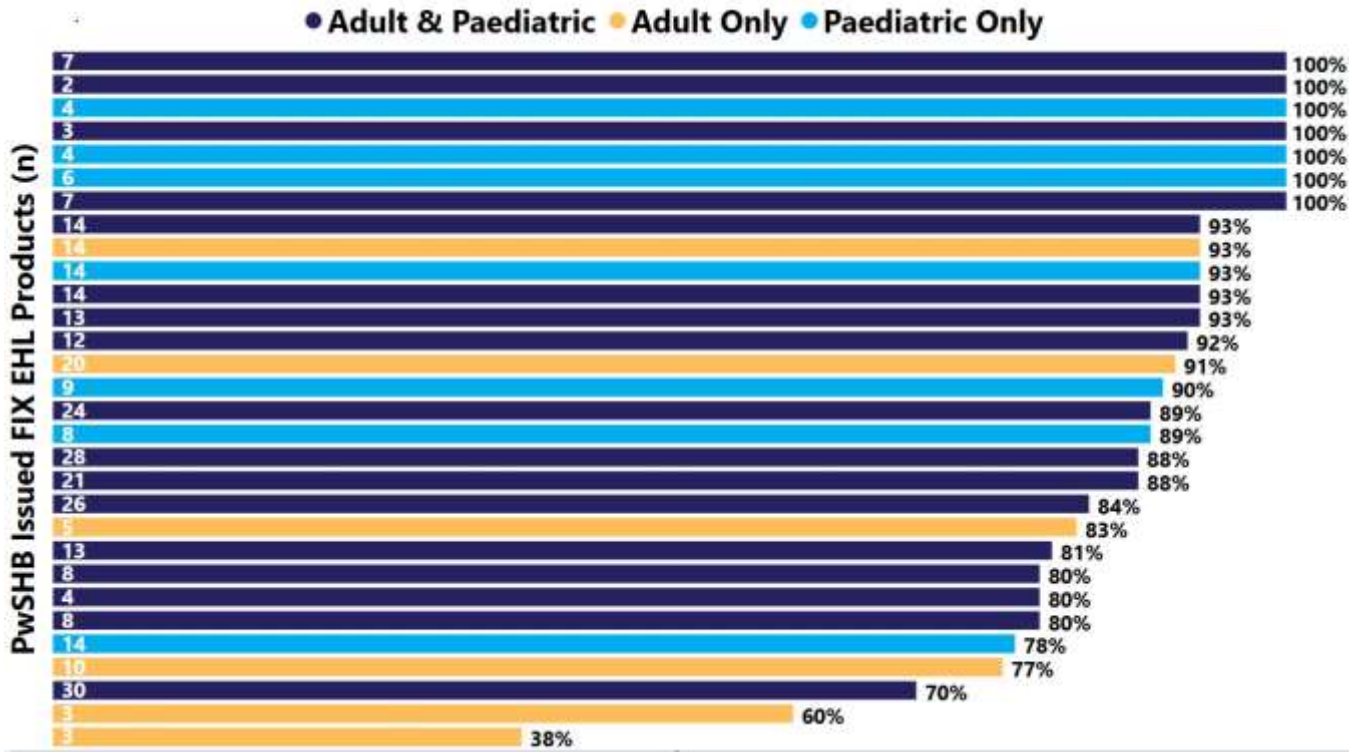


Figure 21: This shows the ranked proportion of people with severe haemophilia B without an inhibitor who were issued EHL products, by centre, in 2025/26. The centres are not identified. The number of people per centre (presented on each bar) is, in many cases, small. Proportional uptake of EHL rFIX concentrates appears to vary amongst centres (median 90%, IQR 80% - 95%), although it is, in general, increasing.

Table 17 Haemophilia joint health scores for people with congenital haemophilia B (FIX <=5 IU/dl) without inhibitors 2015/16 – 2025/26

FIX level	Age (years)	Year	Registered, n	HJHS submitted, n (% of registered)	HJHS evaluable, n (% of submitted)	HJHS = 0, n (% of submitted)	Median (iqr) evaluable HJHS
<1 IU/dl	4-9	2015/16	45	23 (51.1)	22 (95.7)	14 (60.9)	0.0 (0.0 -3.0)
		2020/21	43	13 (30.2)	13 (100.0)	11 (84.6)	0.0 (0.0 -0.0)
		2025/26	37	13 (35.1)	13 (100.0)	7 (53.8)	0.0 (0.0 -4.5)
	10-17	2015/16	44	17 (38.6)	17 (100.0)	11 (64.7)	0.0 (0.0 -4.0)
		2020/21	51	20 (39.2)	19 (95.0)	10 (50.0)	0.0 (0.0 -3.0)
		2025/26	62	22 (35.5)	22 (100.0)	12 (54.5)	0.0 (0.0 -4.0)
	18-49	2015/16	152	43 (28.3)	37 (86.0)	3 (7.0)	13.0 (6.5 -25.0)
		2020/21	150	23 (15.3)	22 (95.7)	4 (17.4)	8.0 (2.0 -16.0)
		2025/26	178	41 (23.0)	36 (87.8)	4 (9.8)	10.0 (2.3 -18.0)
	50-64	2015/16	49	14 (28.6)	11 (78.6)	0 (0.0)	30.0 (7.0 -47.0)
		2020/21	62	9 (14.5)	9 (100.0)	0 (0.0)	24.0 (7.0 -49.5)
		2025/26	50	15 (30.0)	10 (66.7)	1 (6.7)	28.3 (9.5 -36.4)
	65 and above	2015/16	22	4 (18.2)	2 (50.0)	0 (0.0)	61.0 (41.0 -81.0)
		2020/21	22	2 (9.1)	1 (50.0)	0 (0.0)	31.0 (31.0 -31.0)
		2025/26	35	3 (8.6)	3 (100.0)	0 (0.0)	24.0 (12.0 -48.0)
1-5 IU/dl	4-9	2015/16	31	4 (12.9)	4 (100.0)	4 (100.0)	0.0 (0.0 -0.0)
		2020/21	29	5 (17.2)	5 (100.0)	4 (80.0)	0.0 (0.0 -0.5)
		2025/26	22	6 (27.3)	6 (100.0)	5 (83.3)	0.0 (0.0 -0.4)
	10-17	2015/16	25	3 (12.0)	3 (100.0)	2 (66.7)	0.0 (0.0 -16.0)
		2020/21	34	4 (11.8)	4 (100.0)	1 (25.0)	0.8 (0.1 -1.8)
		2025/26	42	11 (26.2)	11 (100.0)	6 (54.5)	0.0 (0.0 -2.0)
	18-49	2015/16	174	29 (16.7)	27 (93.1)	13 (44.8)	1.0 (0.0 -3.0)
		2020/21	164	7 (4.3)	7 (100.0)	2 (28.6)	2.0 (0.0 -13.0)
		2025/26	162	10 (6.2)	10 (100.0)	1 (10.0)	21.5 (3.3 -30.5)
	50-64	2015/16	63	5 (7.9)	4 (80.0)	1 (20.0)	1.5 (0.3 -29.0)
		2020/21	64	3 (4.7)	3 (100.0)	1 (33.3)	2.0 (0.0 -9.0)
		2025/26	76	7 (9.2)	7 (100.0)	2 (28.6)	4.0 (0.0 -19.0)
	65 and above	2015/16	24	4 (16.7)	4 (100.0)	1 (25.0)	4.5 (1.0 -16.3)
		2020/21	35	2 (5.7)	2 (100.0)	0 (0.0)	26.5 (2.0 -51.0)
		2025/26	38	3 (7.9)	3 (100.0)	1 (33.3)	5.0 (0.0 -9.0)

Table 17 (previous page) and Figure 23 (overleaf): This shows HJHS for PwHB without inhibitors over the last ten years. It is hoped that the low submission of HJHS data for people with severe or moderate haemophilia can be improved. In general, HJHS are lower for PwHB compared to PwHA.

Figure 22 HJHS submission for people with congenital haemophilia B (FIX <=5 IU/dl) without inhibitors 2015/16 – 2025/26

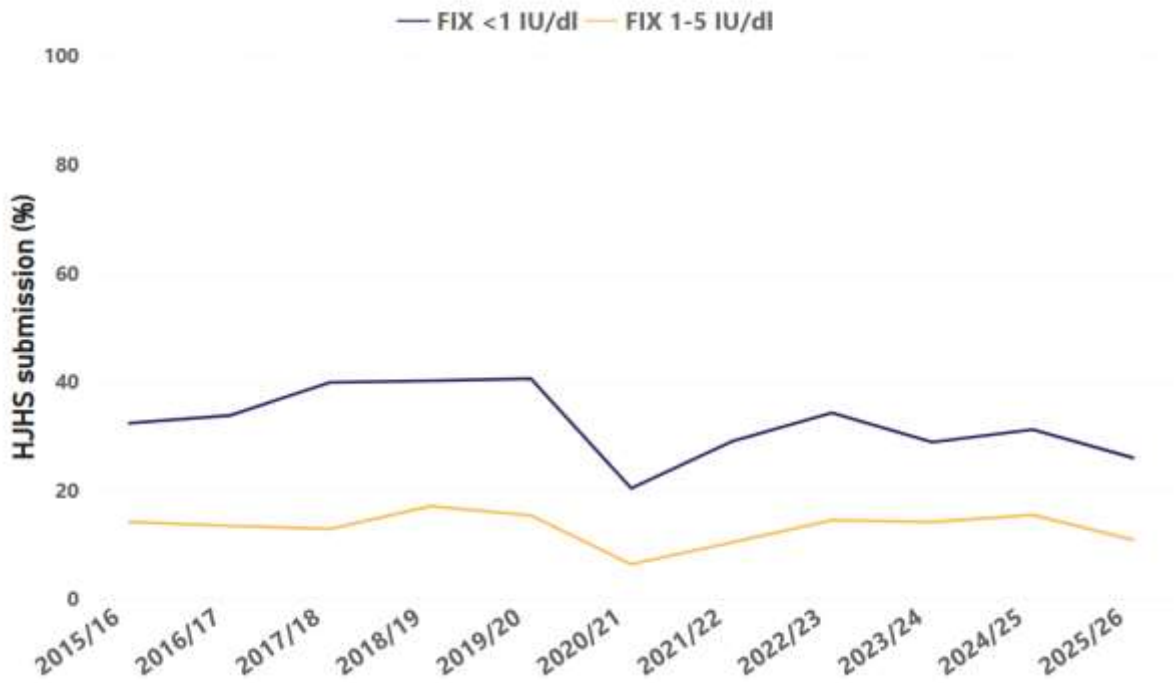
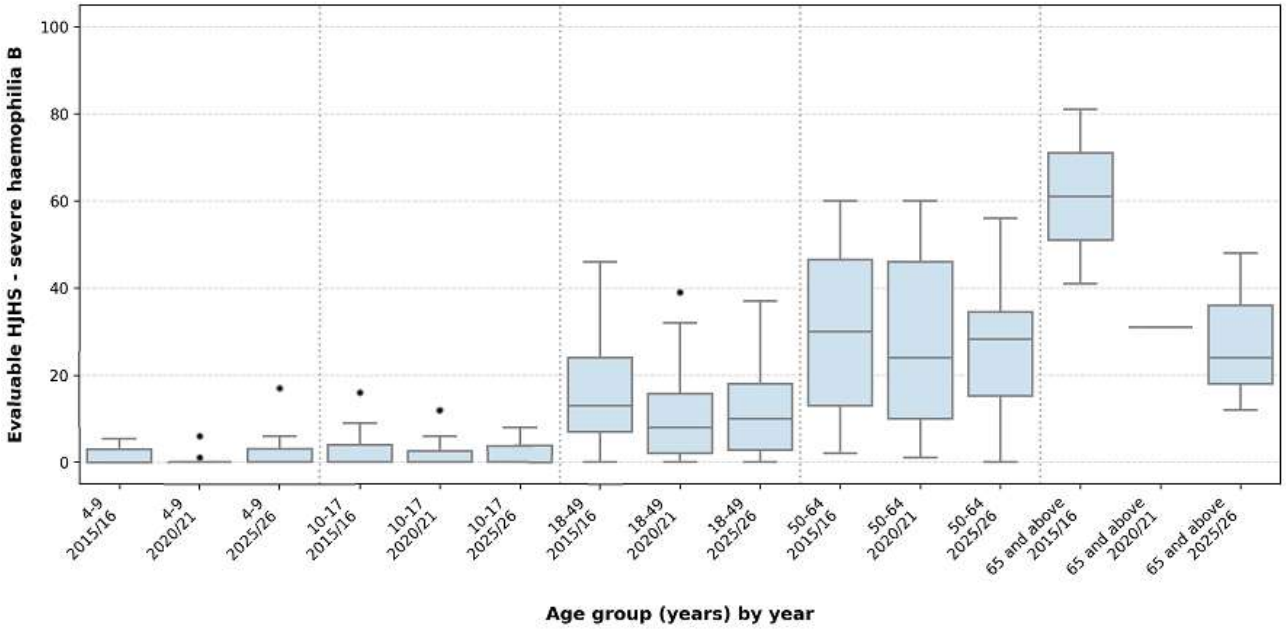


Figure 23 Median evaluable HJHS of people with congenital haemophilia B (FIX <=5 IU/dl) without inhibitors 2015/16 – 2025/26



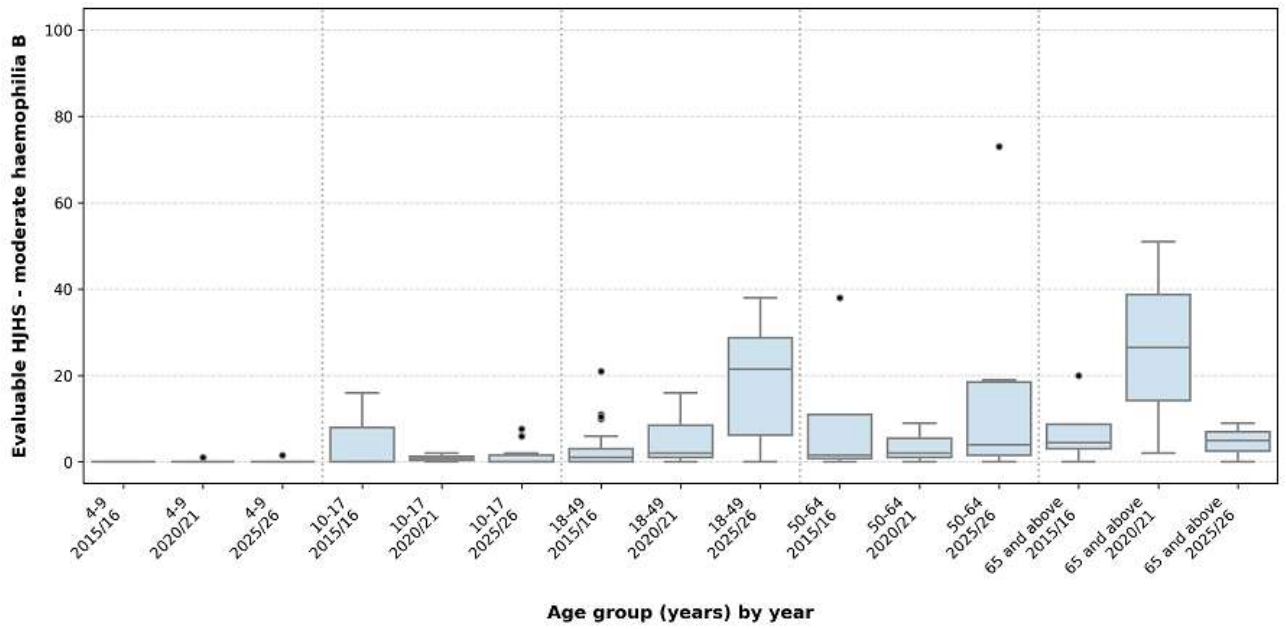


Table 18 Longitudinal within-person haemophilia joint health scores for people with congenital haemophilia B (FIX <=5 IU/dl) without inhibitors 2015/16 – 2025/26

FIX level (IU/dl)	Age (years) 2015/16	Registered 2015/16 (n)	HJHS evaluable 2015/16 (n)	HJHS evaluable 2015/16 and 2025/26	Median (iqr) evaluable HJHS		
					2015/16	2020/21	2025/26
<1	4-17	89	39	11	3 (0-4)	2 (0-5.3)	4 (0-5.5)
	18 and above	223	50	15	17 (6-30)	23 (11-42)	18 (12-33)

Table 18: This shows longitudinal within-person HJHS for PwHB with HJHS assessed in 2015/16 and 2025/26. Age groups for SHB have been collapsed, and results for moderate severity haemophilia B not presented, due to the scarcity of follow-up HJHS data for this group, which impedes conclusions regarding the progression of their joint health.

2.3 Gene Therapy

There follows a brief and preliminary report on gene therapy in the UK. This is divided by diagnosis (Haemophilia A or B) and by trial or commercial gene therapy.

We have limited data on the people who underwent gene therapy in clinical trials because those studies were covered by individual confidentiality agreements. We cannot accurately estimate success rates among people who received gene therapy in clinical trials because treatment dates and doses are generally unknown to us.

Figure 24 Gene therapy trial summary: number of people notified to NHD

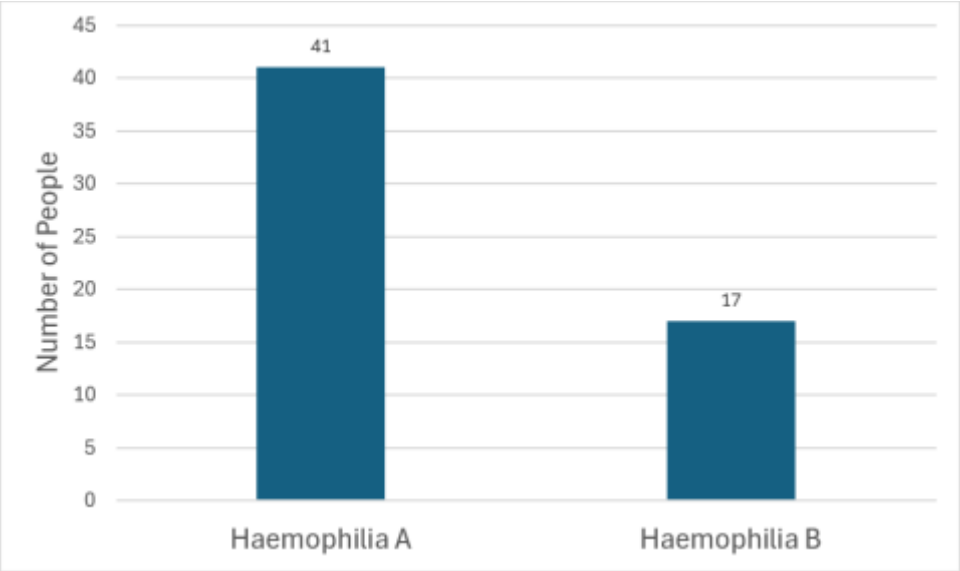


Figure 25 Gene therapy trial follow-up status

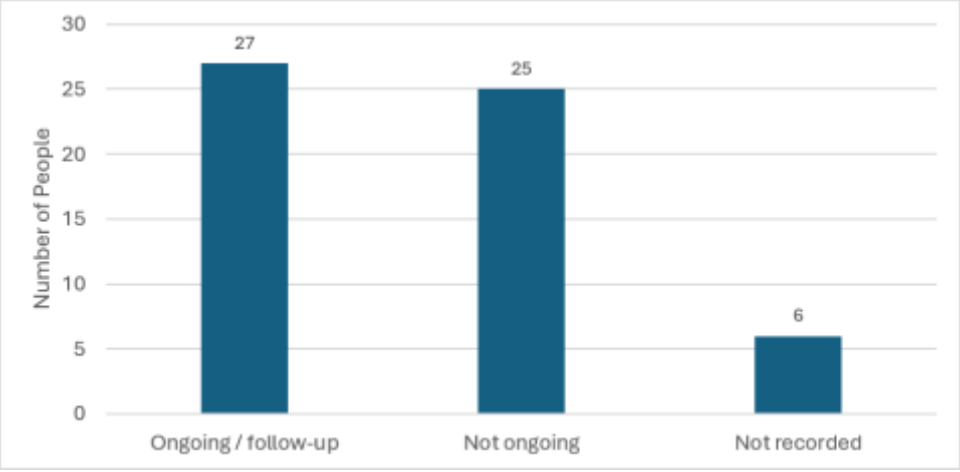
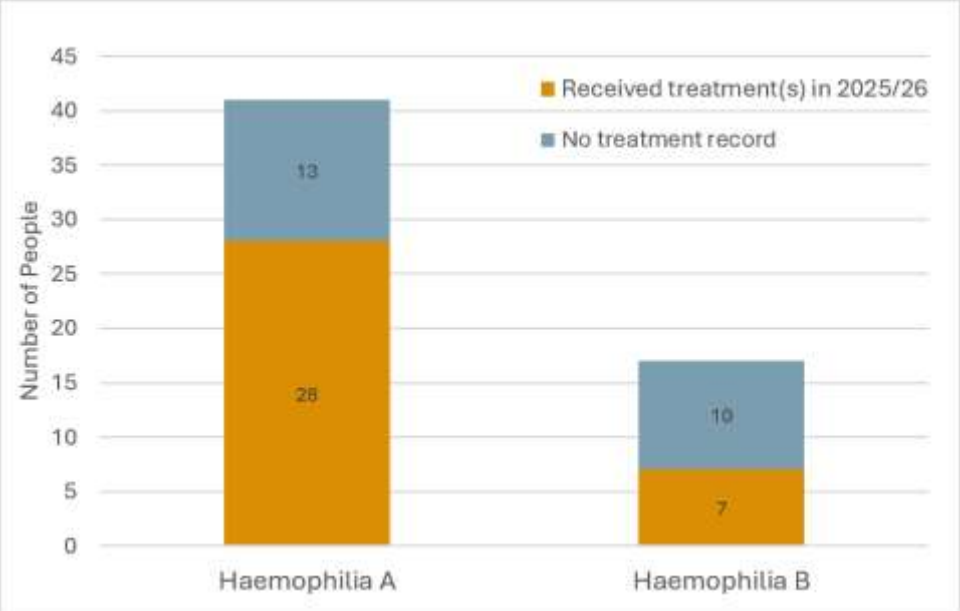


Figure 25: Follow-up status is based on data returned to the NHD by the centre.

Figure 26 Gene therapy trial: treatments received 2025/26



Diagnosis	Total people	Received treatment(s) in 2025/26	%
Haemophilia A	41	28	68.3%
Haemophilia B	17	7	41.2%
Total	**58**	**35**	**60.3%**

Current treatment data was derived from a combination of centre feedback and the factor VIII/IX returns. Some centres did not respond to requests for further data. Given these limitations, only the broadest conclusions may be drawn.

The percentages shown in the table is the proportion of people notified to the NHD who were reported to have received treatment(s) in 2025/26. It is assumed that those people with haemophilia no longer reporting regular replacement therapy, have had a durable response to gene therapy, whereas those reporting regular replacement therapy, either had no response or responded transiently to gene therapy. No conclusions in relation to efficacy can be drawn, however, since a number of different gene therapy constructs and dosage regimens were employed, and in some cases very low doses were administered for assessment of safety only.

Commercial gene therapy (Hemgenix)

Although we are collecting a far more comprehensive dataset on PwHB undergoing commercial gene therapy, median follow-up of this cohort of (currently) nine people is nine months and so it would be premature to estimate a success/failure rate. However, none of these people have been reported to have reverted to regular factor IX replacement therapy so far. Their early outcomes are summarised below.

Median (IQR) follow-up 9 (4-11) months.

Most recent Median (IQR) Factor IX level 35.5 (21.5-43) IU/ml.

This is encouraging. More comprehensive data will be reported elsewhere. Please note that the data presented in this section are complete up to October 2026.

2.4 Von Willebrand Disease

Table 19 People with von Willebrand disease registered and treated 2025/26

Type of von Willebrand disease	VWD Activity IU/dl										Total	Issued concentrate*
	<10	10 - <30	≥30	N/K	Subtotal	<10	10 - <30	≥30	N/K	Subtotal		
	<18 years					≥18 years						
Males												
1	27	241	281	1	**550**	124	524	812	11	**1,471**	**2,021**	125
2A	48	55	14	1	**118**	130	122	55	-	**307**	**425**	108
2B	9	9	5	-	**23**	24	46	28	-	**98**	**121**	22
2M	24	14	5	-	**43**	58	68	16	1	**143**	**186**	38
2N	1	2	3	-	**6**	3	5	45	-	**53**	**59**	9
2 unspecified	15	25	4	-	**44**	39	37	12	-	**88**	**132**	30
3	27	2	1	-	**30**	69	13	3	-	**85**	**115**	88
Low VWF	1	9	114	-	**124**	2	19	220	1	**242**	**366**	5
Other	1	1	1	-	**3**	-	2	2	-	**4**	**7**	-
Unreported	41	89	140	10	**280**	136	300	642	40	**1,118**	**1,398**	111
										Total males	**4,830**	**536**
Females												
1	23	182	185	-	**390**	175	942	2,035	16	**3,168**	**3,558**	149
2A	50	51	16	1	**118**	183	179	80	-	**442**	**560**	140
2B	10	19	7	-	**36**	25	60	48	1	**134**	**170**	45
2M	26	23	4	-	**53**	92	116	45	-	**253**	**306**	65
2N	1	2	14	-	**17**	9	10	95	1	**115**	**132**	18
2 unspecified	18	20	4	-	**42**	43	58	33	-	**134**	**176**	24
3	25	-	1	-	**26**	57	11	1	-	**69**	**95**	75
Low VWF	2	6	122	-	**130**	2	38	637	2	**679**	**809**	11
Other	-	1	1	-	**2**	-	1	8	-	**9**	**11**	2
Unreported	33	101	104	5	**243**	177	589	1,617	60	**2,443**	**2,686**	141
										Total females	**8,503**	**670**
										Total males and females	**13,333**	**1,206**

Sex as registered at birth

**Includes plasma-derived and recombinant products of any factor type*

Table 19 (previous page): This shows the number of people with von Willebrand disease registered and/or issued product, broken down by age, activity level, subtype, and sex at birth. Whilst there is no generally agreed severity classification for VWD, the data are reported by the subdivisions <10, 10-<30 and ≥30% VW activity to give some indication of the distribution of severity amongst the UK cohort.

A VW subtype is reported for approximately 70% of registrations. Efforts are always ongoing to tidy up this part of the database, but there are challenges, including changing classification over time, old data, and changing opinion in relation to the diagnosis of mild type 1 VWD, which may have been over-diagnosed in the past. The HCIS system has been redesigned to make it easier to update the second with the VW subtype. The diagnostic process for VWD is frequently in two stages (basic diagnosis and then subtyping) and the registration may be submitted to the NHD part-way through this process. The registration should be updated when the subtype becomes known. Type 1 defects should be reported at the time of original registration. The new database will send automatic reminders to complete registration of subtypes after initial incomplete registration. Changes in diagnosis should also be registered with the database. It is also going to be possible to capture temporal change in levels.

There remains a relative excess of adult females. For type 1 VWD, this reflects referral bias of women with menorrhagia and possible over-diagnosis of mild type 1 VWD in the past. Some people have been de-registered, or their diagnosis changed when they are re-investigated or when their VW activity level normalises with increasing age.

Table 20 (overleaf)**:** This shows that 626 people with von Willebrand disease were newly registered in the past year, of whom 125 (20%) were registered without a reported subtype.

This table supports previous reports of an apparent relative excess of new female compared to male registrants after menarche, which reflects referral bias.

Table 20 New registrations of von Willebrand disease between 2025/26, by age at mid-year, severity and gender

Type of von Willebrand disease	VWD Activity IU/dl								Total
	<30	≥30	N/K	Subtotal	<30	≥30	N/K	Subtotal	
	<18 years				≥18 years				
Males									
1	22	29	-	**51**	18	19	1	**38**	**89**
2A	5	4	1	**10**	5	4	-	**9**	**19**
2B	-	1	-	**1**	2	1	-	**3**	**4**
2M	1	2	-	**3**	4	-	-	**4**	**7**
2N	-	1	-	**1**	-	7	-	**7**	**8**
2 unspecified	7	-	-	**7**	4	1	-	**5**	**12**
3	-	-	-	**-**	2	-	-	**2**	**2**
Low VWF	1	22	-	**23**	-	14	-	**14**	**37**
Other	1	-	-	**1**	-	-	-	**-**	**1**
Unreported	10	12	-	**22**	12	7	5	**24**	**46**
								Total males	**225**
Females									
1	22	25	-	**47**	33	52	1	**86**	**133**
2A	4	-	-	**4**	8	4	-	**12**	**16**
2B	-	3	-	**3**	2	1	-	**3**	**6**
2M	4	1	-	**5**	9	6	-	**15**	**20**
2N	-	3	-	**3**	-	4	1	**5**	**8**
2 unspecified	8	1	-	**9**	6	5	-	**11**	**20**
3	-	-	-	**-**	1	-	-	**1**	**1**
Low VWF	2	30	-	**32**	7	77	-	**84**	**116**
Other	1	-	-	**1**	-	1	-	**1**	**2**
Unreported	18	11	3	**32**	7	36	4	**47**	**79**
								Total females	**401**
								Total males and females	**626**

Sex as registered at birth

Table 21 Non-trial products issued to treat people with von Willebrand disease (including inhibitors), 2024/25 and 2025/26

Product Type	Manufacturer	Product	2024/25		2025/26	
			Units (IU)	People (n)	Units (IU)	People (n)
Non-factor	Roche	Hemlibra (mg)	-	-	2,160	2
Recombinant	LFB	Cevenfacta	-	-	52	2
	Novo Nordisk	NovoSeven (mg)	2,005	9	2,130	7
		Esperoct	569,000	6	469,500	9
		NovoEight	10,000	4	4,000	1
	Octapharma	Nuwiq	500	1	500	1
	Pfizer	ReFacto AF	59,000	9	38,000	11
	SOBI/Biogen	Elocta	1,771,250	8	1,322,500	11
	Takeda	Advate	1,486,750	103	1,355,400	145
		Veyvondi	13,646,179	645	18,130,410	819
Plasma-derived	CSL Behring	Voncento (FVIII units)	21,875,004	406	21,570,667	348
		Voncento (VWF units)	52,500,010		51,769,600	
	LFB	Willfact /Wilfactin	1,252,000	13	689,000	8
	Octapharma	Wilate (FVIII units)	4,347,500	123	6,153,600	99
		Wilate (VWF units)	4,347,500		6,153,600	
		Octaplex	-	-	3000	1
	Takeda	FEIBA	209000	2	60000	1

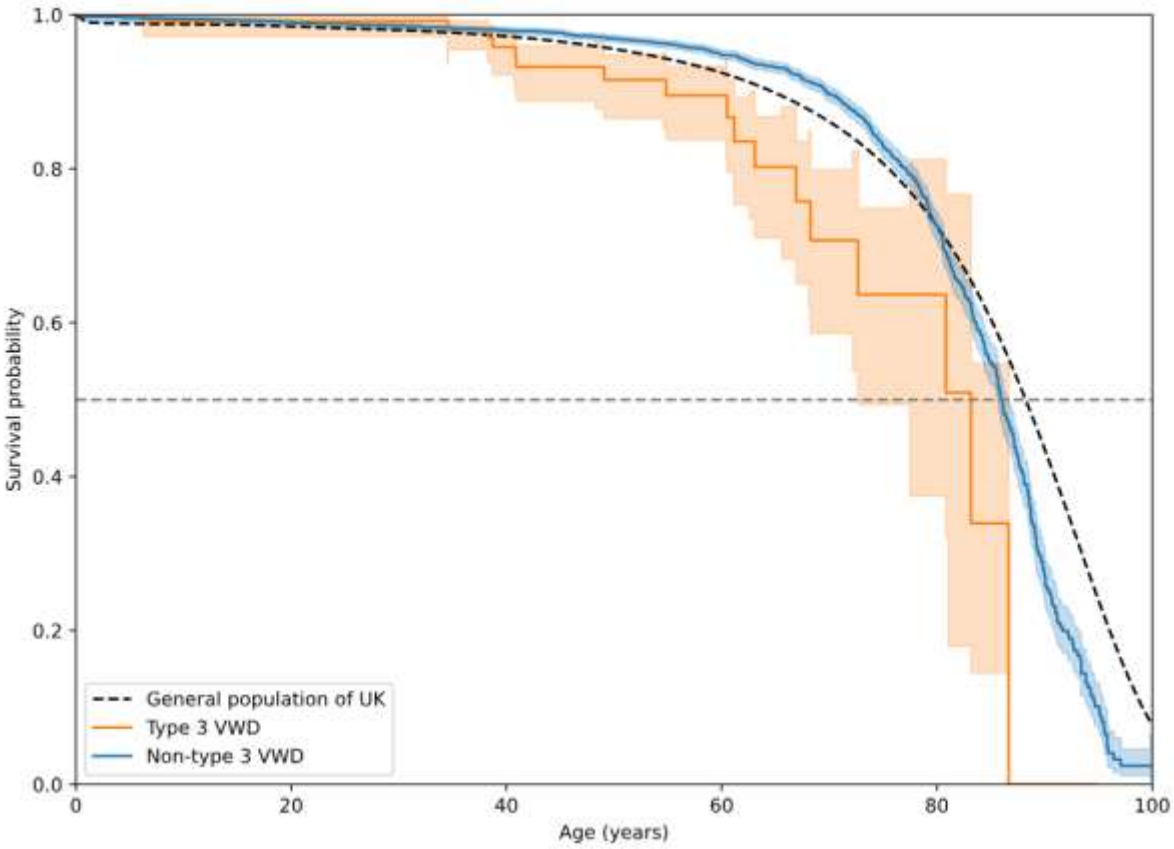
Units in IU unless otherwise stated
Products containing VWF and FVIII are reported separately in VWF and FVIII units

Table 21: This shows a breakdown of products issued to treat people with von Willebrand disease in the UK by supplier. Please note these exclude products issued to treat any additional blood disorders that people with von Willebrand disease may have. These products are generally listed by and priced by their labelled FVIII content, with the exception of Willfact (LFB) and Veyvondi (Takeda), which are labelled, priced and reported here only by VWF content. Veyvondi is currently commissioned only for surgery and on-demand use in England. Where factor VIII and VW units are shown for Voncento and Wilate, the VW units have been derived by converting the factor VIII units issued, using the published FVIII:VWF ratio.

Advate was issued to 215 PwVWD over the last two years, of whom eight also had haemophilia A. Elocta was issued to fifteen PwVWD over the last two years, of whom four also had haemophilia A. Emicuzimab issued to people who also had haemophilia A is not reported here. The emicizumab

issued to PwVWD is presumed to reflect a clinical trial or individual funding request. Octaplex was administered in error.

Figure 27 Survival of people with von Villebrand disease by type, actively registered 1985-2026, compared to the general population of the UK



Median (iqr) survival time (years) for people with VWD type 3: 80 (66-83), non-type 3: 85 (79-90)

Figure 27: This shows the survival curve (and 95% confidence intervals) for people registered with type 3 and non-type 3 von Willebrand disease. The wide confidence intervals around the survival curve for type 3 von Willebrand disease reflect the relatively smaller numbers of this group. Nevertheless, this suggests that survival for people with non-type 3 VWD is comparable to the general population, whereas survival is reduced for people with type 3 VWD.

Figure 28 Units of von Willebrand factor issued by UK haemophilia centres to treat von Willebrand disease 2015/16 – 2025/26

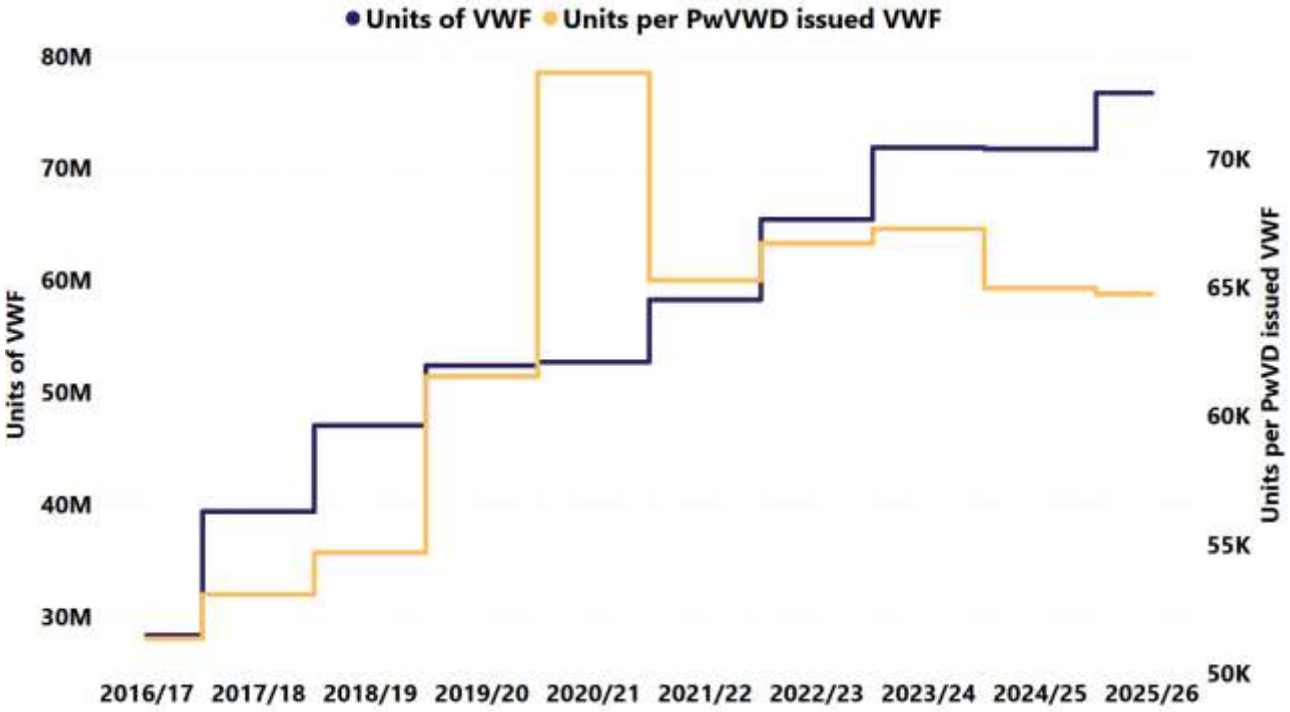


Figure 28: This shows von Willebrand factor units issued to treat von Willebrand disease from 2016/17 to 2025/26, in total and per PwVWD, regardless of type. This shows a steady and marked increase in issues of von Willebrand factor concentrate, probably attributable to increased numbers of PwVWD, increased surgical need and the greater use of prophylaxis in people with type 2 and type 3 VWD. The increased units per PwVWD in 2020/21 is probably attributable to deferral of surgery and other procedures during the COVID-19 pandemic, with issues restricted to intensively treated PwVWD. The number of units issued per PwVWD in more recent years appears relatively stable.

Figure 29 People with type 3 von Willebrand disease issued von Willebrand factor by UK haemophilia centres 2016/17 – 2025/26

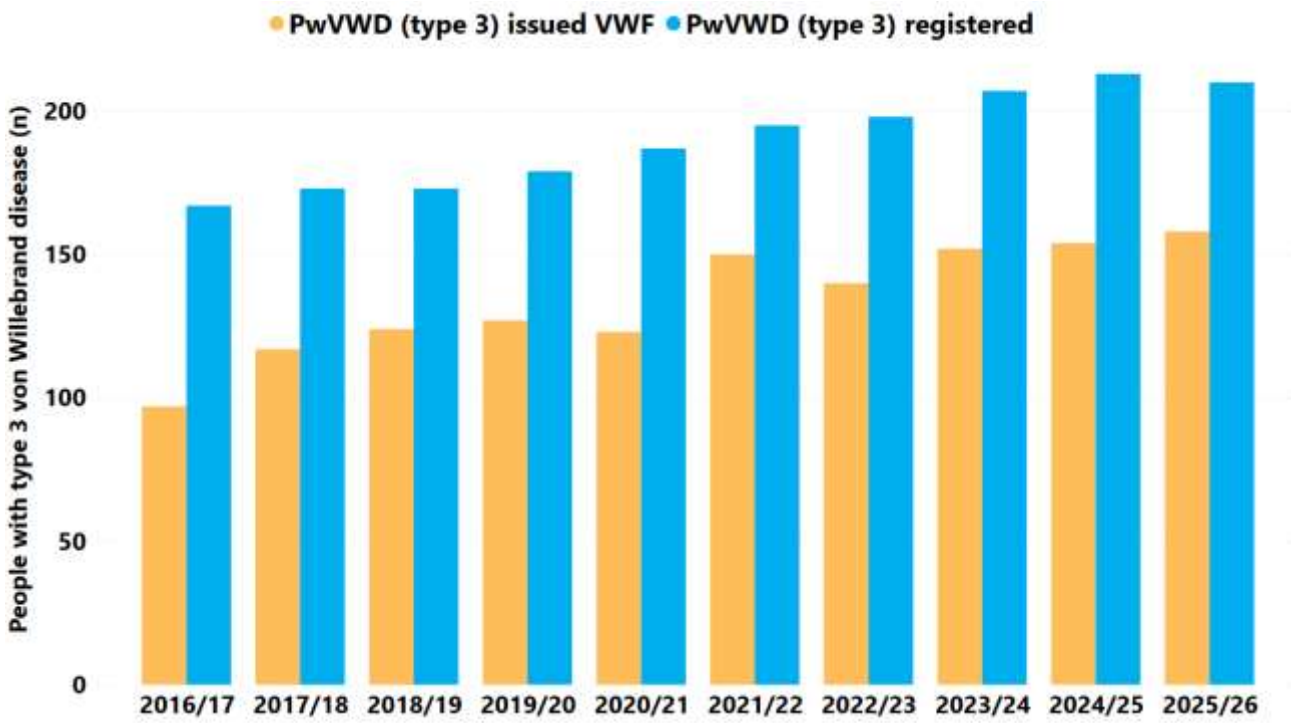
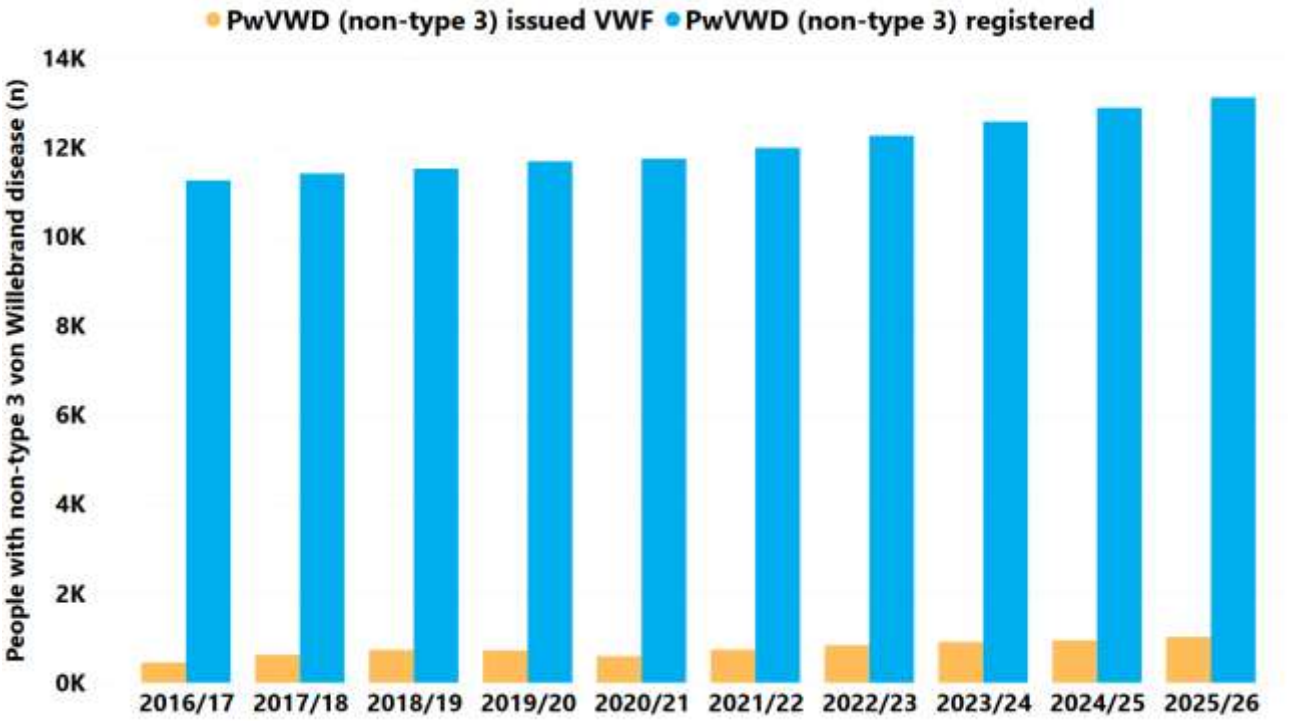


Figure 29: The apparent fall in the number of people issued VWF in 2020/21 is probably attributable to deferral of surgery and other procedures during the COVID-19 pandemic. Approximately 30% of people with type 3 VWD have a mild bleeding phenotype and, as the bar diagram shows, a sizeable proportion seldom need treatment. There has been a 137% increase in VW concentrate issues for type 3 von Willebrand's disease over the last ten years. This is only partly attributable to the 63% increase in the number of people with type 3 VWD issued VWF over the same period, and is probably also attributable to increased use of prophylaxis in this group.

Figure 30 People with non-type 3 von Willebrand disease issued von Willebrand factor by UK haemophilia centres 2016/17 – 2025/26



2.5 Congenital and Acquired Factor Inhibitors

Table 22 Inhibitors by disease severity – congenital haemophilia A, haemophilia B & von Willebrand disease, 2025-26

Diagnosis	Severity (IU/dl) / subtype	Inhibitor status, n (%)					
		Total registered	No inhibitor history	Any inhibitor history	Past	Ongoing	New
Haemophilia A	<1	2,435 (100)	1,874 (77.0)	561 (23.0)	376 (15.4)	172 (7.1)	13 (0.5)
	1-5	807 (100)	724 (89.7)	83 (10.3)	52 (6.4)	29 (3.6)	2 (0.2)
	>5 or not known	7,130 (100)	7,059 (99.0)	71 (1.0)	55 (0.8)	14 (0.2)	2 (0.0)
	Total	**10,372 (100)**	**9,657 (93.1)**	**715 (6.9)**	**483 (4.7)**	**215 (2.1)**	**17 (0.2)**
Haemophilia B	<1	408 (100)	387 (94.9)	21 (5.1)	10 (2.5)	10 (2.5)	1 (0.2)
	1-5	356 (100)	354 (99.4)	2 (0.6)	1 (0.3)	1 (0.3)	0 (0.0)
	>5 or not known	1,557 (100)	1,555 (99.9)	2 (0.1)	2 (0.1)	0 (0.0)	0 (0.0)
	Total	**2,321 (100)**	**2,296 (98.9)**	**25 (1.1)**	**13 (0.6)**	**11 (0.5)**	**1 (0.0)**
Von Willebrand disease	Type 1	5,579 (100)	5,576 (99.9)	3 (0.1)	2 (0.0)	0 (0.0)	1 (0.0)
	Type 3	210 (100)	196 (93.3)	14 (6.7)	6 (2.9)	8 (3.8)	0 (0.0)
	Other/ unreported	7,544 (100)	7,540 (99.9)	4 (0.1)	1 (0.0)	2 (0.0)	1 (0.0)
	Total	**13,333 (100)**	**13,312 (99.8)**	**21 (0.2)**	**9 (0.1)**	**10 (0.1)**	**2 (0.0)**

Any inhibitor history: Sum of past, ongoing and new
Past: Reported in previous years and not in this year
Ongoing: Reported this year and in previous years
New: Reported this year and not in previous years

Table 22 (previous page): This table shows the incidence of new inhibitors in the past year, the history of inhibitors ever registered and the prevalence of those still considered active for haemophilia A, B and von Willebrand disease, broken down by disease severity. There has been a downward trend in the number of reports of new inhibitors in PwSHA over the last few years, from 25 in 2016/17 to thirteen in the past year (**Figure 31**). This is probably a consequence of introduction of emicizumab prophylaxis very early in life, deferring exposure to factor VIII.

Those labelled "new" were reported for the first time in the year 2025/26. Those labelled "ongoing" are reported in previous years and have not been eradicated and remain clinically significant in 2025/26. Those reported as "past" were reported in previous years and not reported to be ongoing in 2025/26 and are therefore assumed to have been tolerised.

An inhibitor is designated as "past" if it is no longer reported in the quarterly returns within 2025/26. There is necessarily some lack of precision surrounding this categorisation, as inhibitors thought to have been eradicated may persist at a variable low level, below the level of detection of the Bethesda assay, although high enough to shorten the FVIII half-life. These inhibitors may re-emerge as have up to 25% of inhibitors after tolerisation (International ITI registry data) or after FVIII prophylaxis has been replaced with emicizumab. We have received a number of reports of recurring inhibitors after switching to emicizumab, all occurring in the first few months of treatment. Some of these were clearly ongoing at a low level before emicizumab started. To add to the "softness" of the "inhibitor" designation, it is clear anecdotally that there may be inconsistency in reporting that an inhibitor has been eliminated when, in some cases, the factor VIII half-life remains very short.

The table shows that a history of inhibitor is over twice as prevalent in severe as in moderate haemophilia A and over twenty times more prevalent than in mild haemophilia A. The proportion of people with non-severe haemophilia A thought to have eliminated their inhibitor cannot be known with certainty, however, since some may have an undetectable inhibitor which may reappear as soon as they have FVIII replacement.

Inhibitors in haemophilia B are far less common, with a prevalence of 2.7% of people registered with severe haemophilia B, and <1% for people registered with non-severe haemophilia B. These arise early in the person's treatment and usually only in people with severe haemophilia B caused by FIX gene deletions. The relatively low numbers of inhibitors in PwHB marked as "past" is consistent with the known difficulty in eradicating factor IX inhibitors through immune tolerance. Inhibitors in von Willebrand disease appear in our cohort predominantly in type 3 VWD.

Figure 31 The incidence of new FVIII inhibitors in people with congenital haemophilia A by year

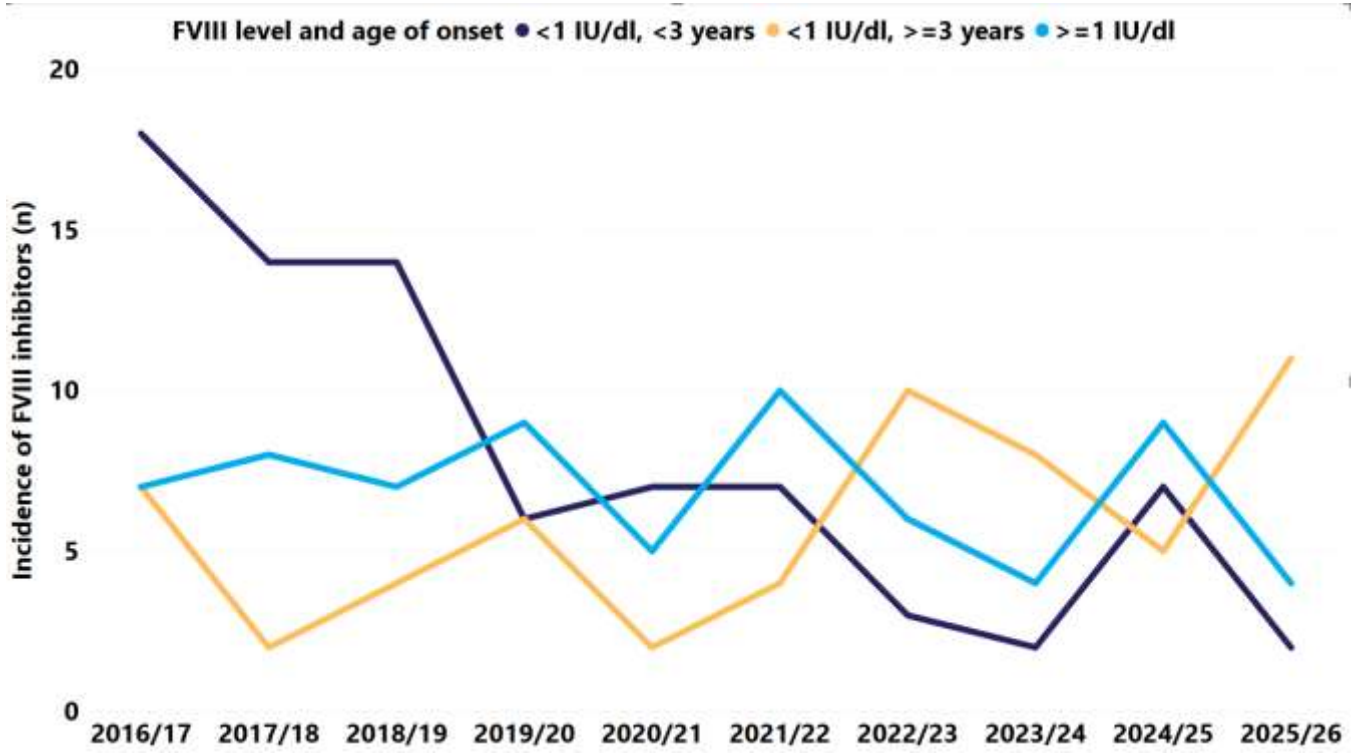


Figure 31: This shows the incidence of FVIII inhibitors from 2016/17 to 2025/26, by baseline FVIII level and age. Although there is no discernable change in the incidence of new inhibitors in PwNHSA, or PwSHA aged 3 years and above, there has been a very marked decline in inhibitor incidence in PwSHA aged under 3 years, as the use of emicizumab defers first treatment with factor VIII concentrate.

Table 23 (overleaf): This shows non-trial products reported to have been issued to people with a current inhibitor during 2024/25 and 2025/26 (excluding issues of investigational products), broken down by diagnosis, supplier and product. It is understood that some PwHB with inhibitors are also receiving trial products.

Table 23 Non-trial products issued to treat people with congenital bleeding disorders reported to have a current inhibitor, 2024/25 and 2025/26

Product type	Manufacturer	Product	2024/25		2025/26	
			People (n)	Units (IU)	People (n)	Units (IU)
Haemophilia A						
Non-factor	Roche	Emicizumab (mg)	172	688,074	174	735,103
Recombinant	LFB	Cevenfacta	3	369	6	1,261
	Novo Nordisk	NovoSeven (mg)	95	8,382	76	7,276
		Esperoct	12	1,525,000	8	1,563,000
		NovoEight	2	47,000	1	280,000
	Octapharma	Nuwiq	7	847,500	7	1,104,250
	Pfizer	ReFacto AF	8	200,500	8	606,000
	SOBI	Altuvoct	-	-	25	1,349,750
		Elocta	22	1,778,500	31	4,441,500
	Takeda	Advate	21	2,319,250	17	1,218,750
		Obizur	1	98,000	4	174,500
Plasma-derived	BPL	BPL FVIII 8Y	-	-	1	131,765
	Octapharma	Octanate	1	10,000	2	989,000
	Takeda	FEIBA	14	1,762,000	6	592,000
Haemophilia B						
Non-factor	Pfizer	Hympavzi	-	-	1	300
Recombinant	CSL Behring	Idelvion	-	-	1	20,000
	LFB	Cevenfacta	2	712	2	2,096
	Novo Nordisk	Refixia	1	50,000	1	96,000
		NovoSeven (mg)	7	8,554	9	6,892
	SOBI	Alprolix	2	1,122,250	1	935,000
Plasma-derived	Takeda	FEIBA	1	45,000	1	39,000
von Willebrand disease						
Recombinant	LFB	Cevenfacta	-	-	1	46
	Novo Nordisk	NovoSeven (mg)	6	1,629	4	1,871
	SOBI	Elocta	2	1,042,000	2	844,000
	Takeda	Advate	1	4,000	1	3,000
		Veyvondi	3	1,173,250	6	779,400
Plasma-derived	CSL Behring	Voncento	4	543,000	1	5,000
Factor VII deficiency						
Recombinant	Novo Nordisk	NovoSeven (mg)	3	3,114	2	2,659
Plasma-derived	Takeda	FEIBA	1	172,000	1	118,089
Factor XI deficiency						
Recombinant	Novo Nordisk	NovoSeven (mg)	1	187	1	7
Plasma-derived	Takeda	FEIBA	1	270,000	-	-
Bleeding disorder of unknown cause						
Recombinant	Novo Nordisk	NovoSeven (mg)	-	-	1	22
Plasma-derived	Takeda	FEIBA	-	-	1	167,000
Combined haemophilia A and von Willebrand disease						
Non-factor	Roche	Emicizumab (mg)	1	4,320	1	5,760
Recombinant	Novo Nordisk	NovoSeven (mg)	1	11	-	-
Plasma-derived	Takeda	FEIBA	1	207,000	1	60,000

Units in IU unless otherwise stated
Excludes issues of investigational products

Table 24 Non-trial products issued to treat people with acquired disorders, 2024/25 and 2025/26

Product type	Manufacturer	Product	2024/25		2025/26	
			People (n)	Units (IU)	People (n)	Units (IU)
Acquired haemophilia A						
Non-factor	Roche	Emicizumab (mg)	7	18,480	4	9,105
Recombinant	Takeda	Advate	1	5,000	1	2,000
	SOBI	Elocta	2	79,000	-	-
	Novo Nordisk	Esperoct	-	-	1	2,000
		NovoSeven (mg)	22	2,826	18	302,541
	Takeda	Obizur	50	4,014,500	56	4,347,000
	Pfizer	ReFacto AF	1	6,000	-	-
Plasma-derived	Baxter	Com FVII	1	42	-	-
	Takeda	FEIBA	95	8,535,400	113	10,050,012
	Octapharma	Fibryga	2	6	-	-
	CSL Behring	Voncento	1	5,000	2	7,200
Acquired von Willebrand disease						
Non-factor	Roche	Emicizumab (mg)	-	-	1	3,600
Recombinant	Takeda	Advate	5	27,000	6	22,000
	SOBI	Elocta	1	2,000	1	2,000
	Novo Nordisk	Esperoct	-	-	1	2,000
		NovoSeven (mg)	-	-	1	8
	Pfizer	ReFacto AF	-	-	1	6,000
	Takeda	Veyvondi	22	1,110,200	25	1,033,500
Plasma-derived	Takeda	FEIBA	-	-	1	77,000
	CSL Behring	Voncento	24	563,500	29	733,050
	Octapharma	Wilate	8	59,500	5	48,000
	LFB Biomedicaments	Willfact /Wilfactin	1	445,000	1	729,000
Other acquired factor deficiency						
Recombinant	Novo Nordisk	NovoSeven (mg)	-	-	1	54
Plasma-derived	BPL	BPL FXI	1	1,225	-	-
	CSL Behring	Beriplex	1	2,500	1	26,000
	Takeda	FEIBA	4	431,000	4	133,000
	Octapharma	Octaplex	1	2,500	-	-

Units in IU unless otherwise stated
Excludes issues of investigational products

Table 24: This shows products issued for people with an acquired inhibitor in 2024/25 and 2025/26, broken down by diagnosis and supplier.

Table 25 FEIBA® issues: breakdown by diagnosis, 2023/24 – 2025/26

Diagnosis	2023/24		2024/25		2025/26	
	People (n)	Units (IU)	People (n)	Units (IU)	People (n)	Units (IU)
Haemophilia A	16	2,428,000	18	2,224,000	10	708,000
Haemophilia B	1	10,000	1	45,000	2	78,100
von Willebrand disease	3	580,000	1	2,000	-	-
Factor VII deficiency	1	130,000	1	172,000	1	118,089
Factor XI deficiency	-	-	1	270,000	-	-
Bleeding disorder of unknown cause	1	8,000	-	-	1	167,000
Combined haemophilia A and von Willebrand disease	1	73,000	1	207,000	1	60,000
Acquired haemophilia A	98	8,384,500	95	8,535,400	113	10,050,012
Acquired von Willebrand disease	-	-	-	-	1	77,000
Other acquired factor deficiency	2	68,000	4	431,000	4	133,000
Total	**123**	**11,681,500**	**122**	**11,886,400**	**133**	**11,391,201**

Table 26 NovoSeven® issues: breakdown by diagnosis, 2023/24 – 2025/26

Diagnosis	2023/24		2024/25		2025/26	
	People (n)	Units (mg)	People (n)	Units (mg)	People (n)	Units (mg)
Haemophilia A	124	12,752	117	10,125	94	9,597
Haemophilia B	10	16,563	8	8,564	9	6,892
von Willebrand disease	5	3,394	8	1,994	7	2,130
Factor V deficiency	3	102	2	529	2	641
Factor VII deficiency	78	7,895	85	6,713	93	6,854
Factor XI deficiency	-	-	2	195	2	133
Glanzmann's Thrombasthenia	57	8,248	66	7,535	77	7,494
Bernard-Soulier syndrome	17	987	12	1,180	14	163
Other platelet disorder	1	21	-	-	1	1
Bleeding disorder of unknown cause	2	16	-	-	2	31
Other bleeding disorders	5	54	5	14	3	25
Combined haemophilia A and von Willebrand disease	-	-	1	11	-	-
Multiple diagnoses	-	-	1	199	-	-
Acquired haemophilia A	14	5,052	22	2,826	18	2,541
Acquired von Willebrand disease	1	144	-	-	1	8
Other acquired factor deficiency	1	120	-	-	1	54
Total	**318**	**55,348**	**329**	**39,885**	**324**	**36,564**

Table 27 Emicizumab issues: breakdown by diagnosis, 2023/24 – 2025/26

Diagnosis	2023/24		2024/25		2025/26	
	People (n)	Units (mg)	People (n)	Units (mg)	People (n)	Units (mg)
Haemophilia A	1,419	6,004,613	1,531	6,431,192	1,697	7,181,105
von Willebrand disease	1	1,680	-	-	2	2,160
Combined haemophilia A and von Willebrand disease	3	7,290	2	7,200	5	14,760
Acquired haemophilia A	5	7,726	7	18,480	4	9,105
Acquired von Willebrand disease	-	-	-	-	1	3,600
Total	**1,428**	**6,021,309**	**1,540**	**6,456,872**	**1,709**	**7,210,730**

Tables 25, 26 (previous page) **& 27** show in greater detail how much FEIBA, NovoSeven and emicizumab were issued for each diagnosis over the last three years. People with any hereditary or acquired bleeding disorder, either with or without inhibitors, are included. Some off-license issues of emicizumab to isolated people with von Willebrand disease and acquired haemophilia A are reported, although there is no estimate of off-label issues, or issues for reversal of over-anticoagulation, as this occurs outside haemophilia centres and is consequently not systematically collected. The rapid decline in the number of PwHA with inhibitors issued FEIBA following the introduction of emicizumab appears to have accelerated, and the number of units issued has fallen dramatically. NovoSeven issues for congenital haemophilia A have also declined over the last three years. It is now used in preference to FEIBA for surgery in people with FVIII inhibitors who are co-prescribed emicizumab. Issues of emicuzimab for von Willebrand disease, acquired haemophilia A and combined factors V and VIII deficiencies are presumed to reflect clinical trials or individual funding requests.

Figure 32 The proportion of people with congenital haemophilia A and an active inhibitor issued treatment products by year

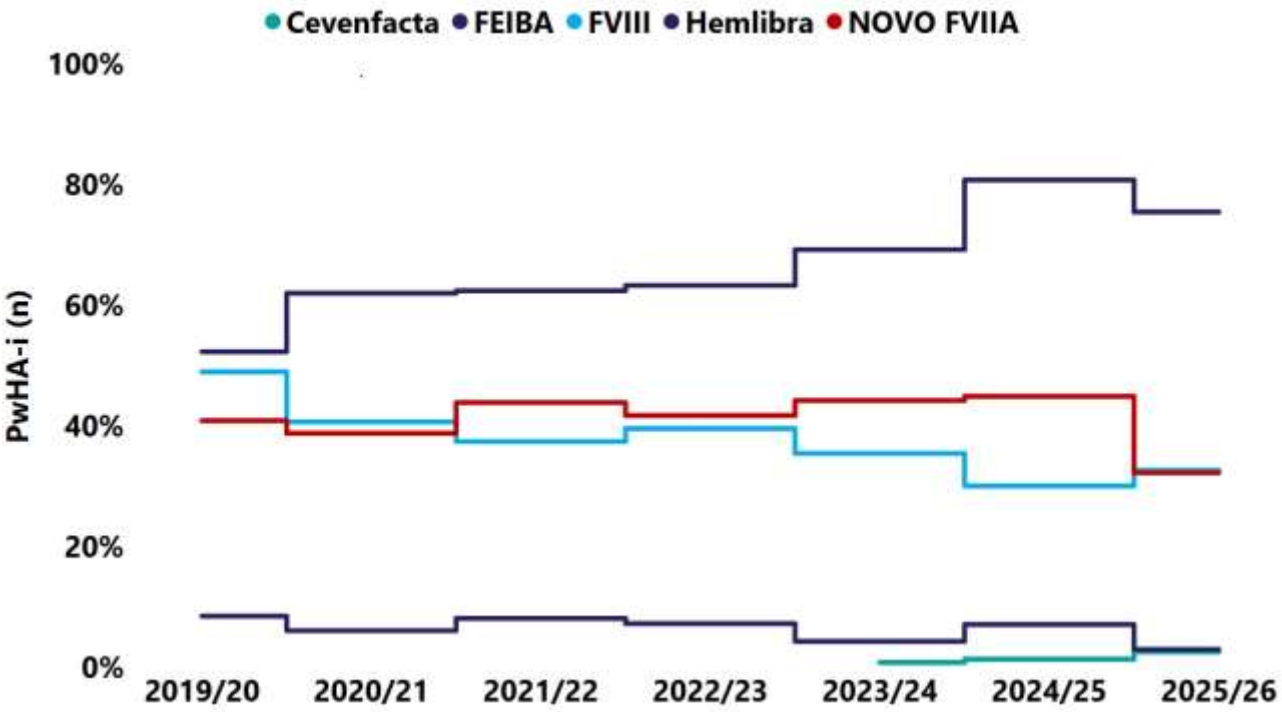


Figure 32: This shows the change in the proportion of PwHA and an inhibitor issued with FEIBA, NovoSeven, FVIII, emicizumab and cevenfacta since emicizumab was licensed for use in this group. People may be issued with more than one product during a given quarter. Novoseven, in particular, is often issued to people treated with other products. The introduction of emicizumab has led to a marked reduction in the use of FVIII and FEIBA in this group, although the proportion issued NovoSeven, which may be used for surgery and intercurrent bleeding in preference to FEIBA for people prescribed emicizumab prophylaxis, remained comparatively stable until the last year. The increase in the proportion of PwHA with inhibitors issued emicizumab appears to have reversed slightly over the last twelve months.

Figure 33 The proportion of people with acquired haemophilia A first registered April 2019 – March 2025 issued treatment products by months since registration

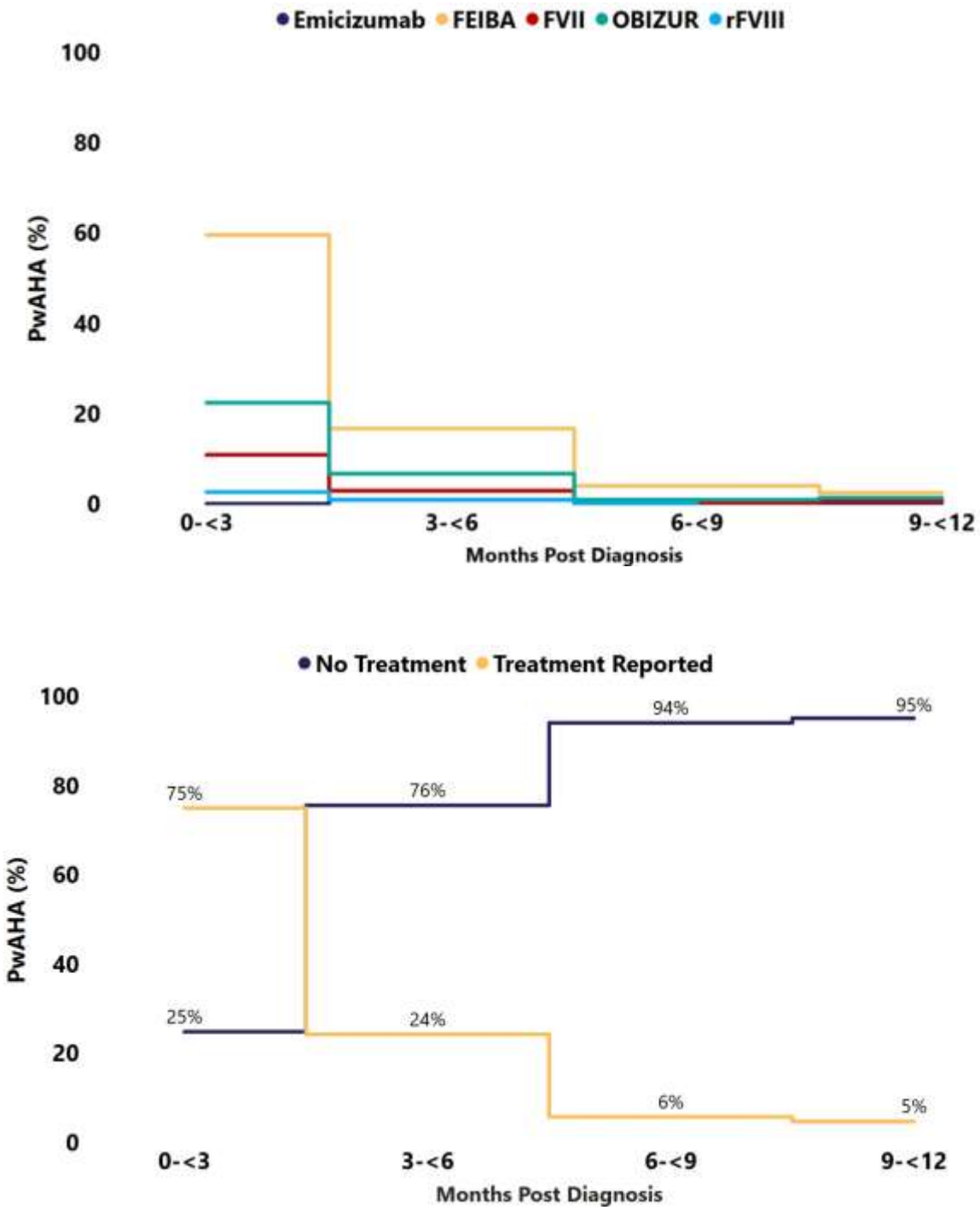


Figure 33: This shows the change in the proportion of surviving people with acquired haemophilia A (first registered between April 2019 and March 2025) issued with FEIBA, NovoSeven, Obizur, rFVIII and emicizumab by months since their first registration. This shows a rapid fall-off in the need for haemostatic treatment as they respond to immunosuppression. A small proportion of non-responders require long-term ongoing haemostatic support. .

Figure 34 Survival of people with acquired haemophilia A newly registered April 2021 – March 2026, from date of registration

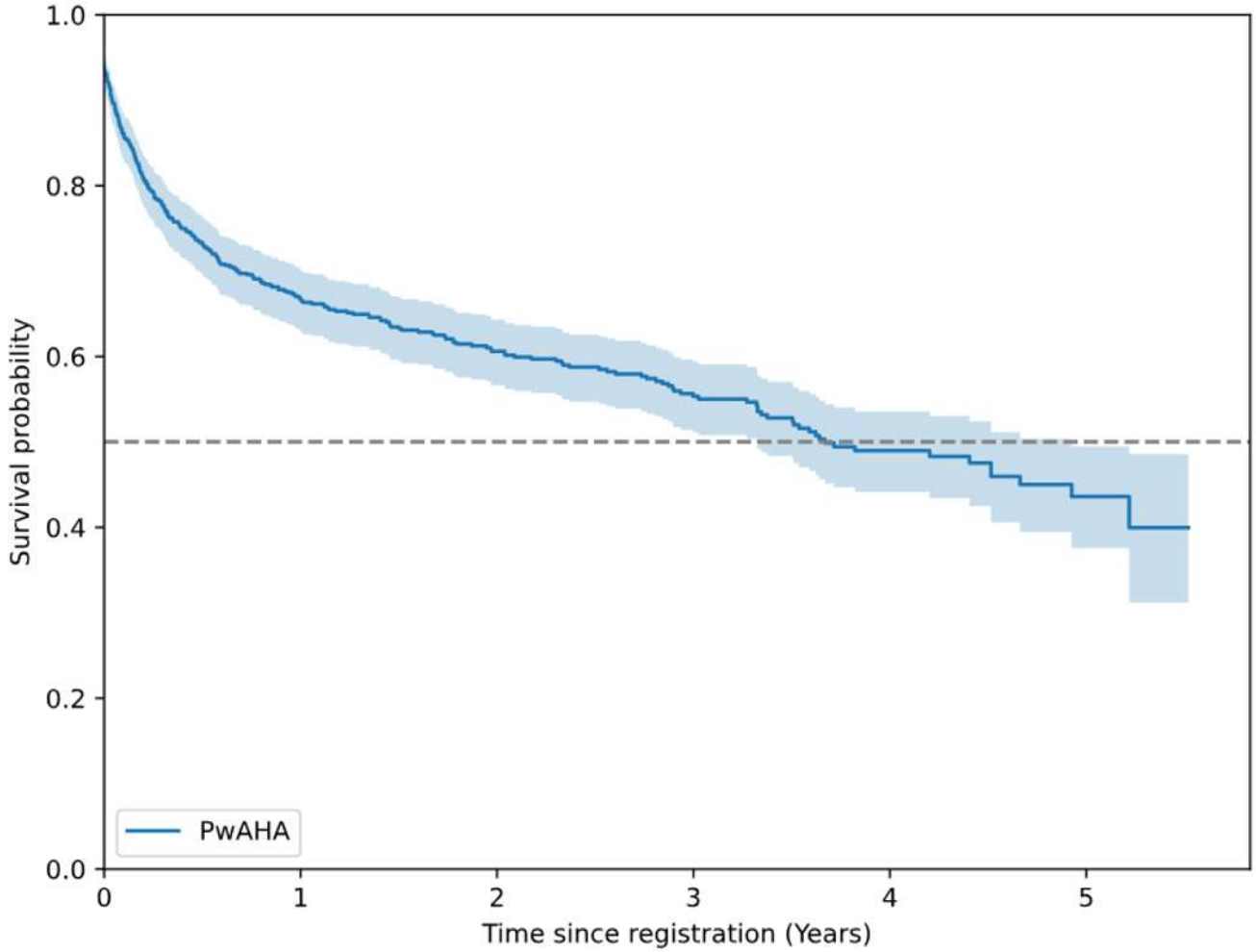


Figure 34: The median survival time of PwAHA from registration (years) is three years and eight months. The survival curve also shows significant early all-cause mortality, with 33% dying within a year of registration.

2.6 Other Bleeding Disorders

Table 28 People with other bleeding disorders registered and issued treatment products 2025/26

Diagnosis	Males (n)			Females (n)			Total (n)		
	Registered	Issued any product	Issued concentrate	Registered	Issued any product	Issued concentrate	Registered	Issued any product	Issued concentrate
Factor V deficiency	143	3	1	250	4	2	393	7	3
Factor VII deficiency	1,335	46	46	1,607	50	49	2,942	96	95
Factor X deficiency	205	21	21	272	24	23	477	45	44
Factor XI deficiency	2,069	19	19	3,112	29	28	5,181	48	47
Factor XIII deficiency	62	43	43	54	29	29	116	72	72
Prothrombin (factor II) deficiency	15	2	2	16	2	2	31	4	4
Dysfibrinogenemia	380	11	11	610	17	17	990	28	28
Hypofibrinogenemia	163	10	10	249	8	8	412	18	18
Hypodysfibrinogenemia	32	3	3	36	1	1	68	4	4
Afibrinogenemia	11	9	9	7	6	6	18	15	15
Bleeding disorder of unknown cause	345	12	10	2,461	9	9	2,806	21	19
Glanzmann's Thrombasthenia	99	39	38	135	43	40	234	82	78
Bernard-Soulier syndrome	78	5	5	94	11	10	172	16	15
Platelet-type Pseudo von Willebrand Disease	15	2	2	29	1	1	44	3	3
Other platelet disorder	1,213	1	1	2,592	2	2	3,805	3	3
Unknown platelet disorder	306	0	0	718	1	1	1,024	1	1
Combined factors V and VIII deficiencies	18	4	4	20	1	1	38	5	5
Acquired haemophilia A	392	85	39	386	62	33	778	147	72
Acquired von Willebrand disease	137	32	32	117	25	24	254	57	56
Other acquired factor deficiency	31	3	0	31	2	2	62	5	2
Other disorders	10	0	0	13	0	0	23	0	0
Awaiting confirmation	16	0	0	84	1	1	100	1	1
Total	**6,975**	**348**	**296**	**12,592**	**326**	**287**	**19,567**	**674**	**583**

Table 28: This shows the number of people with blood disorders other than haemophilia and VWD registered and issued products during the year. FVII was issued to two people with factor V deficiency, and FVIII was issued to a further person with factor V deficiency for surgery as they had low FVIII levels.

Table 29 People with selected other bleeding disorders registered and treated 2025/26, by factor level

Diagnosis	Factor level at birth (IU/dl)	Males (n)		Females (n)		Total (n)	
		Registered	Issued treatment products	Registered	Issued treatment products	Registered	Issued treatment products
Factor V deficiency	<5	19	3	43	3	62	6
	>=5	114	0	196	1	310	1
	Not known	10	0	11	0	21	0
	Total	143	3	250	4	393	7
Factor VII deficiency	<5	84	20	99	28	183	48
	>=5	1,203	26	1,448	21	2,651	47
	Not known	48	0	60	1	108	1
	Total	1,335	46	1,607	50	2,942	96
Factor X deficiency	<5	26	19	23	19	49	38
	>=5	158	2	226	4	384	6
	Not known	21	0	23	1	44	1
	Total	205	21	272	24	477	45
Factor XI deficiency	<5	159	13	184	9	343	22
	>=5	1,847	6	2,845	19	4,692	25
	Not known	63	0	83	1	146	1
	Total	2,069	19	3,112	29	5,181	48

Please note desmopressin issues are excluded

Table 29: It is acknowledged that these other disorders have no recognised classification of disease severity. However, the table above gives an impression of the range of registered levels.

Table 30 New registrations of other bleeding disorders 2025/26, by coagulation defect and gender

Diagnosis	Males (n)			Females (n)			Total (n)		
	Registered	Issued any product	Issued concentrate	Registered	Issued any product	Issued concentrate	Registered	Issued any product	Issued concentrate
Factor V deficiency	18	0	0	19	0	0	37	0	0
Factor VII deficiency	115	4	4	139	6	6	254	10	10
Factor X deficiency	19	2	2	21	0	0	40	2	2
Factor XI deficiency	164	3	3	246	8	7	410	11	10
Factor XIII deficiency	2	1	1	2	0	0	4	1	1
Prothrombin (factor II) deficiency	3	0	0	0	0	0	3	0	0
Dysfibrinogenemia	20	2	2	30	3	3	50	5	5
Hypofibrinogenemia	13	0	0	31	0	0	44	0	0
Hypodysfibrinogenemia	4	0	0	7	0	0	11	0	0
Afibrinogenemia	0	0	0	0	0	0	0	0	0
Bleeding disorder of unknown cause	43	2	0	397	1	1	440	3	1
Glanzmann's Thrombasthenia	29	7	6	32	4	2	61	11	8
Bernard-Soulier syndrome	13	0	0	16	0	0	29	0	0
Platelet-type Pseudo von Willebrand Disease	0	0	0	0	0	0	0	0	0
Other platelet disorder	119	0	0	259	1	1	378	1	1
Unknown platelet disorder	34	0	0	88	0	0	122	0	0
Combined factors V and VIII deficiencies	2	0	0	1	0	0	3	0	0
Acquired haemophilia A	79	62	29	65	51	27	144	113	56
Acquired von Willebrand disease	17	6	6	19	10	10	36	16	16
Other acquired factor deficiency	5	1	0	3	1	1	8	2	1
Other disorders	4	0	0	1	0	0	5	0	0
Awaiting confirmation	2	0	0	18	1	1	20	1	1
Total	**692**	**88**	**53**	**1,359**	**85**	**58**	**2,051**	**173**	**111**

Table 30: This table shows new registrations of bleeding disorders other than haemophilia and VWD during the year. This shows a disproportionately large number of newly registered females for all autosomal disorders, presumably reflecting referral bias of women with menorrhagia.

Table 31 Non-trial products issued to treat people with selected other bleeding disorders between 2025/26

Product type	Manufacturer	Product	Factor V deficiency		Factor VII deficiency		Factor X deficiency		Factor XI deficiency		Factor XIII deficiency	
			Units (IU)	People (n)	Units (IU)	People (n)	Units (IU)	People (n)	Units (IU)	People (n)	Units (IU)	People (n)
Recombinant	Novo Nordisk	NovoSeven (mg)	641	2	6,854	93	2	1	133	2	-	-
		NovoThirteen	-	-	-	-	-	-	-	-	1,560,000	48
	Pfizer	ReFacto AF	1,500	1	-	-	-	-	-	-	-	-
Plasma-derived	BPL	BPL FXI	-	-	-	-	-	-	81,698	44	-	-
		COAGADEX	-	-	-	-	4,200,900	39	-	-	-	-
	Baxter	Com FVII	-	-	1,046,520	2	-	-	-	-	-	-
	CSL Behring	Beriplex	-	-	-	-	118,000	2	2,000	1	-	-
		FXIII	-	-	-	-	-	-	-	-	45,000	2
		Fibrogammin P	-	-	-	-	-	-	-	-	782,000	36
	LFB	Hemoleven (LFB XI)	-	-	-	-	-	-	2,000	1	-	-
	Octapharma	Octaplas (bags)	65	4	-	-	42,000	1	1	1	-	-
		Octaplex	-	-	-	-	422,000	6	-	-	-	-
	Takeda	FEIBA	-	-	118,089	1	-	-	-	-	-	-

Units in IU unless otherwise stated.
Excludes issues of investigational products, desmopressin, rituximab and tranexamic acid

Table 31: This gives a breakdown of products issued during 2025/26 for people with other bleeding disorders, broken down by diagnosis and supplier. People may be issued multiple products. Although cross-diagnosis NHD-reported Octaplas issues sum to 65% of manufacturer-reported sales, it is believed that there may be further, unreported Octaplas issues for Factor V deficiency from local hospitals. ReFacto AF was issued to a person with factor V deficiency for surgery due to borderline low Factor VIII levels.

2.7 Adverse Events

2.7.1 Introduction and Adverse Event Assessment Panel

Pharmacovigilance is an increasingly important function of the database. Treatments are monitored for safety signals and drug-related adverse events, including poor efficacy, are reported to the manufacturer and, through them, to the regulators. Consequently, the conduct of post-license safety and efficacy studies has become a routine for the database. This function has assumed even greater prominence as we enter a new therapeutic era, using non-replacement drugs and antibodies with novel modes of action and with side effect profiles very different from the traditional replacement therapies that we are used to and which they may replace.

In response to this increasing need and the need for an objective, independent and robust evaluation of adverse events an SOP was developed for managing and evaluating adverse events in 2019 and 2021. Adverse Events (AEs) and Serious Adverse Events (SAEs) were defined as for GCP clinical trials. Where required, adverse event reports are further investigated by the Adverse Event Panel.

The Adverse Event Panel meet once a month by video conference to adjudicate on all SAEs. scoring their severity (1-5) and the potential relationship of the reported event to drug therapy (unrelated, possibly related, probably related, or definitely related), again using the same framework that would apply for AE and SAE reporting in GCP-standard clinical trials. Serious Adverse events may be evaluated more urgently by e-mail and ad-hoc meetings, if necessary. All reported adverse events are reviewed by the panel.

The NHD Adverse Event Assessment Panel membership is currently as follows:

Prof Charles RM Hay Chair, Representing NHD
Prof Pratima Chowdary,
Julia Spires HNA
Dr Sarah Mangles
Dr Rhona Maclean
Dr Mary Mathias, Representing the Paediatric Working Party
Dr Charles Percy, Representing the Inhibitor Working Party
Dr Kate Talks, representing the Data Management Working Party

Greg Shone from the Database. administers the meeting and produces the minutes but is not a member of the panel.

The group meets once a month by video conference, and the meetings are recorded to facilitate the production of accurate minutes. The group may meet or communicate between meetings, if required.

All adverse events reported to the database are considered by the group. Where further enquiries or follow up are required to resolve issues in relation to reported events, these are delegated to panel members to follow up and events are not “closed” until data queries have been resolved or enquiries have been exhausted..

Where adverse events are considered possibly or definitely drug-related, the event is reported to the manufacturer and, through them, to the regulator.

Most adverse events are reported to the database spontaneously soon after they occur, using the electronic reporting system. Many adverse events are unresolved at the time of reporting and require follow up from the database and CMWP before the report can be concluded.

Causes of death are under-reported by centres. Where a PwBD has died at home or in another hospital, the centre may not have been informed of the death, and it can be difficult to find out the cause of death if the PwBD does not die in the base-hospital, since the medical records are sent back to the family practitioner committee after death. The NHD has an arrangement with NHS Digital

and for NHS Scotland (but not for Northern Ireland) for them to share death certification data for all PwBD registered with the database. This data comes through quarterly, and more than half of our data on death and the causes of death are derived from those sources. The database will inform the haemophilia centre of deaths notified through NHS Digital but not notified by the centre since the centre may otherwise be unaware that their PwBD has died.

The extent of adverse event reporting varies considerably between centres and, it is clear, that some centres are under-reporting, or not reporting or recording adverse events. **Table 32** shows adverse event statistics over three years from eight anonymised centres chosen purely to demonstrate the range of adverse event reporting by different centres. Group summaries across all centres are also shown. We will shortly send all centres their adverse event reporting statistics for this year and last and the group mean for comparison so that they are better able to review their adverse event reporting practice and to see if it has changed in the last 12 months.

Table 32 Adverse Events Reporting by Centre

PwBD registered at centre (n) (2025)	Mean events reported per 100 PwBD per year, April 2024 - March 2025	PwBD registered at centre (n) (2026)	Mean events reported per 100 PwBD per year, April 2025 - March 2026
1994	2.0	2074	0.7
757	0.8	820	0.5
1946	0.6	1981	0.3
2995	1.0	3013	0.7
2995	0.3	2738	0.3
1951	0.1	2052	0.0
809	0.0	904	0.3
852	0.0	874	0.0
Median (IQR) across all 65 centres		Median (IQR) across all 65 centres	
479 (181 - 993)	0.25 (0.0 - 0.7)	484 (176 - 1031)	0.25 (0.0 - 0.5)

Reports on the following events are actively solicited with monthly reminder “orange email*”. (*successor to the orange reminder postcard!):

Acute or Allergic reactions
Deaths
Infections
Malignancy
Inhibitors and anti-drug antibodies
Intracranial Haemorrhage (paediatric and adult)
Neurological Events
Thrombotic events (including MAHA)
Unexpected poor efficacy
“Other” events

Adverse events are summarised overleaf, and serious adverse events described in more detail. Personal details have been supressed to minimise the risk of a breach of confidentiality.

All adverse events reported by centres who participate in the European Haemophilia Safety Surveillance (EUHASS) program are anonymised and automatically forwarded via the NHD website to avoid the need for double-reporting.

Table 33 Summary of Adverse Events reported between April 2025 & March 2026

Event	People (n)	Events (n)
Allergy Event	5	5
Death Event	434*	434*
ICH Event	20	22
Infection Event	1	1
Inhibitor Event	21**	21**
Malignancy Event (Liver Related)	1	1
Malignancy Event (Not Liver Related)	37	38
Neurological Event	1	1
Other Event	8	12
Poor Efficacy Event	5	5
Thrombotic Event	9	9

**Death events include those reported by NHS Digital in addition to those reported via the adverse event reporting system.*
***Inhibitor events include those reported via quarterly returns (see Table 22) in addition to those reported via the adverse event reporting system.*

Table 33: This summarises the number and category of adverse events *fully* reported to the database by haemophilia centres during 2025/26. These events are described in greater detail in the tables that follow.

Although only 106 deaths were reported to the database by centres, we are aware of 434 deaths in all bleeding disorders when combined with those identified via NHS Digital, who report death certification data to the database on a quarterly basis. Many of these deaths will have occurred in the community or in other hospitals and the haemophilia centre may be unaware of them or of the cause of death. The database will share this data with the managing haemophilia centre in future so that they can complete their record. These deaths and their primary cause of death is summarised in the section on mortality.

Similarly, although only six inhibitor events were reported to the database by centres, we are aware of a total of 21 new inhibitors reported in 2025/6 (13 in PwSHA, 4 in PwNSHA, 1 in PwHB and 2 in PwVWD) when the quarterly returns inhibitor flag is examined in addition to the adverse event reports. Outstanding event details on all these additional inhibitor reports are routinely requested. One inhibitor event reported via the adverse event reporting system this year relates to an inhibitor first detected last year.

All five reported allergic events were considered definitely (2), probably (2), or possibly (1) drug related and were reported to the manufacturer. All inhibitors were considered to have arisen secondary to factor replacement. None of the thrombotic events were considered to be treatment-

related. Of the "other" events, one was considered to be possibly treatment-related. Adverse events considered definitely, probably or possibly treatment-related were reported to the manufacturer.

In future, events of special interest should probably not merely be broken down by bleeding diagnosis, treatment, and treatment-relationship, if any, but also expressed in events per period of risk so that it is possible to compare the incidence of such events in different treatment risk-groups.

Table 34 Allergic/ other reactions reported between April 2025 & March 2026

Event date	Diagnosis	Event	Material	Relationship to material	Outcome
2025/26	Haemophilia A	Reaction occurred within thirty minutes of administration	Esperoct	Definite	Resolved with outpatient treatment
	Haemophilia A	Flushing, mild tachycardia and 'tight' throat within a minute after first dose	Altuvoct	Definite	Resolved with outpatient treatment
	Bleeding disorder of unknown cause	Visual disturbance in peripheries of left eye when given as bolus- fine when given over 40 minutes	FEIBA	Possible	Resolved without treatment
	von Willebrand disease	Symptoms consistent with anaphylactic reaction	Veyvondi	Probable	Hospitalisation with treatment
	von Willebrand disease	Coldness in left side of chest when infused	NovoSeven	Probable	Not reported

Table 34: In each case the events were evaluated by the Adverse Events Assessment Panel and reported to the manufacturer.

Table 35 Infection Events reported between April 2025 & March 2026

Event date	Diagnosis	Event	Cause of Event	Material	Relationship to material
2025/26	Haemophilia B	Infection	E. coli	Alprolix	Unrelated

Table 36 Intracranial haemorrhage (all ages) reported between April 2025 & March 2026

Event date	Diagnosis	Age group (years)	Trauma Present	Maintenance therapy	Outcome
2024/25	Haemophilia A, severe	18-39	Fell and hit head	Prophylaxis	Survived
	von Willebrand disease, type 2A*	>=70	Slipped and hit head	On demand	Alive
			Fell at home		Alive
			Fell at home		Deceased
2025/26	Haemophilia A, severe	<1	Born with significant bruising to the back of the head	Prophylaxis	Alive
	Haemophilia A, severe	<1	Venteuse method used during delivery	Prophylaxis	Alive
	Haemophilia A, severe	10-17	None reported	Prophylaxis	Alive
	Haemophilia A, severe	40-69	None reported	Prophylaxis	Alive
	Haemophilia A, moderate	>=70	None reported	Prophylaxis	Deceased
	Haemophilia A, mild	18-39	Possible bone injury	On Demand	Alive
	Haemophilia A, mild	>=70	None reported	Prophylaxis	Alive
	Haemophilia A, mild	>=70	Unwitnessed fall	On Demand	Alive
	Haemophilia B, mild	40-69	Fell and hit head	On demand	Alive
	von Willebrand disease, type 1	>=70	None reported	On demand	Alive
	Factor XI deficiency	1-9	None reported	On demand	Alive
	Dysfibrinogenaemia	40-69	Fell and hit head	On demand	Alive
	Glanzmann's Thrombasthenia	18-39	Hit head	On demand	Deceased
	Acquired Haemophilia A	>=70	Fell and hit head	On Demand	Alive
	Acquired haemophilia A	>=70	None reported	ITI	Deceased
	Acquired von Willebrands	>=70	None reported	On Demand	Deceased
	Acquired von Willebrands	>=70	Fell	Prophylaxis	Alive
	Acquired factor V deficiency	>=70	None reported	On Demand	Alive

**Please note these three events relate to one PwVWD*

Table 37 Inhibitors reported between April 2025 & March 2026

Event date	Diagnosis	Age group (years)	Material	Exposure days
2024/25	Haemophilia A, severe	10-19	Elocta	<=50
2025/26	Haemophilia A, severe	<1	Nuwiq	<=50
	Haemophilia A, severe	1-9	Elocta	<=50
	Haemophilia A, severe	1-9	Elocta	<=50
	Haemophilia A, mild	40-69	Advate	<=50
	Haemophilia B, severe	1-9	Idelvion	>50

Table 37: Full reports were submitted for six inhibitors between April 2025 and March 2026. These included four relating to PwSHA, one relating to a PwNSHA, and one relating to a PwSHB.
See Table 22 for further details of new, ongoing and historic inhibitors.

Table 38 Malignancy Events reported between April 2025 & March 2026

Event date	Malignancy	People (n)
2015/16	Leukaemia & Myeloma	1
2022/23	Genitourinary	1
2023/24	Breast	1
	Gastrointestinal	1
	Other	2
2024/25	Breast	1
	Gastrointestinal	1
	Leukaemia & Myeloma	1
	Prostate	2
2025/26	Breast	6
	Gastrointestinal	3
	Genitourinary	3
	Hepatocellular carcinoma	1
	Leukaemia & Myeloma	1
	Lung	4
	Lymphoma	2
	Prostate	2
	Skin	2
	Other	4
	Total	**38**

Table 38: This shows the malignancy events reported between April 2025 and March 2026, although the event date precedes April 2025 for 11 of the 38 cases. The bleeding diagnosis has not been shown since the malignancies reflect both the types and frequencies seen in the general

population, as a broad generalisation, and are found in all groups of people with bleeding disorders with no specific associations. The exception to this is hepatocellular carcinoma. The HCC report above relates to a person with a history of HCV.

Table 39 Poor Efficacy Events reported between April 2025 & March 2026

Event date	Diagnosis	Event	Material	Trauma Present
2024/25	Haemophilia A	Spontaneous bleed to L ankle, presented with worsening pain which improved with Elocta	Hemlibra	None
	Haemophilia B	Soft tissue bleed L upper limb, R ankle bleed, L bicep bleed, L elbow bleed, R ankle bleed, L elbow bleed, all within two months	Idelvion	Not reported
2025/26	Haemophilia A	Did not increment FVIII levels	Esperoct	None
		Suspected mild soft tissue bleed	Esperoct	Not reported
		Bleed not responding to treatment	Esperoct	Not reported

Table 40 Thrombotic Events reported between April 2025 & March 2026

Event date	Diagnosis	Event	Type of treatments	Related to treatment material?
2023/24	Combined factors V and VIII deficiencies	Pulmonary embolism	On demand	No
2024/25	Mild haemophilia A	Thrombotic stroke	On demand	No
	FLI1-related platelet disorder	Arterial embolism	On demand	No
2025/26	Severe haemophilia A	Central venous line	Prophylaxis	No
	Severe haemophilia A	Deep vein thrombosis	Prophylaxis	No
	von Willebrand disease	Thrombotic stroke	Concomitant drugs	No
	Factor VII deficiency	Pulmonary embolism	On demand	No
	Factor XI Deficiency	Deep vein thrombosis	On demand	No
	Acquired haemophilia A	Deep vein thrombosis	On demand	No

Table 41 Neurological Events reported between April 2025 & 2026

Event date	Diagnosis	Event	Cause of Event
2025/26	Mild haemophilia A	Cardioembolic stroke	Received Advate for TAVI. Procedure complicated by dysphasia. Acute frontotemporal infarct.

Table 42 Other Events reported between April 2025 & March 2026

Event date	Diagnosis	Event	Material	Relationship to material	Outcome
2024/25	von Willebrand disease	Acute bleeding at the hepatic flexure	Willfact /Wilfactin	None	Right hemicolectomy
2025/26	Severe haemophilia A	Groin abscess	Hemlibra	None	Debridement of right groin necrotic hematoma
	Severe haemophilia A	Football injury to back of knee/top of calf muscle	ReFacto AF	None	Extra factor doses taken before attending hospital. No further extra doses required.
	Severe haemophilia A	Visual disturbance, chest tightness and headache after dose	Esperoct	Possible allergic reaction	Not reported
	Severe haemophilia B	Sleep disturbance, anxiety, mania, pressure of speech and paranoia	Hemgenix	None	Treated with zopiclone and lorazepam. Mood normalised as prednisolone dose reduced. Prednisolone wihtdrawn.
	Severe haemophilia B*	Felt cold evening after infusion	Hemgenix	None	Not reported
		Feverish & fatigue symptoms over weekend after 5K walk	Hemgenix	None	Not reported
		Fatigue and night sweats over weekend	Hemgenix	None	Resolved
		Night sweats Saturday, feeling cold, unable to warm up Sunday	Hemgenix	None	Not reported
	von Willebrand disease	Fell and hit head. ED staff administered Octaplex in error.	Octaplex	None	Incident form completed
	Acquired Haemophilia A	Admission with neutropenic sepsis	Rituximab	None	Four weekly infusions rituxima. FVIII normalised. Recurrent neutropenia on monitoring. Received G-CSF.

**Please note these four events relate to one PwSHB*

These events were adjudicated by the membership of the Co-Morbidities Working Party.

2.8 Mortality

Table 43 Causes of death in people with congenital haemophilia A and B between April 2025 & March 2026

Cause of Death	Number of people with congenital haemophilia A by factor VIII level (IU/dl)			Number of people with congenital haemophilia B by factor IX level (IU/dl)		
	<1	>=1	Total	<1	>=1	Total
Bleeding	2	4	6	0	0	0
Cancer	1	18	19	1	5	6
Cardiomyopathy	0	2	2	0	0	0
Frailty/ dementia	0	15	15	0	1	1
Haemopericardium	1	0	1	0	0	0
Infection (bacterial)	2	7	9	0	5	5
Ischaemic heart disease	3	3	6	0	1	1
Pneumonitis	0	0	0	0	1	1
Suicide	0	1	1	0	0	0
Not known	2	7	9	0	1	1
Total	**11**	**57**	**68**	**1**	**14**	**15**

Tables 43 & 44 (overleaf): These show the causes of death amongst people with haemophilia A and B (including carriers), broken down by haemophilia severity (Table 43) and for other bleeding disorders (Table 44) during 2025/26. These include centre reports for the whole of the UK and death certification data provided by NHS Digital for England and Wales and NHS Scotland. We do not have death certification data for Northern Ireland, though we do have centre reports. The proportion of PwBD whose cause of death is unknown has decreased since last year. Even NHS digital are unable to provide the cause of death in some registrants whose registration details may have been incorrect.

Table 44 Causes of death in people with other bleeding disorders between April 2025 & March 2026

Cause of Death	Number of people by bleeding disorder					
	Von Willebrand disease	Acquired haemophilia A	Acquired von Willebrand disease	Other acquired factor deficiency	Other bleeding disorders	Total
Acquired haemophilia A	0	4	0	0	0	4
Bleeding	6	5	1	1	9	21
Cancer	17	9	6	1	30	63
Frailty/ dementia	13	14	1	0	7	35
Infection (bacterial)	18	29	1	1	29	77
Ischaemic heart disease	5	14	1	0	18	38
Liver failure	0	0	0	0	5	5
Stroke	0	2	1	0	3	6
Thrombosis - venous	0	2	0	0	1	3
Other	7	5	0	0	7	19
Not known	22	22	4	2	30	80
Total	**88**	**106**	**15**	**5**	**139**	**351**

Figure 35 Cumulative incidence of deaths where primary cause of death is reported to be hepatocellular carcinoma or liver failure in people with bleeding disorders in the UK 1969 - 2025

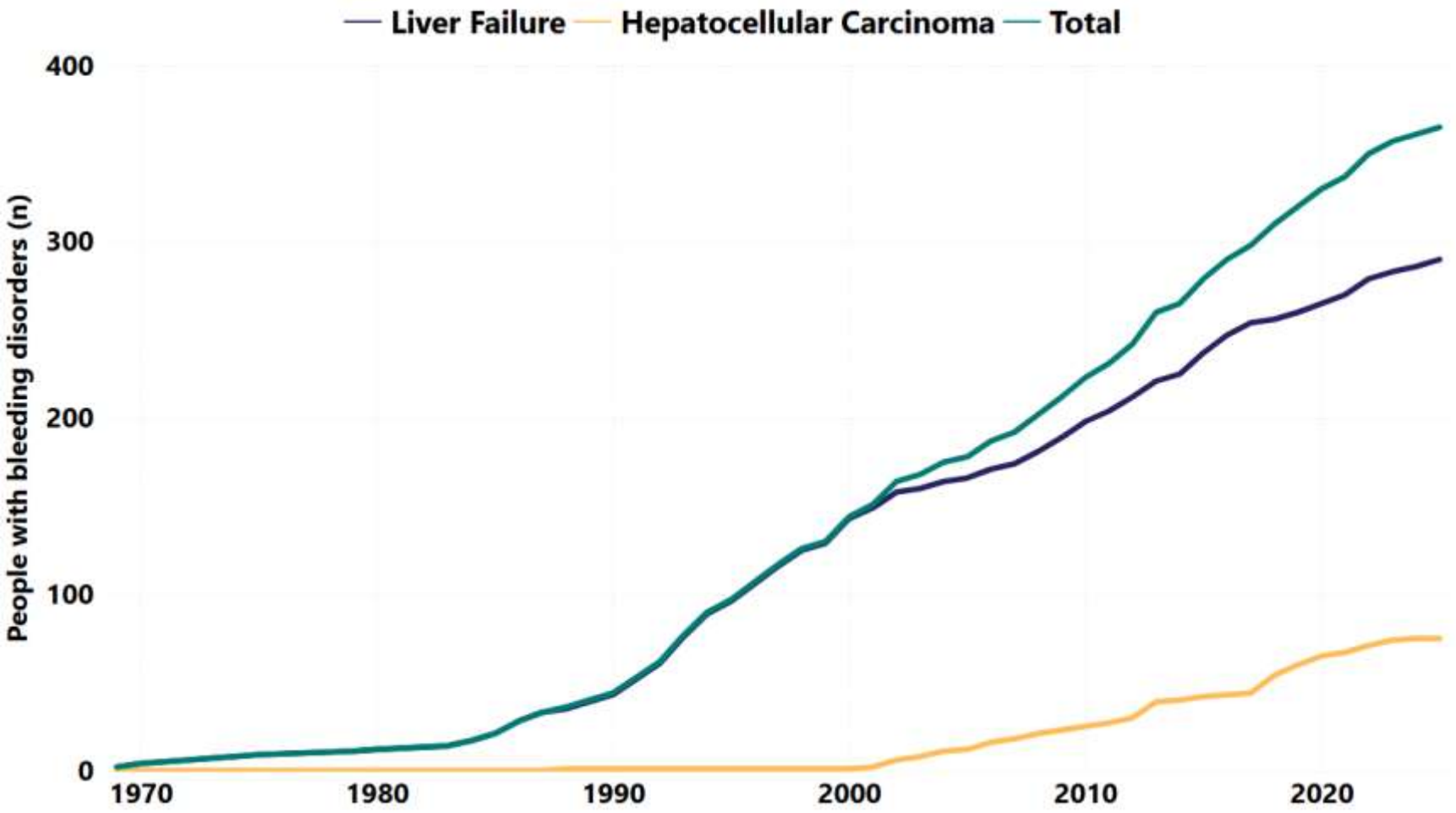


Table 45: Deaths where primary cause is reported to be hepatocellular carcinoma or liver failure by HIV/HCV status in people with bleeding disorders in the UK 1969 – 2025

Year	Hepatocellular Carcinoma				Liver Failure				Total
	HIV positive	HCV positive	Exposed to an at-risk product, HIV/HCV status not known	HCV negative or status not known	HIV positive	HCV positive	Exposed to an at-risk product, HIV/HCV status not known	HCV negative or status not known	
1969-1974	0	0	0	0	0	4	3	1	8
1975-1979	0	0	0	0	0	0	3	0	3
1980-1984	0	0	0	0	1	0	3	2	6
1985-1989	0	0	1	0	7	2	12	1	23
1990-1994	0	0	0	0	30	11	7	2	50
1995-1999	0	0	0	0	19	15	4	2	40
2000-2004	1	8	0	1	19	13	1	2	45
2005-2009	4	6	1	1	11	11	1	2	37
2010-2014	0	12	5	0	3	21	0	12	53
2015-2019	1	13	2	4	0	13	0	22	55
2020-2025	0	7	1	7	0	5	1	24	45
Total	**6**	**46**	**10**	**13**	**90**	**95**	**35**	**70**	**365**

Figure 35 (previous page) **and Table 45**: This shows deaths where either liver failure or hepatocelular carcinoma is reported to be the primary cause of death. Liver disease may have been a contributory cause of death in other cases, but that is far more difficult to determine and quantify, and we do not have complete data. The table documents the number whose death certificate listed liver disease as the principal cause of death or who were reported to the NHD by their centre as having died from complications of HCV (i.e. cause 1A on the death certificate). Liver disease may have been a subsidiary contributory factor in other deaths although not listed as the primary cause.

Deaths from hepatocellular failure or hepatocellular carcinoma have not levelled off despite successful HCV eradication from almost all people with bleeding disorders infected with that agent. As HCV has now been eradicated from almost all surviving people, one might expect a reduction in the incidence of hepatocellular carcinoma (HCC), which declines after viral eradication, even in the presence of ongoing cirrhosis. It is sobering, however, that new cases of hepatocellular carcinoma continue to be reported, occurring as a consequence of the legacy of serious liver disease in some PwBD. A reduction in this complication of hepatitis C may take some time to become evident. There may also be a delay before a further reduction in deaths from hepatocellular failure is seen, as some people have advanced cirrhosis with hepatocellular failure and not all are suitable for transplantation or have a donor. However, successful viral eradication will result in complete recovery of early cirrhosis or less advanced liver disease, and those individuals should not go on to develop advanced cirrhosis and will have a greatly reduced risk of HCC, which usually complicates cirrhosis.

3.0 Haemtrack Annual Report for the calendar year 2025

Introduction

This report is reported by calendar year rather than by financial year since 10% of the data is reported on paper, incurring a significant delay.

Haemtrack is used by people to report home therapy to their haemophilia centre and so its use is not limited to haemophilia A or B but includes other, rarer, bleeding disorders for which people also use home therapy. Both haemophilia centres and people vary in their reporting compliance with Haemtrack and so the quality of individual person self-reported data varies and the proportion of people using the system also varies from centre to centre.

In general, data quality is improving. Reporting compliance is best for severe haemophilia A and B and less good for von Willebrand's disease and rarer conditions but is improving in those conditions. This data is extremely valuable however and we would urge centres to press their PWBD to report in all their home therapy so that we are in a better position to assess relative efficacy of different products and regimens.

Haemtrack should become a routine part of home-therapy management and a valuable tool for the review and optimisation of home-therapy and for person education. For that to happen, compliance will have to be reinforced by Health Care Professionals (HCP's) reviewing Haemtrack records with people in clinic and checking the data for accuracy before downloading into HCIS, where it should be checked by HCPs prior to uploading into the National Haemophilia Database.

Haemtrack should also be used in multidisciplinary team meetings (MDTs). Many haemophilia centres already do this and in those centres recruitment and data quality are steadily improving. This requires a consistent investment in time by the centre staff which results in improving compliance with both home therapy and record keeping.

Some haemophilia centres appear not to have realised the full clinical utility of this reporting system and consequently return sub-optimal data, which may reflect some degree of non-engagement by both HCPs and their PWBD. It is important to demonstrate to the person, by referring to Haemtrack data on screen in clinics, that collecting and reporting treatment data is useful for their clinical management, and that its collection is not just an empty bureaucratic exercise.

Haemtrack Update

Haemtrack continues to be a fundamentally important component of the UKHCDO Haemophilia IT Strategy. It integrates with the Haemophilia Clinical Information System (HCIS) and the National Haemophilia Database (NHD) providing PwBD-entered data on treatments and bleeds that is unavailable from any other source. The data from Haemtrack is invaluable to support centres in the management of therapy for PwBD and optimising treatment regimens, whilst also providing its data nationally to support research and introduction of new treatments and regimens.

We have extended the use of Haemtrack to inpatient use (data entered by centre staff) so that it will provide a complete treatment record. Some centres are using this routinely and others not. We would encourage the universal adoption of inpatient use of Haemtrack so that the treatment record becomes complete.

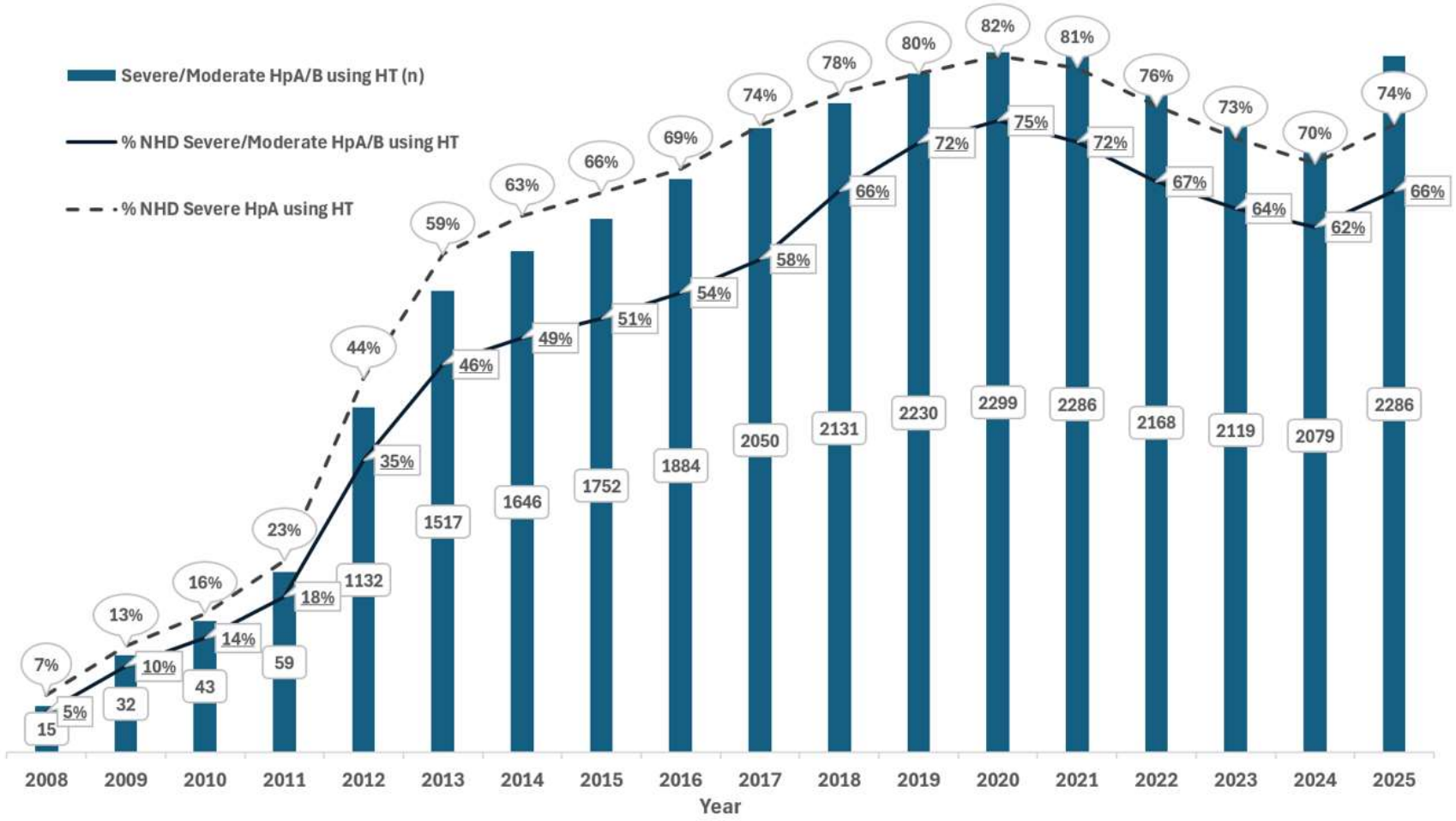
3.1 People's Haemtrack Usage Analysis

3.1.1 Overall

Figure 1 (overleaf) presents an overview of people with severe and moderate haemophilia A or B using Haemtrack from 2008 to 2025. The blue columns give the numbers of people that use Haemtrack, and the lines show the proportion of NHD people who use Haemtrack. This illustrates rapid growth in 2012, when recruitment was the subject of a CQUIN and increased growth from 2017 when Haemtrack became a condition for access to new treatments. Figure 1 also reveals that there has been a gradual rise in the rate of recruitment, especially in severe haemophilia A cohort but that this has tailed off for three years but has improved in the past year.

Among people issued treatment recorded in the NHD, 59 of 160 people with type 3 VWD (36.9%), and 64 of 438 people with congenital bleeding disorders other than HA, HB or VWD (14.6%) reported treatments to Haemtrack.

Figure 1 Number of people using Haemtrack and recruitment rate, 2008-2025



3.1.2 Haemtrack usage analysis at centre level - people with severe haemophilia

Figures 2 and 3 display the proportion of people with severe haemophilia A/B using Haemtrack in each CCC (Figure 2) and HC (Figure 3).

Figure 2 Comparison of recruitment to Haemtrack by centre for people with severe haemophilia A/B: Comprehensive Care Centres (CCCs) in 2025

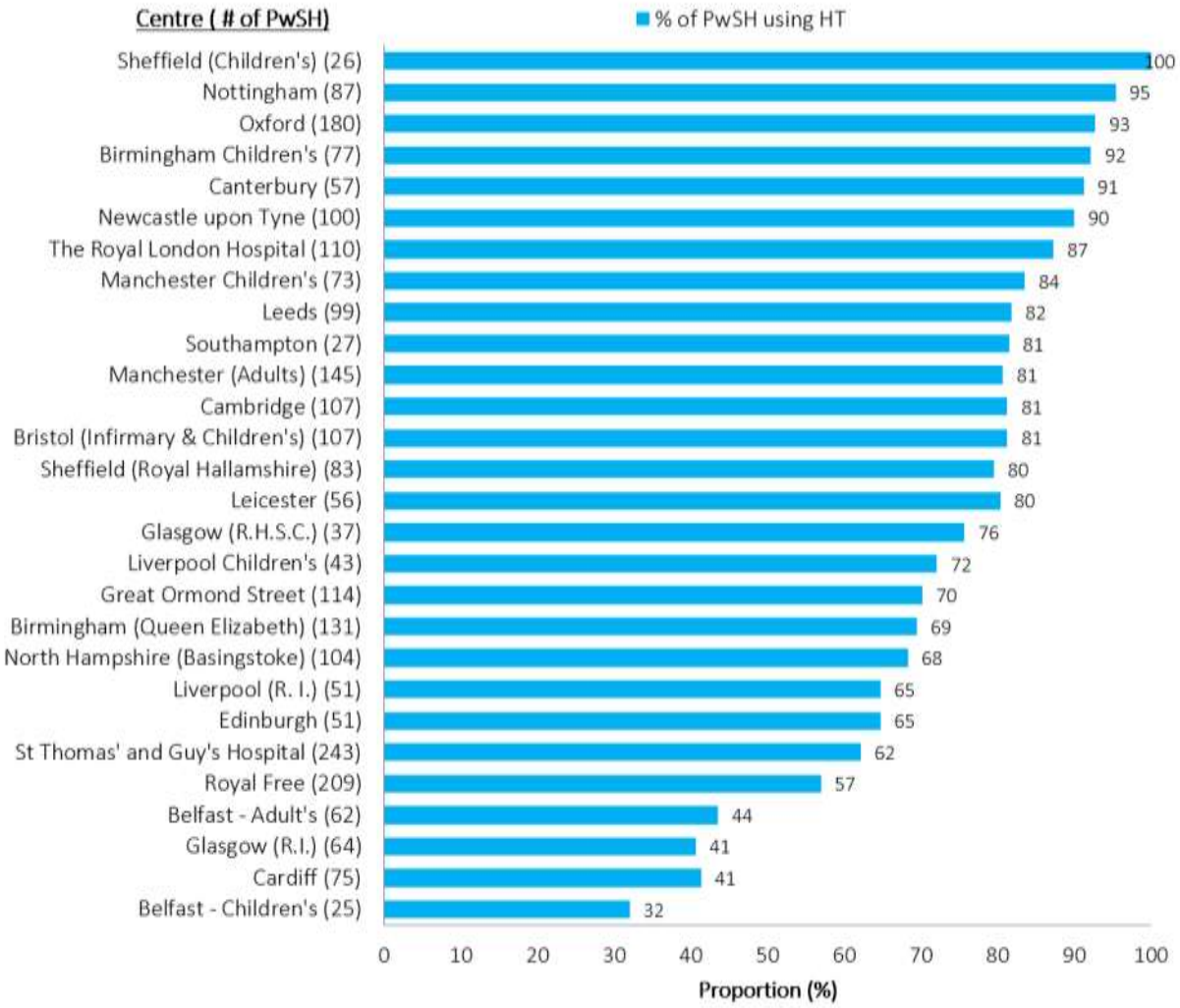
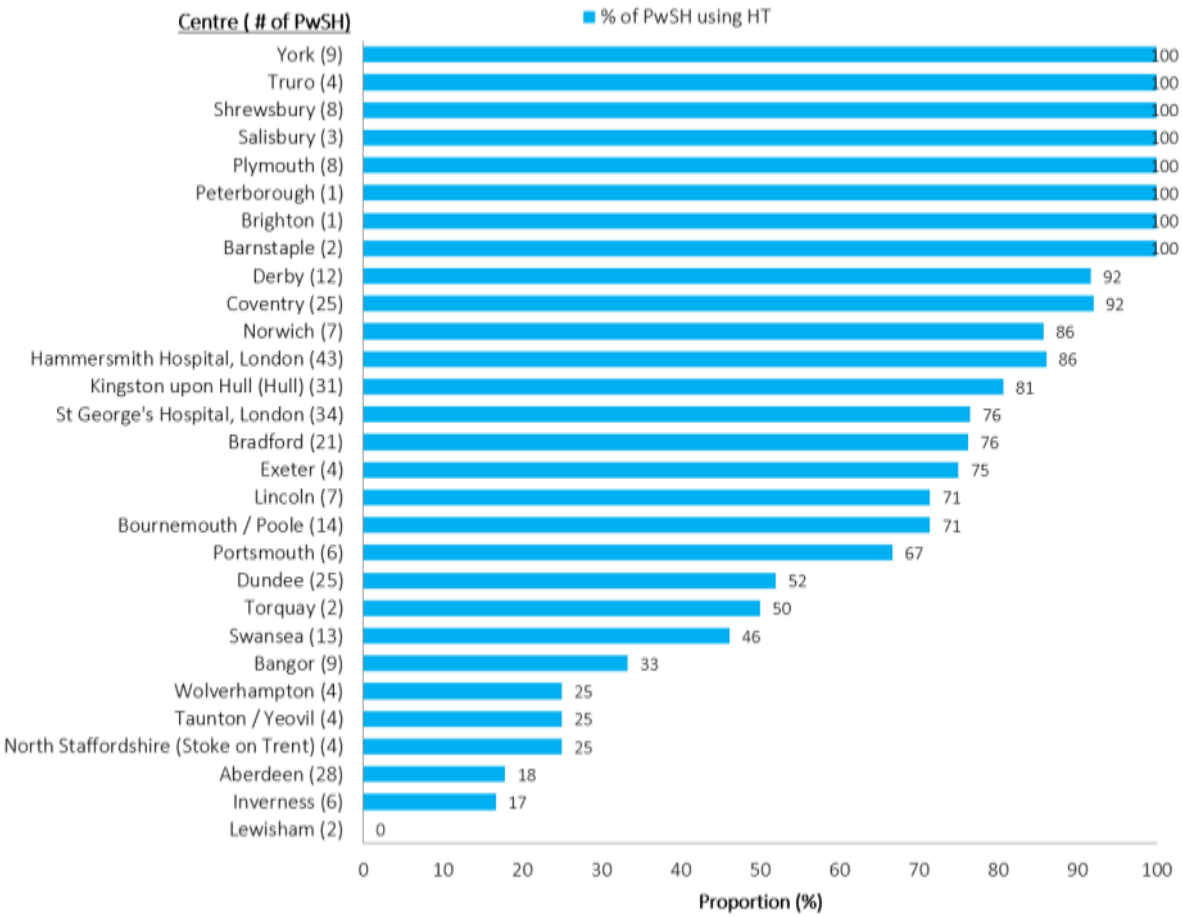


Figure 3 Comparison of recruitment to Haemtrack by centre for people with severe haemophilia A/B: Haemophilia Centres (HCs) in 2025



4. Data Management Working Party

Membership

Chair:	Dr Gary Benson
Commissioner representative:	Will Horsley
Co-Directors of the National Haemophilia Database:	Professor Pratima Chowdary
	Professor Charles Hay
Haemophilia Nurses Association representative:	Emma Franklin
Haemophilia Physiotherapists Group representative:	Dr David Stephensen
Haemophilia Society representatives:	Kate Burt
	Debra Morgan
MDSAS representative:	Dr Rob Hollingsworth
PwBD representatives:	William McKeown
	Paul Sartain

Representatives of Northern Ireland, Scotland and Wales:

Northern Ireland	Dr Gary Benson
Scotland	Dr Ryan Rodgers
Wales	Dr Samya Obaji

UKHCDO Clinical Leads:

Gene Therapy	Dr Paul Batty
Haemtrack	Dr Kate Talks
Musculoskeletal	Dr Paul McLaughlin
Rare bleeding disorders	Dr Gill Gidley

UKHCDO Working Party Chairs/ co-chairs:

Co-morbidities Working Party	Dr Susie Shapiro
Genetics Working Party	Dr Suthesh Sivapalarantnam
Inhibitor Working Party	Dr Charles Percy
Musculoskeletal Working Party	Dr Gary Benson
	Dr Paul McLaughlin
Paediatric Working Party	Dr Mary Mathias
Von Willebrand Working Party	Dr Carolyn Millar
Laboratory Working Party	Dr Annete Bowyer
	Dr Andrew Page
Women and Bleeding disorders Working Party	Dr Nicola Curry
Peer Review Working Party	Dr Sarah Mangles

UKHCDO Executive Committee:

Chair	Professor Pratima Chowdary
Vice Chair	Dr Gary Benson
Secretary	Dr Mary Mathias
Treasurer	Dr Sarah Mangles

Members of the NHD as nominated by the Director(s) of the National Haemophilia Database:

NHD Manager	Andrew McNally
Business Support Partner - Administration & Executive Support	Greg Shone
Data and General Administrators	Anna Connolly
	Grace Leach
Head of Data Analytics	Dr Hua Xiang
Data Scientist	Dennis Glover
Data Analysts	James Chetter
	Ben Palmer

Over the past twelve months, the UKHCDO Data Management Working Party has delivered a significant programme of work focused on modernising national haemophilia data systems and strengthening the infrastructure needed to support clinical care, research and regulatory requirements. Central to this work has been the continued development of NHD2, including new PwBD registration processes, integrated consent management, adverse event reporting, quarterly returns, gene therapy data collection and enhanced reporting capabilities. Additional developments to Haemtrack and HCIS have improved the collection and accessibility of PwBD data across the UK.

The Working Party has also made substantial advances in information governance and data security. The achievement and maintenance of ISO 9001, ISO 27001 and ISO 14001 accreditations reflect the organisation's commitment to quality, information security and environmental management. Governance arrangements have been strengthened, ensuring that national haemophilia data continues to be managed securely while supporting a growing range of clinical and research activities.

Implementation of the national consent programme has been a major achievement during the year. A new consent model was introduced within NHD2, supported by training across UK haemophilia centres and the development of supporting guidance and resources. By September 2026, more than 300 PwBD had provided consent, creating a strong foundation for future research and post-marketing surveillance while ensuring transparency and personal choice.

Improving data quality has remained a key priority. Work has focused on increasing data completeness, strengthening validation processes, improving adverse event monitoring and introducing automated reporting tools. These developments are helping centres move towards a more proactive approach to data quality management and providing greater confidence in the use of national datasets.

The Working Party has also enhanced national adverse event surveillance through improved reporting processes, better alignment with EUHASS requirements and the introduction of gene therapy-specific monitoring. These developments strengthen PwBD safety oversight and support regulatory reporting obligations.

Research capability has continued to expand through improved access to national datasets, stronger collaboration between working parties and the development of governance processes for data requests. Increasing emphasis has been placed on collecting meaningful PwBD outcomes and generating real-world evidence to support future treatment and service developments.

Alongside these core programmes, specialist working parties have progressed a range of important initiatives, including new data collections in paediatrics, women and bleeding disorders, rare bleeding disorders, musculoskeletal health, co-morbidities and genetics. Collectively, these projects are helping to broaden the scope and value of national haemophilia data collection.

Overall, the Working Party has evolved from principally overseeing data collection activities to leading a broad programme of digital transformation. The progress achieved during the year has created a more secure, research-ready and person-centred data environment that will support clinical care, service evaluation and future research across the UK haemophilia community.

Dr Gary Benson
Chair, UKHCDO Data Management Working Party
October 2026

5. Data Analysis Group

Membership

Co-Chair (Director of NHD):	Professor Charles Hay
Co-Chair (Outgoing Chair of DMWP):	Dr Kate Talks
User representatives:	Paul Sartain
	Dr Richard Gorman
UKHCDO members and NHD Clinical theme leads:	Professor Pratima Chowdary
	Dr Susie Shapiro
	Dr Mary Mathias
	Dr Gillian Lowe
	Dr Ryan Rodgers
	Professor Peter Collins
	Dr Gill Gidley
	Dr Paul Batty
	Dr Paul McLaughlin
	Dr Nikki Curry
	Dr Gary Benson
Haemophilia Nurses and physiotherapy representatives:	Dr David Stephensen
Nurse representative:	Vacant
National Haemophilia Database:	Andrew McNally
	Ben Palmer
	Dr Hua Xiang
	Greg Shone

James Chetter

Dennis Glover

Grace Leach

Anna Connolly

The Data Analysis Group (DAG) is a subgroup of the Data Management Working Party. Its role is to assess and prioritise applications for analyses data held by NHD, including Haemtrack and joint score data. The group meets once a month by videoconference which last on average 60-90 mins. The terms of reference of the DAG are available on the UKHCDO website. Over the last year the clinical membership has grown reflecting in part the inclusion of the new NHD Clinical Leads.

Requests for analyses are submitted on a standardised form, which is available on the NHD website. All applications are assessed on data governance considerations, scientific merit and resource requirements. Requests for data analyses have been submitted by individual members of UKHCDO, UKHCDO working parties, Haemophilia Centres, NHS England, NHS Wales, PwBD societies and pharmaceutical companies. A number of requests have been made by NICE to support technical appraisals. The DAG reviews and discusses all applications. It provides feedback to the applicant and works with them to refine the proposal, if necessary.

The data analyses that are generated from the requests are reviewed and commented on by the group and may be further revised, if necessary, before release. Reports often contain caveats about data limitations that impact on the interpretation of reports. Some straightforward requests, for example, those from NHS commissioners may be progressed on chair action and discussed at the next meeting. The redevelopment of the NHD database as part of the NHD2 project provides an opportunity to provide automation of reports and develop online dynamic dashboards for different stakeholder groups. Work to define the requirements for different stakeholders and develop a service model is ongoing.

The contributions from the user representatives have been particularly useful in assessing the applications and interpreting results.

All members of UKHCDO and UKHCDO working parties are encouraged to suggest analyses and are invited to collaborate with the DAG on these projects. Members of UKHCDO are encouraged to join the DAG and anyone interested should contact one of the Co-chairs. The DAG is also looking for a nurse representative to join the group.

Dr Kate Talks, Chair UKHCDO Data Management Working Party

Prof Charles Hay, Co-Director NHD

October 2026

6. Specialised Blood Disorders NHSE Clinical Reference Group

Membership

- Dr Susie Shapiro, National Speciality Adviser, and CRG Chair
- Will Horsley, Lead Commissioner and Pharmacist
- Dr Charles Percy, Clinical Member & Procurement Lead
- Dr Kate Talks, Clinical Member
- Dr John Grainger, Clinical Member representing paediatrics
- Dr Sarah Mangles, Clinical Member
- Prof Charles Hay, Affiliate Member, National Haemophilia Database (Director)
- Prof Pratima Chowdary, Affiliate Member, UK Haemophilia Centres Doctor's Organisation (Chair)
- Marie Eales, Affiliate Member, Haemophilia Nurses Assoc.(Chair)
- Robert Barnard, Affiliate Member, Haemophilia Chartered Physiotherapists Assoc. (Chair).
- Debra Morgan, Haemophilia Society UK, Patient and Public Voice representative
- Laurence Woollard, Patient and Public Voice representative
- Giles Ratcliffe, Public Health Consultant

This group is designated as a 'Lead and Inform' NHSE Clinical Reference Group (CRG) which is the middle tier of three in terms of expected outputs and activity. The CRG covers haemophilia and other bleeding disorder services including von Willebrand disease, platelet disorders, acquired bleeding disorders, and some other coagulopathies such as thrombotic thrombocytopenic purpura.

The CRG meets routinely for two hours every three months using an online meeting interface; however there is additional activity between each CRG meeting. Recent meetings have been held in October 2025, and January, April & July 2026. Regular guests at CRG meetings include senior personnel from NHS England's acute specialised commissioning team and programme of care, Prof Marie Scully and commissioners in respect of TTP, and NHS colleagues involved in national procurement of medicines, amongst others.

During 2025/2026 the CRG and members have continued to be regularly engaged with the Infected Blood Inquiry (IBI), supporting and advising the national infected blood psychological support service, and advising how to meet the recommendations in the IBI report.

The CRG is active across multiple other projects. It has overseen the publication of a new NHSE service specification (involving all four devolved nations) in September 2026. Alongside the new specification, new SMART national service metrics were introduced in April 2026. The CRG plays a key role in supporting development of new commissioning policies; notably, an updated commissioning position and funding agreement was obtained for the use of emicizumab for prophylaxis in people with moderate haemophilia A without inhibitors; and on-going policy developments for the use of emicizumab in Acquired Haemophilia A and vonicog alfa for prophylaxis

in von Willebrand disease are currently being considered by NHSE. The CRG has worked alongside NICE in developing technology appraisals for blood disorders, with guidance issued for efanesoctocog in severe haemophilia A, and marstacimab for haemophilia A and B. Alongside the clinical commissioning policies, including NICE, the CRG supports the national (UK) procurement of various blood products and replacement factors to ensure wide access to licensed medicines at good value for the NHS and taxpayers.

Will Horsley and Dr Susie Shapiro, September 2026

7. Co-Morbidities Working Party

Membership

Chair	Dr Susie Shapiro, Oxford
UKHCDO representatives:	Dr Gary Benson, Belfast Dr Gillian Evans, Canterbury Dr Sarah Mangles, Basingstoke Dr Emily Millen, Nottingham Dr Kate Musgrave, Newcastle Dr Kate Talks (DAG/DMWP)
Haemophilia Nurses Association Representative:	Cathy Harrison, Sheffield

Remit

To consider comorbidity issues in PwBD within the UK and review any unmet need with respect to data collection, guidelines and PwBD-related information / material.

To develop a Work Plan for the CMWP.

To advise the DMWP as to what data the NHD should collect regarding comorbidities in people with haemophilia and bleeding disorders.

Any publications arising from the CMWP should be approved by the UKHCDO Executive in line with the UKHCDO publication policy.

Meetings

The group has had 3 formal Teams meetings in the last year with additional 'sub-group' meetings with MDSAS and email discussions to support progression of Work Plan.

Activities

The main work has been to establish a prospective registry for haemophilia and atrial fibrillation (AF), with the support of the NHD. The registry will help to determine the prevalence, antithrombotic therapy and thrombotic complications of AF in people with haemophilia in the UK. The specific aims of the planned prospective registry for people with haemophilia and AF are: (a) To determine the prevalence of AF in PWH over the age of 50 years in a subset of haemophilia centres in the UK; (b) To document the use of antithrombotic therapy in PWH and AF; (c) To prospectively determine the bleeding and thrombotic risks in these PwBD. The plan is for data to be collected initially by the members of the working party from their CCCs, under research registry ethics of the NHD.

The group piloted draft forms for initial data collection in Excel and then worked with MDSAS to develop in to a more sophisticated data entry form within the NHD. Forms for initial data entry for

people with AF and for matched controls have been 'live' since May 2025. The CMWP members have therefore started initial data entry for their local PwBD with AF and matched controls.

Next steps include early data analysis and presentation of update to UKHCDO; consider whether other Centres would like to be involved; development of 'annual review' forms for prospective data collection of bleeding/thrombotic events.

Dr Susie Shapiro,
Chair, Co-Morbidities Working Party
August 2025

8. Genomics Working Party

The UKHCDO Genomics Working Party convenes virtually every two months.

Current Membership:

- Dr Kate Talks - Newcastle
- Dr Matt Sims - Sheffield
- Dr Ruth Wheeler - London
- Dr Brenda Sempasa - Manchester
- Dr Jayashree Motwani - Birmingham
- Dr Victoria Cloke - Edinburgh
- Dr Suthesh Sivapalaratnam - Chair – London
- Dr. Andrew Page – Edinburgh
- Dr. Claire Lentaigne - Exeter

Contact:

greg.shone@ukhcdo.org

Objectives for 2026/2027:

1. To produce a comprehensive report on the current state of genomics in Haemostasis and Thrombosis incorporating a survey on current practices in the UK starting with sending out a questionnaire
2. To explore the integration of gene variants into the National Haemophilia Database (NHD) and investigate the feasibility of linking genetic laboratory outputs directly to the NHD, aiming to enhance diagnostics and support research initiatives. To date we have had conversations with the NHD, MDSAS, NHS Genomics services.
3. To continue education in the form of national genomics MDTs. To date we have had one on Platelet disorders with predisposition to malignancies, Prenatal Diagnostics, HPS and we will have one on BDUC.

Dr Suthesh Sivapalaratnam,
Chair, Genomics Working Party
October 2026

9. Genetic Laboratory Network (UKHCDO-GLN)

Background

The UKHCDO GLN was formed in 2002, arising out of the UKHCDO Genetic Working Party (UKHCDO GWP), with the aim of improving collaboration between laboratories and of ensuring quality and equity of service across the U.K. The network currently comprises of 8 centres involved in the molecular genetic analysis of inherited bleeding, thrombotic and platelet disorders (many of the laboratories are also involved in other areas of haematology as well). These laboratories include Belfast City Hospital, Central and South Genomic Laboratory Hub (GLH), North East and Yorkshire GLH, North West GLH, Royal Free Hospital London, Royal Infirmary Edinburgh, South East GLH, and St. James' Hospital Dublin.

Representatives of the Network attend meetings of the UKHCDO Genetics Working Party.

Meetings

The UKHCDO GLN holds bi-annual meetings. The network met virtually in December 2025. We held an in-person meeting in Oxford in May 2026.

Chair & Secretary

Megan Sutherland and Catriona Keenan continue in their roles as Chair and Secretary, respectively.

Current activities

1. **NHS England Genomic Laboratory Hubs:** The new structure of service provision in England went live in February 2021. The NHS England genomic test directory specifies which disorders and gene targets will be investigated under this service model and by which methodologies they should be performed (https://www.england.nhs.uk/publication/national-genomic-test-directories/). The 'Non-malignant Haematology' service, including the investigation of bleeding, thrombotic and platelet disorders, is provided by four Genomic Laboratory Hubs in England. At the GLN meetings we review the gene content of the relevant panels to ensure that the most up to date panels are being used for analysis.

2. **Laboratory Audit – ISO 15189**: Laboratories in the Network are accredited by the United Kingdom Accreditation Service (UKAS). Laboratories are required to adhere to ISO 15189 quality standards. The GLN continues to share examples of good practice, practical advice and knowledge as the inspection process is applied to member laboratories. All laboratories continue to participate in the UKAS inspection process cycle.

3. **Bleeding Disorder Genetic Analysis Best Practice Guidelines:** The UK Best Practice Guidelines (BPG) for Haemophilia A and Haemophilia B are in the process of being reviewed and updated in accordance with the NHS England genomic test directory. In addition, a working group has been established to produce a BPG for the genetic investigation of rare bleeding disorders, this will be produced in conjunction with the UKHCDO GWP. The UK Best Practice Guidelines (BPG) for phenotypic and genetic analysis of VWD were previously published (Platton et al (2024) PMID: 38532595).

4. **UK NEQAS Genetics of Heritable Bleeding and Thrombotic Disorders scheme:** The UK NEQAS Genetics of Heritable Bleeding and Thrombotic Disorders EQA scheme provides up to four EQA exercises per year, two of these are the traditional 'wet' exercises which always include analysis of one of *F8*, *F9* or *VWF*. The two additional 'paper' exercises provide a clinical scenario and genetic variant for a person which are to be interpreted by the participants and a report produced. The paper exercises aim to expand the scope of gene targets for interpretation to include rare bleeding and thrombotic disorders. The results for each round of the scheme are reviewed and discussed at the following GLN meeting and any relevant comments fed back to the NEQAS steering group.

5. **Participation in other groups:** Representatives of the Network input to the UKHCDO GWP. A representative of the Network is a member of the World Federation of Hemophilia Laboratory Science Committee.

6. **General:** At each of the GLN meetings there is an open forum to discuss scientific and technical issues. We also aim to include an educational session at least once a year to focus on difficult areas for interpretation. Our main focus continues to be on the classification of rare or novel variants with reference to the current ACGS variant classification guidelines, and the sharing of this information throughout the network. There is also a current focus on discussions about gene specific classification guidelines. It is recognised within the group that the sharing of knowledge and expertise is an essential mechanism for the interpretation of previously uncharacterised genetic variants. The educational sessions this year have focussed on classification of variants in *VWF*, *CYCS*, *SERPINC1*, 'semidominant' genes, and genes associated with risk for haematological malignancy.

Megan Sutherland,
Chair, UKHCDO Genetic Laboratory Network
August 2026

10. Girls and Women with Bleeding Disorders Working Party

Date of inception: 23rd October 2023

List of members:

Professor R Abdul-Kadir (Co-Chair), Dr. N Curry (Co-Chair), Dr. G Benson, Dr. T Biss, Dr. A Carvalhosa, Professor J Clarke, Dr. S Garside, Dr. C Lentaigne, Dr. Gill Lowe, Dr. E Millen, Dr. P Raheja, Dr J Mistry (secretary), Dr C Brown, Hayley Wiles.

Co-opted members:

- Members from BSH guideline writing committee, as standard, for the best practice guideline
- Doctor-in-training co-opted member planned to assist with data collection work stream and PPIE

Meetings:

October 2025, January 2026, April 2026 – whole committee, Teams meetings

The aims of the GWBD working party were set out in our agreed terms of reference, and are as follows:

Aims:

To direct and lead national changes to both clinical and personal focused practices which will improve the care of girls and women with IBD across the UK, with an initial focus:

1.1 To develop a core data set of a) clinically important and b) self reported outcomes with the aim of piloting data collection at a small number of sites

1.2 To set standards for the care of GWBD

1.3 To support and facilitate research in the field of girls and women with bleeding disorders

1.4 To share expertise and best practices from existing joint clinics (gynae-haem and obs-haem) to then support UK haemophilia centres develop an MDT service for girls and women

1.5 To support educational programmes to increase awareness of GWBD among all HCPs involved in care of girls and women

The specific aims for 2025-2026 were two-fold:

A: Developing a national standard for an MDT haem-gynae service, with a focus on all age groups – particularly adolescent age group. Looking at best practices for GP referrals into secondary care/management of acute HMB in ED and how to support NHS trusts to recognise the importance

of these types of clinics. The group formed a Good Practice paper writing group, chaired by Dr T. Biss, completed this work, in conjunction with the BSH H&T writing committee. The paper has been accepted for publication by The British Journal of Haematology, July 2026, and is entitled:

BSH Good Practice Paper. Implementation and value of providing a multidisciplinary haematology and gynaecology service for individuals with bleeding and thrombotic disorders: A British Society for Haematology & United Kingdom Haemophilia Centre Doctors' Organisation Good Practice Paper.
Biss et al, in production, July 2026.

B: Data collection for GWBD across all ages. A smaller data group has been formed with the plan to develop a core data set for collection of robust data relating to the care of GWBD. The NHD and the GWBD WP have fostered an excellent working relationship and are developing a pilot data collection within the NHD focusing on gynaecological health.

In addition, the GWBD WP are working with NHD and the DWParty to seek funding from multiple industrial partners to support the development of a comprehensive App for gynaecological and other bleeding for GWBD, which will be a new section within HaemTrack, again, focusing on gynaecological health. This will offer a safe platform, for GWBD to document their outcome measures, and will be used for direct real-time care of our underserved PwBD group. To date, the BWGD have applied for BSH Innovator funding and are in the process (as of July 2026) of contacting all relevant drug companies to pitch the funding opportunity to them. We aim to spread the funding across 5+ companies over a 2-year period.

In addition, we continue to work with GWBD, and the Haemophilia Society, through several PPIE groups to look at how best to collect real-time relevant data for GWBD.

An audit of practice has been completed across 13 hospitals – on an individual personal level to look at the care of GWBD, with a particular focus on heavy menstrual bleeding. In addition to this, a national survey of centre-specific practice has been conducted, and the data includes 100% of CCC and approximately 30% of the haemophilia centres.

This has now been published, and presented at national and international conferences (BSH, and ISTH, 2026).

Knox L, Swart-Rimmer I, Rahimi N, Harris C, Abdalla L, Benson G, Brown C, Campbell H, Carvalhosa A, Clarke JT, Garside S, Lentaigne C, Mistry J, Raheja P, Warren C, Abdul-Kadir R, Lowe G, Curry N. Current gynaecological management of women and girls with bleeding disorders in the United Kingdom: A UKHCDO haemophilia treatment centre survey and evaluation of real-world clinical practice for the British Journal of Haematology. Br J Haematol. 2026 Feb;208(2):661-669. doi: 10.1111/bjh.70295.

Guidelines:

The UKHCDO Gynaecology Working Party has responsibility for the Gynaecology Guideline that was published in late 2022. This will continue to be reviewed annually, and no update is currently required.

Publications

BSH Good Practice Paper. Implementation and value of providing a multidisciplinary haematology and gynaecology service for individuals with bleeding and thrombotic disorders: A British Society for

Haematology & United Kingdom Haemophilia Centre Doctors' Organisation Good Practice Paper. Biss et al, in production, July 2026.

Knox L, Swart-Rimmer I, Rahimi N, Harris C, Abdalla L, Benson G, Brown C, Campbell H, Carvalhosa A, Clarke JT, Garside S, Lentaigne C, Mistry J, Raheja P, Warren C, Abdul-Kadir R, Lowe G, Curry N. Current gynaecological management of women and girls with bleeding disorders in the United Kingdom: A UKHCDO haemophilia treatment centre survey and evaluation of real-world clinical practice for the British Journal of Haematology. Br J Haematol. 2026 Feb;208(2):661-669. doi: 10.1111/bjh.70295.

Curry N, Lowe G, Clark TJ. Inherited bleeding disorders in heavy menstrual bleeding: The case for joint haematological and gynaecological care. BJOG. 2022 Dec 2. doi: 10.1111/1471-0528.17353.

Curry N, Bowles L, Clark TJ, Lowe G, Mainwaring J, Mangles S, Myers B, Kadir RA. Gynaecological management of women with inherited bleeding disorders. A UKHCDO Guideline. Haemophilia. 2022 Nov;28(6):917-937. doi: 10.1111/hae.14643. Epub ahead of print. PMID: 35976756.

The group will meet again in the autumn of 2026 to set their targets for 2026 – 2027.

Professor R Abdul-Kadir, Dr. N Curry
Co-chairs, Gynaecology Working Party
July 2026

11. Inhibitor Working Party

Membership

Charles Percy (Chair)

Kate Talks

Anne Riddell

Ben Palmer

Mary Mathias

Paul Batty

Deepan Gosrani

Laith Tafesh

Jireh-Ann Batac

Meetings

Following the last AGM, the inhibitor working party was dissolved and reconstituted with new membership. There have been three formal meetings of the inhibitor working party since. Communication has been virtual. The revision of the guideline on acquired coagulation factor inhibitors has published shortly after the AGM in 2025. Work in conjunction with the paediatric working party has commenced on updating the guideline on the diagnosis and treatment of factor VIII and IX inhibitors in congenital haemophilia. Other activities have included:

1. Contribution to and feedback on the draft commissioning policy for emicizumab in acquired haemophilia A.
2. Preparation of a data collection proforma for the NHD, should emicizumab become available for acquired haemophilia A.
3. Dialogue with MDSAS and the NHD regarding refinements to data collected on remission status in acquired haemophilia A.
4. Meetings with relevant parties regarding availability of prophylactic treatment options for people with haemophilia B and inhibitors outside of a clinical trial.
5. Participation in other meetings: Data Management Working Party, NHD Adverse Events Review Panel.

Dr Charles Percy
Chair, Inhibitor Working Party
September 2026

12. Laboratory Working Party

Membership since 2025

Laboratory

Anne Riddell	Royal Free Hospital, London
Annette Bowyer (Co-chair)	Royal Hallamshire Hospital, Sheffield
Caroline Lawrence	Glasgow Royal Infirmary
Sean Platton	Royal London Hospital
Jill Martin	Aberdeen Royal Infirmary
Stephen Macdonald	Addenbrooke's Cambridge

One laboratory member place currently unfilled

Clinical

Dr Mohammed Khan	Aberdeen Royal Infirmary
Dr Andrew Page (Co-chair)	Edinburgh Royal Infirmary

Invited representation

UKNEQAS Blood Coagulation	Anna Williams
NIBSC	Stella Williams

Purpose of the Committee

To provide a coordinated national framework to ensure that laboratory diagnosis, monitoring and quality standards for haemophilia and allied bleeding disorders are consistent and fit for purpose. This includes setting of national standards to harmonise laboratory practices, advising on laboratory issues with current and new therapies, development of guidance and protocols for complex testing or new methods, identification and resolution of gaps in laboratory testing and facilitation of education for HCPs working in the area of bleeding disorders.

Activities

The group held online committee meetings over the past 12 months on 26/11/25, 4/3/26 and 1/7/26 with the next scheduled 7/10/26. There is still a requirement for a replacement scientist (for Janenne Sanders who stepped down in 2025).

The guidelines for the laboratory monitoring of Altuvoct (efanesoctocog alfa) were published in January 2026.

Bowyer AE, Khan M, Lawrence C, Macdonald S, Martin J, Platton S, Riddell A, Sanders J, Williams

A, Williams S, Page A. The Laboratory Monitoring of Altuvoct (Efanesoctocog Alfa): Recommendations from the Laboratory Working Party of the United Kingdom Haemophilia Centres Doctor's Organisation. Haemophilia. 2026 Jan-Feb;32(1):279-283. doi: 10.1111/hae.70152. Epub 2025 Nov 7. PMID: 41201885.

Joint collaboration between UKHCDO, the Haemostasis and Thrombosis Task Force of BSH proposal for "The use of drug-specific calibrators for clotting factor assays- recommendations for the laboratory establishment and practice from BSH and UKHCDO" has just been approved by BSH. LWP members include Caroline Lawrence, Andrew Page, Stephen Macdonald, Annette Bowyer and Sean Platton.

Guidelines associated with LWP

- Bowyer AE, Khan M, Lawrence C, Macdonald S, Martin J, Platton S, Riddell A, Sanders J, Williams A, Williams S, Page A. The Laboratory Monitoring of Altuvoct (Efanesoctocog Alfa): Recommendations from the Laboratory Working Party of the United Kingdom Haemophilia Centres Doctor's Organisation. Haemophilia. 2026 Jan-Feb;32(1):279-283. doi: 10.1111/hae.70152. Epub 2025 Nov 7. PMID: 41201885. **New - review not required.**
- Jennings I, Baker P, Bowyer A, Crossette-Thambiah C, Gomez K, Lester W. Reporting haemostasis assays in IU/dL-A recommendation for harmonisation from the British Society for Haematology Haemostasis and Thrombosis Task Force, UK NEQAS for Blood Coagulation and the UK Haemophilia Centres Doctors Organisation. Br J Haematol. 2025 Oct;207(4):1698-1701. doi: 10.1111/bjh.70003. Epub 2025 Jul 16. PMID: 41070683. **New - review not required.**
- Platton S, Baker P, Bowyer A, Keenan C, Lawrence C, Lester W, Riddell A, Sutherland M. Guideline for laboratory diagnosis and monitoring of von Willebrand disease: A joint guideline from the United Kingdom Haemophilia Centre Doctors' Organisation and the British Society for Haematology. Br J Haematol. 2024 May;204(5):1714-1731. doi: 10.1111/bjh.19385. Epub 2024 Mar 26. PMID: 38532595. **Reviewed 4/3/26 - addendum needed for Veyvondi.**
- Bowyer A, Gray E, Lowe A, Murphy P, Platton S, Riddell A, Chowdary P, Lester W, Jenkins PV. Laboratory coagulation tests and recombinant porcine factor VIII: A United Kingdom Haemophilia Centre Doctors' Organisation guideline. Haemophilia. 2022 May;28(3):515-519. doi: 10.1111/hae.14536. Epub 2022 Mar 13. PMID: 35279922. **Review required.**
- Jenkins PV, Bowyer A, Burgess C, Gray E, Kitchen S, Murphy P, Platton S, Riddell A, Chowdary P, Lester W. Laboratory coagulation tests and emicizumab treatment A United Kingdom Haemophilia Centre Doctors' Organisation guideline. Haemophilia. 2020 Jan;26(1):151-155. doi: 10.1111/hae.13903. Epub 2019 Dec 20. PMID: 31859415. **Review required – planned for after Denecimig licensing.**
- Gray E, Kitchen S, Bowyer A, Chowdary P, Jenkins PV, Murphy P, Platton S, Riddell A, Lester W. Laboratory measurement of factor replacement therapies in the treatment of congenital haemophilia: A United Kingdom Haemophilia Centre Doctors' Organisation guideline. Haemophilia. 2020 Jan;26(1):6-16. doi: 10.1111/hae.13907. Epub 2019 Dec 17. PMID: 31846168. **Reviewed 4/3/26 - addendum needed for Altuvoct.**

Items in progress and future plans

The laboratory FVIII, FIX and treatment monitoring questionnaire report to participants is in progress alongside a letter of submission to a journal.

To develop an educational networking program for laboratory scientists with an interest in haemostasis.

Development of test repertoire for haemophilia comprehensive care centre peer review. Lab standards are needed for inclusion into the review.

Exploration of a committee-wide project for the laboratory monitoring of Veyvondi is in progress. Samples have been identified for testing but there is a hurdle in funding for distribution around the members.

Proposal for BDUC diagnostic guidelines with a diagnosis survey is under discussion.

Dr Annette Bowyer & Dr Andrew Page, Co-Chairs
Laboratory Working Party
August 2026

13. Musculoskeletal Working Party

Membership

Co-chairs: Dr Paul McLaughlin (Physiotherapist, London)
Dr Gary Benson (Haematologist, Belfast)

Members: Trupti Bhandari (Paediatric Physiotherapist, London)
Dr Nicola Curry (Haematologist, Oxford)
Dr Emma Fosbury (Paediatric Haematologist, Manchester)
Jessica Hedden (Physiotherapist, Cardiff)
Dr Emily Symington (Haematologist, Cambridge)
Dr Thynn Yee (Haematologist, London)

The group meet virtually (Teams) 3 times per year.

The main focus for the group this year has been to support the newly established MSK Lead for NHD to improve HJHS reporting within HCIS. A webinar was held in June 2026 highlighting the need to improve HJHD data collection as a first step to better, broader MSK data. Ongoing support from the MSK WP will be vital in analysis of future HJHS data and developing approaches for clinical support for bleeding disorder-related MSK dysfunction.

The limited success of implementing MSK Ultrasound into routine practice has been identified as a pressing clinical issue. Inequitable access/availability of US machines and a lack of support locally from Radiology departments have been identified as significant barriers. However, training and support for clinicians is also lacking. Whilst the HCPA group are working to provide training days for specialist physiotherapists, there is no support for haematologists who may also be interested in US in practice. The MSK WP is exploring the viability and logistics of a multi-professional US training course.

A practice survey on the management of haemophilia ankle arthropathy is currently ongoing across all professional groups' membership – UKHCDO, HNA and HCPA. It is hoped that the survey results will identify where support should be focussed for clinicians and help improve quality and equity of PwBD care and outcomes.

The WP has reviewed the practice guidance document *'Management of Iliopsoas muscle haematoma: clinical guidance for people with bleeding disorders'*. This document, developed by the HCPA, provides an up to date review of the current best practice in the management and rehabilitation of iliopsoas bleeds. This document is now hosted on the UKHCDO website (under the HCPA tab). Further similar reports/guidance documents are encouraged, and the MSK WP would encourage the membership to provide topics of interest.

Following completion and publication of UK haemophilia centres' peer review reports, the WP has agreed that a report focussing on MSK care provision is important to clarify current care provision,

areas of good practice, and issues of ongoing inequity. This is planned to be completed in the next 6 months.

Dr Paul McLauglin
Co-chair Musculoskeletal Working Party
August 2026

14. Paediatric Working Party

Membership

Mary Mathias (Chair)	London (GOSH)
Jeanette Payne (Secretary)	Sheffield
Jayanthi Alamelu	London (Evelina)
Saket Badle	Oxford
Tina Biss	Newcastle
Jayashree Motwani	Birmingham
Emma Fosbury	Manchester
Simone Stockley	Nottingham
Alice Taylor	London (GOSH)
Fernando Pinto	Glasgow
Christine Macartney	Belfast
Arun Mahendrayogam	Cambridge
Deepan Gosrani	Cardiff
Jessica Sandham	Liverpool

Meetings

Since the last AGM the PWP has reformed. A face-to-face meeting occurred in February with virtual meetings in June and September.

Summary of activities

1. The article on **emicizumab PUPs and MTPs** data at a national level was submitted for publication but rejected by Haemophilia. Adjustments are being made with a plan to re-submit to an alternative journal. Data was returned on 88 boys from 19/23 centres with eligible PwBD: 41 PUPs and 47 MTPs.

2. UK data on ITI in severe haemophilia B under 18ys was published in a letter in Haemophilia and experience with Veyvondi in UK children was presented by Dr Alamelu at ISTH.
    - Mathias, M., Alamelu, J., Bhatnagar, N., Biss, T., Grainger, J., Green, S., Kelly,A., Motwani, J., Payne, J. and Stokley, S. (2026), UK Experience of Children With Inhibitors in Severe Haemophilia B: A Report by the UKHCDO Paediatric Working Party. Haemophilia
    - Recombinant von Willebrand Factor, Vonicog alfa: United Kingdom experience of its use in children under 18 years of age(2026), Volume32, IssueS2. Supplement: Abstracts of the 2026 International World Congress of the World Federation of Hemophilia 19-22 April 2026 Kuala Lumpur, Malaysia

3. **PUP registry on the NHD.** The data collection process via the NHD/MDSAS needs to be re-considered as, whilst remaining very valuable information, is not currently fit for purpose.

4. **The national advisory group/MDT** continues 3 monthly teleconferences, with terms of reference, for discussion and recording of outcomes. Calls for cases to discuss are sent out to paediatric treating centres prior to the dates with a data pro forma. Ad hoc emailing of complex cases in between meetings is possible if there is a clinical necessity, with follow up and minuting at the next meeting. Minutes are circulated and saved at the NHD. There is a planned EAHAD abstract describing this MDT with national feedback on clinican satisfaction.

5. **PWP membership at other UKHCDO meetings:** Inhibitor WP, DMWP, DAG and Adverse events panel.

6. **Guidelines relevant to WP:** Prophylaxis and Inhibitor. Members of the working party are involved in updating the Inhibitor Guidelines and other members will volunteer to be involved in updating the Prophylaxis Guidelines

7. Members of the Working Party are also involved in the national survery of paediatric bleeding disorders provision in and out of hours

Dr Mary Mathias

Chair, Paediatric Working Party

September 2026

15. Peer Review Working Party

Membership

Chair

Dr Sarah Mangles, Southern Haemophilia Network (Basingstoke)

UKHCDO representatives

Pratima Chowdary (Royal Free)

Kate Talks (Newcastle)

Gary Benson (Belfast)

John Grainger (Manchester Childrens)

Joannes Hermans (Nottingham)

Gillian Lowe (Birmingham)

Gillian Evans (Kent and Canterbury)

Keith Sibson (GOSH)

Haemophilia Nurses' Association representatives

Elsa Aradom (Royal Free)

Amy Conquergood (Oxford)

Kate Forsyth (Barts and Royal London)

Helen Hupston (Birmingham and HNA committee member)

Sharon Thind (Liverpool – Alderhey)

Nisha Shrivastava-Moss (Cardiff)

Emily Bloxham (Bristol)

HCPA representatives

David Hopper (Newcastle)

Stephanie Taylor (Oxford)

Psychology representatives

Grainne O'Brien (Edinburgh)

PwBD representatives

Nigel Miller (Haemophilia Wales)

Debra Morgan (Haemophilia Society - England)

Alan Martin (Haemophilia Scotland)

Remit

To review previous peer review standards and update

To work with project manager to ensure all CCC, interim CCC and HC are audited in each peer review cycle

To ensure training of all peer reviewers

To write summary report once all peer reviews completed

Meetings

Virtual meetings to discuss peer review standards, report templates, plan for peer review, as well as email review of documentation.

Activities

1. All 2024 reports finalised and uploaded to UKHCDO website
2. Questionnaire sent to all centre directors (August 2026) asking for progress report on peer review findings
3. Committee working on reviewing standards, removing duplication, and clarifying the evidence required to meet the standard
4. Next peer reviews to be held in 2028, with new standards distributed in 2027

Dr Sarah Mangles

Chair, Peer Review Working Party

September 2026

16. Von Willebrand Working Party

Date of inception: 2020

Meetings since last AGM: 4 (virtual)

Current membership

Cathy Farrelly

Vince Jenkins

Will Lester

Carolyn Millar (Chair)

Susie Shapiro

Purpose

The purpose of the Working Party is to:

1. Monitor, review and update BSH/UKHCDO Guidelines on the Clinical Diagnosis and Management of VWD
2. Registration, update and reclassification of PwVWD within the National Haemophilia Database.

The principal focus of the VWD working party 2025/6 has been the revision and update of the BSH/UKHCDO 2014 VWD guideline.

At the time of writing, the manuscript 'Guideline for Clinical Diagnosis and Management of Von Willebrand Disease: A joint guideline from the United Kingdom Haemophilia Centre Doctors' Organisation and the British Society for Haematology' is under review having been submitted for publication in the British Journal of Haematology. A number of meetings were held over the course of the year including with the BSH haemostasis and thrombosis task force. Other ongoing work of the WP has includes the continued development of the new PwVWD registration process with the NHD; work also continues on the NHD update and reclassification of PwVWD.

Dr Carolyn Millar
Chair, Von Willebrand Working Party
August 2026

17. Dental Task Force

Membership

Dr Julia Anderson (Chair, Consultant Haematologist)

Dr Sara Boyce (Secretary, Consultant Haematologist)

Mr Andrew Brewer (Associate Specialist, Oral Surgery)

Dr Janet Davies (Consultant Paediatric Dental Surgeon, British Paediatric Dental Association representative)

C/N Jayne Keaney (Haemophilia Nurses Association)

Dr Bella Madan (Consultant Haematologist)

Dr Lochana Nanayakkara (Consultant Dental Surgeon)

Dr Emily Symington (Consultant Haematologist)

Dr Alice Taylor (Consultant Paediatric Haematologist)

Dr Albert Yeung (Public Health Dentist)

The Dental Task Force met on October 7, November 11, January 6, January 27, March 3, May 5 2026 (via MS TEAMS, organised by UKHCDO secretariat)

Group membership consists of a multidisciplinary group of adult and paediatric haemophilia consultants, adult and paediatric dental and oral surgeons, and nurse representatives. Our nurse representative, Jayne Keaney has just retired and we greatly thank her for input and support for the group's work.

The group are finalising a new set of guidance and aim to publish a 2-part serial in the British Dental Journal. The guidance is primarily intended for dental practitioners, and also haemophilia treaters.

The manuscript has been offered for comment to the UK Haemophilia Society, Haemophilia Scotland, Northern Ireland and Wales, in addition to the British Society of Special Care Dentists, the British Society of Oral Surgeons and the British Paediatric Dental Association and has been recently sent to UKHCDO Advisory Group for comments prior to manuscript submission.

Julia A M Anderson

Chair, UKHCDO Dental Task Force

August 2026

18. Emergency Care Guideline Re-write Task Force

A guidance document entitled ""Standards for Emergency Care in Haemophilia and Heritable Bleeding Disorders: Guidance from the UK Haemophilia Doctors' Organisation", first submitted in November 2025, has been resubmitted to Haemophilia following substantial re-formatting. We await peer review of this manuscript. If successful in achieving publication, it is proposed to re-engage with the Royal College of Emergency Medicine in order to support aligned guidance targeted at emergency care professionals.

Lishel Horn

4 November 2025

19. Haemophilia Gene Therapy Hub Panel

Introduction

The Haemophilia Gene Therapy Hub Panel was established in its current form in September 2024. Over the last year the panel has met monthly to support the setup of the gene therapy hub centres, according to UKHCDO and NHSE guidelines. This annual report outlines the key activities, progress, and future goals of the hub panel, reflecting on the collaborative efforts made to ensure the safe and effective implementation of gene therapy for the treatment of haemophilia in England and the devolved nations.

Membership

As of **2025/2026**, the membership of the Haemophilia Gene Therapy Hub Panel is as below:

1. Catherine Bagot and Emily Symington – Co Chairs
2. Representation from each of the gene therapy hub centres
3. Will Horsley – Lead commissioner for specialised blood disorders for NHSE
4. Susan Caldwell – Senior Research Nurse, UKHCDO – now stepped down
5. Rob Hollingsworth – National haemophilia database
6. Greg Shone – Administrator

The Haemophilia Gene Therapy Hub panel would like to thank Susan Caldwell for all of her hard work in the last year. She has kept up to date with where all of the hubs are with set up and kept track of all of the people who have so far been treated with Hemgenix. She has also been a huge support for data entry onto the NHS for those people who have been treated with Hemgenix. Her contribution to the panel has been invaluable.

Meeting Frequency and Format

- Monthly meetings of the panel with CSL Behring joining for the last 30 minutes on most occasions.
- Each meeting is 60 minutes.
- All meetings have been virtual to date.
- At each meeting there is an update from each hub on readiness to treat people with gene therapy. There is also an update from each hub on people that have been treated.
- Ad hoc meetings have been arranged in cases needing urgent discussion.

Activities and Achievements

Over this last year the panel has supported the gene therapy hubs in completing set up and overcoming local barriers to getting the service running. The majority of hubs in England and Wales have completed set up. The final hubs in England and in Scotland are close to completion of set up.

There has been a total of 9 people treated with Hemgenix over the last year. The first person was treated in June 2025. All of the people have had a good response with measurable increase in Factor IX levels and are no longer taking any regular prophylaxis.

One person had an adverse event related to corticosteroid treatment and the panel convened an emergency meeting to discuss management. The person is now well. This led to a discussion about timing of treatment with corticosteroids and the need for some national guidance around this.

The panel has supported the data entry onto the NHD for people who have been treated with Hemgenix. The systematic collection of gene therapy data within the NHD will provide a uniquely valuable resource for evaluating the use of these treatments in routine UK clinical practice. Long-term, standardised data will allow assessment of treatment uptake, efficacy, durability of factor expression, bleeding outcomes, changes in factor concentrate use, adverse events and the need for immunosuppressive therapy. Linking these outcomes with baseline clinical characteristics may help identify predictors of response and complications, while national coverage will support pharmacovigilance, benchmarking, audit and evaluation of equitable access. The database will therefore complement clinical trial evidence, inform PwBD and clinicians through shared decision-making, support future guidance and commissioning decisions, and enable high-quality national and international research into the long-term benefits and risks of gene therapy.

Guidelines and Review Status

- UKHCDO PwBD information leaflet for Gene Therapy with Hemgenix - renewed.
- Healthcare Professional checklist for pre-consent PwBD discussion and consent form - renewed.
- Panel's Terms of reference – renewed.
- Guideline on Management of Transaminitis following treatment with haemophilia gene therapy – in progress.

Future Plans

Looking ahead to 2026/2027, the Haemophilia Gene Therapy Hub panel to focus on the following key areas:

- Transitioning to the title of National Haemophilia Gene Therapy Panel once all the hubs are established in England and the devolved nations.
- Supporting the haemophilia gene therapy hubs as more people are treated with Hemgenix.
- Supporting timely and accurate data entry, pertaining to people who are receiving gene therapy, into the NHD.

- Developing national guidelines on management of transaminitis to optimise outcomes of treatment with Hemgenix whilst avoiding short- and long-term side effects of corticosteroids and immunosuppressive therapies

Dr Catherine Bagot and Dr Emily Symington
Co-chairs, Haemophilia Gene Therapy Hub Panel
September 2026

20. Haemophilia Nurses' Association

Haemophilia Nurses Association UK

Committee

Chair: Marie Eales (Oxford University Hospitals)
Vice Chair: Helen Hupston (Queen Elizabeth Hospital Birmingham)
Secretary: Geraldine Green (University Hospitals Coventry)
Treasurer: Katie Moore (Cardiff University Hospital)
Committee member: Dawn Jenner (Southampton General Hospital)
Committee member: Clare James (Evelina Children's Hospital, London)
Committee member: Laura Otto (Birmingham Children's Hospital)
Committee member: Sarah-Jane Harvey (Swansea Hospital)
Education Team:
Director of Education: Cathy Harrison (Sheffield Teaching Hospital, Sheffield)
Education leader: Sarah Pool (Oxford University Hospital NHS Trust)
Education leader: Julia Spires (Great Ormond Street Hospital)
Education leaders (Physiotherapist Experts): *Paul McLaughlin and Melanie Bladen*

Achievements

- **214 members nationally**
- **75 nurses attended the 2026 Annual Meeting**
- **45 participants completed Introduction to Bleeding Disorders between November 2025 and July 2026, with 30 participants currently registered for the next course**
- **23 participants in CCC 2025, with 21 successfully passing at Level 6 or Level 7**
- **14 participants enrolled in CCC 2026**
- **5 buddy-mentor partnerships established**

Introduction

The Haemophilia Nurses Association UK (HNA-UK) has continued to represent, connect and support nurses and allied health professionals working within bleeding disorders services across the UK. 2025-2026 has been another particularly active year for the Association. Alongside maintaining our established education programme and national meeting, we have continued to develop our role as a national nursing network, strengthening professional connections, providing opportunities for

shared learning and ensuring that the nursing voice remains represented within the changing UK bleeding disorders landscape.

Our membership remains at over 200 professionals nationally, providing an important network through which nurses can share expertise, seek peer support and contribute to developments in clinical practice, education and service delivery.

HNA-UK continues to work in partnership with The Haemophilia Society, a relationship which has provided important administrative and financial infrastructure for our activities. This partnership was highlighted as fundamental to the organisation and delivery of HNA-UK education and meetings in our previous report.

HNA-UK Annual Meeting 2026

The HNA-UK Annual Meeting and AGM took place at Conference Aston, Birmingham, on 6-7 March 2026, bringing together approximately 75 nurses working across bleeding disorders services in the UK. The meeting provided an important opportunity for education, professional networking and discussion of contemporary issues affecting bleeding disorders nursing.

Industry sponsorship continued to enable nurses from across the country to attend, helping HNA-UK maintain accessibility to national professional education despite increasing pressures on NHS study leave and departmental budgets. Feedback from the meeting was extremely positive and reinforced the importance of maintaining a dedicated national forum in which nurses can discuss clinical practice, service challenges and emerging therapies.

Planning is now underway for the 2027 HNA-UK Annual Meeting, with the theme “Keeping it Real”, focusing on the realities of contemporary bleeding disorders nursing, clinical decision-making and supporting PwBD within an increasingly complex treatment landscape.

Educational and Professional Development

The **Introduction to Bleeding Disorders** programme continues to provide accessible foundation-level education for professionals working within bleeding disorders services. Between November 2025 and July 2026, 45 participants completed the programme, with a further 30 participants currently registered, demonstrating continued strong demand for this educational resource. Due to the level of interest, some participants may be offered places on courses taking place during 2027.

Importantly, participation reflects the breadth of the contemporary multidisciplinary team and has included specialist nurses, Advanced Nurse Practitioners, research nurses, physiotherapists, data managers, psychologists working within both centres and Infected Blood Inquiry services, pharmacists, service managers, podiatrists and social workers.

The course remains **free to participants** and is delivered virtually via Microsoft Teams by Cathy Harrison and Sarah Pool. Content includes an introduction to haemostasis, haemophilia with and without inhibitors, acquired haemophilia, von Willebrand disease, rare bleeding disorders, genetics, multidisciplinary working and opportunities for further education.

Demand for the programme has remained consistently strong, with sufficient numbers to run every planned session over the last three years. The first 2027 courses are confirmed for **1-2 March and 5-6 July 2027**, supporting continued access to introductory bleeding disorders education across the multidisciplinary workforce.

The Contemporary Care for Bleeding Disorders Course (CCC) continues to provide the next stage of specialist professional development. The 2025 cohort comprised 23 participants, including nurses, physiotherapists, an occupational therapist and a psychologist. Of those completing assessment, 12 of 13 Level 7 participants and 9 of 10 Level 6 participants successfully passed the course.

The programme has subsequently been re-accredited by Middlesex University, with the academic credit increased to 30 credits per module, available at either Level 6 (degree level) or Level 7 (Master's level). This represents an important development for the programme and recognises the academic and professional value of specialist bleeding disorders education.

The 2026 cohort currently comprises 14 fully enrolled participants: 13 nurses and one physiotherapist. A number of late withdrawals occurred due to sickness and staffing pressures, illustrating some of the challenges healthcare professionals continue to face in accessing protected professional development. Demand for the 2027 programme is already evident, with five deferred participants registered for the next cohort.

The course costs £1,250 per participant, inclusive of teaching, accommodation and meals during the residential programme. HNA-UK considers this to represent good value for a 30-credit university-accredited specialist module and continues to seek funding opportunities to support equitable access.

The teaching faculty includes Cathy Harrison, Sarah Pool, Julia Spires, Paul McLaughlin and Melanie Bladen, supported by expert guest speakers. The 2026 programme includes contributions from Professor Pratima Chowdhury, Dr Anne Kelly, Dr Rachel Swancott, Clive Smith, Laurence Woollard and Robyn Dale, demonstrating the multidisciplinary expertise supporting the programme.

HNA-UK Webinar Series

During 2026, HNA-UK launched a new webinar series to provide members with accessible educational opportunities throughout the year.

Our first HNA-UK webinar focused on Genetics and was delivered by nursing colleagues from Guy's and St Thomas'. The session was attended by 33 HNA-UK members and was very well received, demonstrating strong interest in shorter, accessible educational sessions alongside our established education programmes.

This webinar marks the beginning of a wider HNA-UK Webinar Series, with future sessions focusing on topics identified and chosen by our members. The aim is to respond directly to the educational needs of the HNA-UK community, utilise the considerable expertise that exists within UK bleeding disorders services, and provide regular opportunities for shared learning and professional development.

Advanced Nursing Practice

As the complexity of bleeding disorders care continues to increase, many HNA-UK members are practicing with significant clinical autonomy, including independent assessment, prescribing, treatment decision-making, management of novel therapies and leadership of nurse-led services.

Supporting and recognising advanced nursing practice therefore remains an important priority for HNA-UK.

A dedicated HNA-UK Advanced Clinical Practice meeting is planned for **19 January 2027**, providing an opportunity for advanced practitioners to come together for focused education and shared learning. Proposed areas include non-medical prescribing updates, clinical decision-making and differential diagnosis, alongside opportunities to discuss practice and learn from colleagues working at an advanced level.

HNA-UK hopes this will also provide an opportunity to explore how advanced nursing roles can contribute to future workforce models within bleeding disorders services.

HNA-UK Buddy System

During 2026, HNA-UK launched the **HNA-UK Buddy System**, providing an additional route for peer support and professional connection between nurses working within bleeding disorders services across the UK. The initiative recognises that nurses may work within small specialist teams, be new to bleeding disorders or encounter areas of practice where informal support from an experienced colleague in another centre can be invaluable.

The programme currently has **five buddies matched with five mentors**, providing peer support, shared experience and practical guidance across the HNA-UK network. The Buddy System complements HNA-UK's formal education programme by recognising that professional development extends beyond courses and academic learning. Connecting colleagues between centres can help build confidence, share good practice, strengthen professional relationships and reduce professional isolation.

HNA-UK intends to continue developing the programme during 2027, increasing awareness across the membership and encouraging nurses both to seek support and to share their expertise as mentors.

The Evolving PwBD Population and Changing Role of the Bleeding Disorders Nurse

Workforce capacity remains an important concern raised by HNA-UK members. The role of the specialist bleeding disorders nurse has expanded significantly. Nurses are supporting an ageing population with increasing comorbidity alongside children, young people and families whose treatment pathways are becoming increasingly individualised.

HNA-UK also recognises the changing needs of an ageing bleeding disorders population and the increasing importance of identifying and responding to frailty. As people with inherited bleeding disorders live longer, nurses and the wider MDT are increasingly supporting individuals with age-related comorbidities, functional decline and more complex health and social care needs. HNA-UK is working collaboratively with the HCPA to develop a position paper on frailty, with the aim of raising awareness and supporting a consistent multidisciplinary approach to recognising and managing frailty within bleeding disorders services.

New factor and non-factor therapies have transformed care but have not necessarily reduced nursing workload. They have instead changed the nature of that workload, increasing requirements around education, shared decision-making, surveillance, treatment choice and coordination of care.

Nurses are also increasingly required to provide education and support outside specialist centres, including to emergency departments, primary care, schools and other healthcare professionals.

HNA-UK therefore continues to advocate for appropriate specialist nursing capacity, succession planning, protected education time and recognition of advanced nursing roles.

Infected Blood Inquiry and Compensation

The implementation of recommendations following the Infected Blood Inquiry and the continuing compensation process remain highly significant for our PwBD, families and nursing workforce. Nurses have continued to provide considerable clinical, practical and emotional support to people affected by infected blood.

As highlighted in our previous report, specialist nurses have frequently acted as trusted intermediaries between PwBD, families, healthcare services and other agencies during an exceptionally difficult period. HNA-UK continues to provide an important peer network for nurses undertaking this work and will continue to represent the impact of these additional responsibilities upon specialist services.

Improving Identification and Care of Women and Girls

Women and girls with bleeding disorders remain an important area of focus. HNA-UK members have continued discussions around how services can become more proactive in identifying women and girls who may have an undiagnosed bleeding disorder, including potential carriers within known haemophilia families and girls presenting with heavy menstrual bleeding.

Rather than relying solely upon women finding their way into haemophilia services, there is an opportunity for specialist teams to work more proactively across paediatrics, adolescent services, primary care, emergency medicine and gynaecology. HNA-UK would welcome continued collaboration with UKHCDO and other professional groups to improve awareness, identification and pathways of care for this population.

Children, Young People and Transition

Transition continues to be an important area of nursing practice. HNA-UK members are contributing to work examining how transition from paediatric to adult bleeding disorders services can become more consistent, structured and centred around the readiness of the young person rather than simply their chronological age.

There is an opportunity nationally to share existing good practice and develop greater consistency around transition readiness, self-management, treatment knowledge, psychosocial development and preparation for adult care. This is particularly important within the changing treatment landscape, where young people may reach adulthood having experienced very different disease and treatment burdens compared with previous generations.

National Representation and Collaboration

HNA-UK members continue to represent nursing within national and international groups and professional networks. Nursing representation is maintained within UKHCDO working parties, including the **Girls and Women with Bleeding Disorders Working Party** and the **Peer Review Working Party**, helping to ensure that nursing expertise and perspectives contribute to the development of national practice, standards and service improvement.

HNA-UK members also contribute to the **Clinical Reference Group for Specialised Blood Disorders, EAHAD, WFH** and other national and international professional initiatives.

HNA-UK continues to engage with The Haemophilia Society and wider stakeholders to ensure that nursing perspectives are represented in discussions relating to workforce, education, service development and PwBD care. Maintaining these relationships is essential to ensuring that the nursing voice remains visible within national decision-making.

HNA-UK and The Haemophilia Society

Our partnership with The Haemophilia Society continues to develop. The Haemophilia Society has provided valuable organisational infrastructure and support for HNA-UK while enabling the Association to retain its professional nursing identity. During 2026, discussions have progressed around how this partnership can become more sustainable and how closer working could support education, communications, professional engagement, funding and delivery of national programmes.

This provides an opportunity to create greater continuity for HNA-UK while maintaining the principle that the Association remains: **developed by nurses, for nurses.**

Looking Ahead – 2027

HNA-UK enters 2027 with a growing national network and an ambitious programme of work. Priorities for the coming year include strengthening the national education pathway; expanding the webinar programme; supporting advanced nursing practice and succession planning; advocating for sustainable specialist nursing workforces; **working collaboratively with HCPA to support recognition of frailty within the evolving bleeding disorders population**; improving care for women and girls; supporting transition and young people's services; and maintaining strong representation within UKHCDO and other national organisations.

We are also very much looking forward to our next HNA-UK Annual Meeting and AGM, which will take place on **12–13 March 2027 at Conference Aston, Birmingham**. Building on the success of our 2026 meeting, the 2027 event will provide another important opportunity for our members to come together for education, networking, discussion and shared learning.

Importantly, HNA-UK also recognises the need to consider its own sustainability. Much of the Association's success has historically depended upon significant voluntary contributions from nurses alongside demanding NHS roles. Developing a sustainable infrastructure that enables HNA-UK to continue delivering education, professional representation, communication and national programmes will therefore be an important priority for the next phase of the Association.

HNA-UK remains committed to ensuring that specialist bleeding disorders nurses are connected, educated, supported and represented. As treatment continues to evolve, the role of the nurse is evolving alongside it. Our challenge is therefore not simply to respond to changes in treatment, but to ensure that the workforce, education and professional structures required to deliver high-quality care evolve with them.



Marie Eales (Chair, HNA-UK)

Marie, Geraldine, Katie, Helen, Dawn, Clare, Laura & Sarah

HNA- UK Committee

In partnership with The Haemophilia Society (registered charity no 288260 in England and Wales, SCO39732 in Scotland)

21. Haemophilia Chartered Physiotherapists' Association

The HCPA consists of Specialist Physiotherapists working in Haemophilia and Allied Bleeding Disorders services across the UK and Ireland. We aim to define, promote and encourage best practice for physiotherapy within haemophilia care, providing professional leadership and directing national physiotherapy policy.

Executive Committee:

Chair: Rob Barnard
Vice Chair: Jim Cartwright; Caroline Clegg
Secretary: Katie Lindsay
Treasurer: Kate Millar
Research Lead: Prof. David Stephensen

General Committee: David Hopper (former chair); Stephanie Taylor (Former Treasurer); Zamira Jaffer; Mark McGowan; John Snaith

The committee was elected at the 2025 AGM. The position of secretary will be elected at the 2027 AGM.

Iliopsoas Muscle Haematoma Management Guidelines

Richard Davies, Nicola Hubert and Jane Padkin authored Iliopsoas Muscle Haematoma Management Guidelines, published on UKHCDO website in June 2026. The guideline stands as best practice to support Physiotherapists, and MDT's identifying and managing, what is a potentially limb, or life-threatening event. HCPA thanks Richard, Nicola and Jane for their expertise, this document is due for revision in 2031.

Working Parties

UKHCDO Working Party	HCPA Representative
Musculoskeletal	Dr Paul McLaughlin
Peer Review	David Hopper; Steph Taylor
Emergency Guidelines	David Hopper

National Service Specification	Rob Barnard
Data Management	Prof David Stephensen
Gene Therapy	David Hopper; Steve Classey

Ongoing Research

HCPA members are actively involved in numerous research projects. Currently key focus is on the development of a competency framework for the use of point of care ultrasound in bleeding disorders, understanding the needs of women and girls with bleeding disorders and the Physiotherapists' that care for them. Identifying physical performance screening tools for routine PwBD care and expanding best practice to support our aging population.

AGM

The AGM was held virtually, on 30th April 2026. 19 members attended. The new committee were formally elected, with transition of roles occurring following the 2025 Educational Conference.

Educational Conference

Held at the Clayton Hotel on 11/12th June 2026. With 43 members attending. This meeting was kindly sponsored by CSL Behring, Novo Nordisk, Pfizer, Roche and Sobi.
The first day of conference focused on the management of Elbows, with presentations from Specialist Physiotherapists and Orthopaedic colleagues. The second day hosted a range of expert presenters from within our field, with particular emphasis on Women and Girls with Bleeding Disorders. This day included a free papers session for members to showcase their work short oral presentation.

International Conferences

EAHAD 2026

HCPA members were heavily involved in EAHAD 2026, in Dublin. Including Oral presentations, Panel discussions and poster presentation.

WFH 2026

HCPA members attended WFH in Kuala Lumpur, where they participated in oral presentations and poster submissions.

International Representation

International Prophylaxis Study Group (IPSG)

Prof. David Stephensen is co-chair, with Mel Bladen a member of this group. IPSG are a collaborative group of health care professionals involved with the assessment and care of individuals with inherited

bleeding disorders, which is currently exploring the utility and modification of the Haemophilia Joint Health Score (HJHS).

EAHAD

Paula Loughnane and Jessica Hedden currently sit on the EAHAD Physiotherapists' Committee. The HCPA congratulates Jessica on her successful application to the committee and thanks Dr Paul McLaughlin for his time representing the HCPA in this international forum.

Publications 2025/26

Cruz-Montecinos C, Calatayud J, Andersen LL, Daffunchio C, Soto-Arellano V, López M, Perez-Alenda S, Chimeno-Hernández A, **Stephensen D**, Núñez-Cortés R. Physical Activity in People with Hemophilia. *Semin Thromb Hemost.* 2026 Jan 8. doi:10.1055/a-2778-9890.

Stephensen D, Wall C, Xiang H, Palmer B, Chowdary P, Collins PW, Gorman R, Matthias M, Percy C, Sartain P, Shapiro S, Talks K, Hay CRM. Emicizumab utilization, safety, and outcomes in people with severe hemophilia and no inhibitors: 3-year follow-up. A report from the UK Haemophilia Centre Doctors' Organisation. *Res Pract Thromb Haemost.* 2025;9(6):103164.

McLaughlin P, Chowdary P, Harrison C, **Stephensen D**, Roussel N. Gap analysis investigating healthcare professionals' skills and knowledge for pain management in haemophilia: a qualitative study. *Haemophilia.* 2025 Aug 15.

Holdsworth C, **Bladen M**, **Harbidge H**, Drechsler W, Mahaffey R, Perez-Alenda S, **Sayers F**, Strike K, Timmer M, **Stephensen D**, et al. Measuring Physical Function Capacity in Persons With Haemophilia: A Systematic Review of Performance-Based Methods. *Haemophilia.* 2025. doi:10.1111/hae.70081.

McKeown W, **Taylor S**, Shapiro S. Frailty and frailty syndromes in persons with hemophilia: a review. *J Thromb Haemost.* 2025;23(11):3409-3423. doi:10.1016/j.jtha.2025.07.020.

Key Documents

HCPA-Constitution-2025.pdf

Adult Service Provision of Physiotherapy in Haemophilia and Other Inherited and Acquired Bleeding Disorders

Children's Service Provision of Physiotherapy in Haemophilia and Other Inherited and Acquired Bleeding Disorders

Iliopsoas Muscle Haematoma Management Guidelines

2026/27

Clinical and Academic

The HCPA will continue to encourage members to take active steps in research activities.
The HCPA will support ongoing service specification review, providing recommendations on staffing provisions.
The HCPA will support preparations towards the next cycle of Peer Reviews.

Meetings

AGM to be held in Spring 2027, including Election of Secretary and General Committee positions.
Educational Conference to be held in June 2027.

Rob Barnard
Chair, Haemophilia Chartered Physiotherapist Association
August 2026

22. Haemophilia Psychology Association

The Haemophilia Psychology Association (HPA) is made up of Practitioner Psychologists working within the health service across the UK & Ireland. There continues to be an increase in our membership over the past 12 months due to the creation of new psychology posts in NHS England, to support individuals and families, impacted by Infected Blood & Blood Products. These posts are located within Haemophilia centres. A benchmarking survey is currently being completed to understand psychology capacity within Inherited Bleeding Disorders (being completed by Dr Carolyn Gordon, Clinical Psychologist). A primary role of the HPA is to support and educate those new to working in the area.

The group meets virtually once a month for case discussions, peer support and sharing of best practice. The HPA are planning to have an online CPD event for psychologists working in IBDs in the New Year with hopes of planning an 'in-person' CPD event in the future.

Members from the HPA have represented the group and shared psychology insights at meetings and working groups for the implementation of the English Infected Blood psychology service and the Peer Review Working Group. Members of the group have attended numerous regional IBCA stakeholder meetings and given feedback to Government Consultations on IBI Compensation, in an effort to advocate for fair treatment of individuals' and their families. HPA has close working relationships with the PwBD support groups across the nations and tries to support their events and work, whenever possible.

Over the past year, the HPA has had representation on the Psychosocial committees of both the World Federation of Haemophilia (WFH; Dr Sarah Whitaker, Clinical Psychologist) and the European Association for Haemophilia and Allied Disorders (EAHAD; Dr Gráinne O' Brien, Clinical Psychologist), with key presentations from HPA members at both the EAHAD's congress in Dublin, February 2026 and the WFH's congress in Kuala Lumpur, April 2026.

Education about the unique psychological needs of those with Inherited Bleeding Disorders has been a key activity for many psychologist working in the area including education sessions being delivered to Trainee Clinical Psychology on a number of courses, at the annual Contemporary Care Course run by the HNA, regional Psychology meetings and Citizen Advice Staff.

Research activity has included the supervision of a trainee psychology project exploring the psychosocial needs of women with a bleeding disorder, using a delphi methodology focused on highlighting the voices of experts by experience with the intention to create specific guidelines and the evaluation of the application of the Psychologically Informed Environment (PIE) framework to a haemophilia CCC (Dr Sophie Buckley, Clinical Psychologist).

Dr Gráinne O' Brien
Clinical Psychologist & Chair, Haemophilia Psychology Association
August 2026

23. British Society for Haematology Haemostasis & Thrombosis Task Force

Membership

Dr Will Lester (Chair)
Dr Ian Jennings
Dr Stella Williams (MHRA Representative)
Dr Karen Breen
Dr Lara Roberts
Dr Jayashree Motwani
Dr Martin Scott (UKHCDO Representative)
Dr Nicola Curry
Dr Claire Lentaigne
Dr Matthew Rogers
Dr Eman Hassan (Trainee Representative)
Dr Anette Bowyer
Ms Roslind Byrne
Ms Emma Gee
Mr Sean Platton (Vice Chair)
Mr Chris Reilly-Stitt (UK NEQUAS representative)
Mr Stephen MacDonald

Meetings

Dr Lester chaired the BSH H&T Task Force until September 2026, when his term expired. Sean Platton has been Vice-Chair, but will assume the role of chair from September 2026 onwards. A replacement Vice-Chair is yet to be confirmed.

The Task Force met on 29th January 2026, 20th March 2026, 22nd June 2026 and 8th September 2026

UKHCDO Standalone Guidelines and other publications published 2026

UKHCDO paediatric working party position statement on medico legal requests for haemostatic investigations in children with possible non-accidental injury.

BSH/ Joint BSH/UKHCDO Guidelines Published 2026

Diagnosis and monitoring of thrombotic thrombocytopenic purpura: Guidance for laboratories from the British Society for Haematology. MacDonald S, Pitchford T, Singh D, Fretwell R, Jenkins PV, Lawrence C, Gooding R, Platton S; BSH Committee Br J Haematol. 2026 Sep;209(3):928-938.

Implementation and value of providing a multidisciplinary haematology and gynaecology service for individuals with bleeding and thrombotic disorders: A British Society for Haematology & United Kingdom Haemophilia Centre Doctors' Organisation Good Practice Paper. Biss T, Millen E, Warren C, Raheja P, Garside S, Motwani J, Stone A, Lowe G, Clark TJ; BSH Committee & UKHCDO Girls and Women with Bleeding Disorders Working Party. Br J Haematol. 2026 Sep;209(3):919-927.

Use of andexanet alfa: A British Society for Haematology position statementBuka, R. J., Arachchillage, D. J., Bagot, C. N., Benson, G., Bradbury, C. A., Curry, N., Hunt, B. J., Sutton, D. J., Thomas, M. R., Westwood, J. P., & Breen, K. Br J Haematol. 2026; 208 (6), 1939-1941

Guideline for the management of hepatitis B and C infection and subsequent liver disease surveillance (where indicated) in people with congenital bleeding disorders: A joint guideline from the British Society of Haematology and the British Viral Hepatitis Group. Brown A, Aspinall RJ, Barclay ST, Gillyon-Powell M, Jeffery K, Kennedy PT, McDougall N, Pembroke T, Scott M, Shapiro S; BSH Committee Br J Haematol. 2026 Mar;208(3):855-863

Laboratory investigation and clinical management of acquired coagulation factor inhibitors: A joint British Society for Haematology and United Kingdom Haemophilia Centre Doctors' Organisation Guideline. Percy C, Riddell A, Talks K, Anderson J, Cotton S, Riat R, Saja K, Makris M; BSH Committee. Br J Haematol. 2026 Jan;208(1):67-82

Guidelines in Preparation:

Clinical diagnosis and management of von Willebrand Disease (VWD). Writing group chair: Dr C Millar

BSH guideline of D-Dimer testing. Writing group chair: Dr W Lester

Guidance on the Dental Management of Patients with Haemophilia and Inherited Bleeding Disorders (UKHCDO guideline: working party members: Chair: Dr J Anderson, Sara Boyce, Andrew Brewer, Janet Davies, Jayne Keaney, Bella Madan, Lochana Nanayakkara, Emily Symington, Alice Taylor, Albert Yeung

The use of drug-specific calibrators for clotting factor assays- recommendations for the laboratory establishment and practice from BSH and UKHCDO. Writing group chir: Dr Annette Bowyer

Dr Martin Scott

UKHCDO Representative for BSH Haemostasis and Thrombosis Taskforce

October 2026

24. The Haemophilia Society

July 2025 to July 2026

The Haemophilia Society (THS) has almost 6,000 members from across the UK living with or caring for someone with a bleeding disorder who look to us to help them get the best treatment and care. As well as members with haemophilia A and B and von Willebrand disorder we also support people with rarer conditions, including Glanzmann thrombasthenia and factor VII deficiency.

In February 2026 we were awarded a one-year grant from the Department of Health and Social Care in response to a recommendation from the Infected Blood Inquiry.

THS has, rightly, invested a huge amount of resources into the support of the infected blood community and we are pleased to see the impact of this recognised through this award.

The grant will be used in support of everyone with a bleeding disorder. The inquiry recognised the importance of the 'patient voice' at the heart of decision making and we see the facilitation of this as a central part of our role.

We will use the grant to enhance services and support for the bleeding disorder community with additional bespoke outreach support for those impacted by infected blood.

The grant has enabled us to begin to expand our team, including a new policy engagement role who will lead on the development of our work in support of women and girls with a bleeding disorder.

We are committed to holding in-person events where possible to lessen the isolating impact of living with a rare disorder. Most are free to our members and it is free to join the Haemophilia Society.

In July we hosted our first *Family Camp*, a weekend event in Staffordshire for young people with bleeding disorders, their siblings and parents or carers. It was an opportunity to try new activities, such as sailing and climbing and to meet other families who live with a bleeding disorder. We also held education workshops on wellbeing, the role of a haemophilia social worker and maintaining good dental health.

We were pleased to join forces with Liverpool Haemophilia Centre in June to host *VWD and me,* a support and information day for people living with von Willebrand disorder and their families. We value the opportunity to partner with treatment centres welcome new ideas which support increased engagement with people with a bleeding disorder.

In May we also hosted *Rare Together*, a weekend conference in Birmingham for anyone with an ultra rare condition. While experiences differ across conditions, there was a great deal of common ground in terms of feelings of isolation and concern at lack of treatment options.

Our annual Big Get-Together conference in Northampton in November was a chance to connect people with a bleeding disorder from across the UK to share experiences and learn about new treatments. We also offered one-to-one information and advice sessions for members of the infected blood community.

This year we continued to liaise regularly with IBCA and the Cabinet Office to try to improve the system and to highlight areas where the compensation scheme was not working.

We were also members of a working group to look at the Infected Blood Inquiry's recommendations on improvements in haemophilia care, although we are concerned that progress in this area appears to have stalled. We hope to challenge this in collaboration with our partners in the Haemophilia and Bleeding Disorder Alliance which brings together PwBD and clinician groups from across the UK to push for higher standards and better access to treatment and care.

In addition, we continue to be a member of the specialised blood disorders Clinical Reference Group (CRG) as one of the two PwBD representatives on the group. We also work with NICE, supporting the process of evaluating new treatments for use in the NHS by advocating for the needs of PwBD and demonstrating the need for new treatments.

This year we were also part of the NICE ATMP Engage project. We also commissioned research into the implementation of gene therapy in the UK, published in late summer 2026.

We are members of NHS England's Specialised Commissioning Stakeholder Forum and the Specialised Health Care Alliance (SHCA) which allows us to raise wider issues about how NHS treatment and care is commissioned and delivered across England. We also work with the Haemophilia Chartered Physiotherapists' Association (HCPS).

As always, we are grateful for the support of many specialist haematology professionals in volunteering at our events and for providing advice and sharing expertise.

Kate Burt,
CEO, The Haemophilia Society
September 2026

The Haemophilia Society







25. Haemophilia Scotland

Events and Projects

Haemophilia Scotland's vision is for Scotland to be a place where people with haemophilia, von Willebrand and other rare bleeding disorders, along with their families and carers, can live healthy, happy lives.

During 2025-26, we reached more people affected by bleeding disorders, expanded the support available to members and created new opportunities for people to connect, learn and share experiences. Membership grew from 415 to 461 during the year, representing a 12% increase and demonstrating the growing awareness of Haemophilia Scotland and the services we provide.

Bringing members together was one of our key objectives for the year. We delivered a Recently Diagnosed Family Weekend, a Learn and Connect event in Inverness and our Annual General Meeting and Members' Day was held at Edinburgh Zoo. These events gave members the opportunity to meet others with shared experiences, learn from healthcare professionals and build valuable support networks.

Our Financial Wellbeing Service also saw significant success and growth. During the year, the service supported 25 successful benefit applications, helping members secure more than £182,000 in additional annual benefit entitlements and almost £27,000 in backdated payments. Referrals from haemophilia centres increased as awareness of the service grew, helping more members access specialist support and advice.

Engagement

Working closely with haemophilia centres and healthcare professionals remains an essential part of our work. During the year, we maintained regular contact with centres across Scotland, helping to raise awareness of our services, encourage referrals and better understand the needs of people living with bleeding disorders.

We also remained actively involved in the Scottish Inherited Bleeding Disorders Network (SIBDN), with our Director continuing as Chair of the Education and Communications Sub-group. Members of our team contributed to the Network's Annual Education Day, sharing updates on our work and helping ensure that PwBD experiences remain central to discussions about treatment and care.

Alongside this, we continued to work with partner organisations across the UK through the Haemophilia and Bleeding Disorders Alliance. This provided an opportunity to discuss shared challenges, influence UK-wide discussions and promote improvements in care and services for people living with bleeding disorders.

Advocacy

Our advocacy work during the year mainly focused on developments relating to the Infected Blood Compensation Scheme. We worked closely with the Scottish Infected Blood Forum, UK haemophilia organisations, the Infected Blood Compensation Authority (IBCA) and both the

Scottish and UK Governments to ensure that the views of infected and affected people in Scotland were represented as the scheme expanded.

This included contributing to discussions that led to the publication of the Infected Blood Inquiry's Additional Report on Compensation, responding to the UK Government's public consultation on proposed changes to the scheme and participating in ongoing engagement with IBCA. We also continued to represent Scotland on several national groups overseeing implementation of the Inquiry's recommendations.

Good progress was also made towards establishing a permanent Scottish memorial to recognise those who lost their lives because of contaminated blood and blood products. During the year, Edinburgh Council gave in-principle approval for a memorial to be located within Princes Street Gardens, representing an encouraging step forward for the project.

Alongside our infected blood work, we continued to advocate for improvements in treatment and care, including better access to specialist physiotherapy services and equitable access to new treatment options. We also participated in reviews of new medicines through the Scottish Medicines Consortium, helping ensure that the patient voice remains part of decisions affecting people with bleeding disorders across Scotland.

Alan Martin

Director, Haemophilia Scotland

August 2026

26. National Haemophilia Database - IT Update

Over the past year, we have continued to strengthen and enhance the digital services that support the NHD, clinical teams and people with bleeding disorders (PwBD). This report outlines key developments, system improvements and security enhancements delivered during the year, together with planned future initiatives. As technology and user needs continue to evolve, we remain focused on providing secure, reliable and effective systems that support the haemophilia community. We thank all stakeholders for their ongoing engagement, collaboration and support.

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Haemtrack (Home Therapy Platform)

Haemtrack continues to evolve as a secure, PwBD-focused platform supporting people with bleeding disorders (PwBD) receiving treatment at home. Having facilitated the recording of almost three million home treatments, the platform remains an important component of the bleeding disorders digital ecosystem, enabling PwBD to record treatments and bleeds while providing clinical teams with timely information to support safe, effective and personalised care.

Over the past year, development has focused on enhancing flexibility, interoperability and support for emerging clinical and service requirements. Significant progress has been made in strengthening integration between Haemtrack and the National Haemophilia Database (NHD), enabling data captured within Haemtrack to be linked with national datasets for analysis and reporting purposes. Delivering this capability has required the development of secure interfaces and APIs to facilitate data exchange between systems operating across different network environments, with Haemtrack hosted on internet-facing infrastructure and NHD within the NHS HSCN network.

Further work has been undertaken to improve data consistency across systems through the synchronisation of treatment product catalogues and naming conventions. This ensures that new products introduced into clinical practice can be represented consistently across Haemtrack, NHD and other associated systems, improving data quality, reducing administrative overhead and supporting more accurate national reporting and analysis.

A major enhancement this year has been the introduction of functionality that enables new data collections and questionnaires to be created and configured dynamically through the administration interface, without the need for software development or code changes. This significantly increases the agility of the platform, allowing new datasets to be deployed rapidly in response to evolving clinical, research and regulatory requirements.

The enhanced platform also provides improved support for newly introduced therapies and products that require the capture of additional treatment information, including different vial sizes, product-specific attributes and administration requirements. These developments ensure that Haemtrack can adapt more readily as treatment options continue to expand and evolve.

Improvements have also been delivered to product barcode management, including closer collaboration with manufacturers to improve the supply and maintenance of barcode reference

data. These enhancements help streamline treatment entry for PwBD, improve the accuracy of product recording and reduce the burden of manual data entry.

Alongside these developments, work has continued to evaluate and support the implementation of quality of life data collection within Haemtrack. The new dynamic data collection capability provides the technical foundation for deploying quality of life questionnaires and other PwBD-reported outcome measures, supporting a broader understanding of PwBD experiences and treatment effectiveness.

Building on the platform's ability to support multiple datasets and clinical pathways, development is anticipated to begin shortly on the new data collection pathway for women with bleeding disorders. This initiative will utilise a dedicated dataset within Haemtrack, with integration to the NHD to support national data collection, analysis and service development in this important and growing area of care.

Collectively, these developments further strengthen Haemtrack's position as a modern and adaptable home therapy platform, capable of supporting the changing needs of people, clinicians and researchers while providing a scalable foundation for future innovation across bleeding disorders services.

Haemophilia Centre Information System (HCIS)

The rollout and development of HCIS has remained a major area of focus throughout the year, with significant investment in both platform enhancement and implementation activities. Multiple software releases have been delivered, introducing new functionality, addressing user feedback and further strengthening integration with both Haemtrack and the National Haemophilia Database (NHD).

Considerable effort has also been directed towards refining the HCIS implementation process. While rollout activities continue to be influenced by local governance and technical requirements within NHS organisations, improvements have been made to deployment methodologies that reduce reliance on internal Trust IT departments and streamline implementation activities. As a result, several additional treatment centres have successfully gone live during the year, with a growing number of sites progressing through the final stages of deployment and preparing for implementation.

A significant milestone has been the completion of a major new development programme delivering a web-based version of HCIS. This next-generation platform provides a modern and flexible foundation for future service delivery, removing many of the challenges associated with traditional desktop deployments. The web-based architecture enables centres to access HCIS without the need for local software installation, simplifies the delivery of system updates and enhancements, and reduces dependency on local IT support teams for ongoing maintenance and deployment activities.

The new platform also supports closer collaboration between treatment centres operating within regional clinical networks. By providing a more accessible and connected environment, the web-based HCIS will enable centres to work together more effectively, improve information sharing and strengthen integration with national systems including NHD. In addition, the modernised architecture provides a more efficient framework for future developments, interoperability initiatives and service improvements.

The progress achieved during the year reflects a substantial commitment of development, implementation and support resources. As rollout continues to accelerate, HCIS is becoming an increasingly important component of the national bleeding disorders infrastructure, providing centres

with a secure, modern and sustainable clinical information system designed to support the future needs of haemophilia services.

NHD Central Online Information System

The continued development of NHD Online 2 has been a major focus during the year, supporting the ongoing modernisation of the National Haemophilia Database and the gradual transition away from the legacy NHD Online platform. Building on the successful introduction of modules such as the Gene Therapy Database, adverse event reporting and the new consent management functionality, NHD Online 2 has continued to expand with the delivery of several significant new features and enhancements.

During the year, a new PwBD management system was introduced, providing improved tools for the administration and maintenance of PwBD records within NHD. In addition, a new Bleeding Disorders Card function has been developed to support the management and presentation of key PwBD information, helping to improve accessibility of important clinical details. The live rollout of the new NHD consent management system has also progressed, providing centres with enhanced capabilities to manage consent activity, monitor completion rates and maintain electronic records of consent documentation. Further development of the Gene Therapy Database has continued in response to the growing use of the database, with additional functionality introduced to support data collection, PwBD monitoring and long-term follow-up requirements.

Most recently, a redesigned Quarterly Returns submission system has been delivered within NHD Online 2, providing centres with a more streamlined and intuitive process for reviewing service activity data. Enhanced validation and workflow functionality have been introduced to improve the quality and efficiency of data submission while reducing administrative burden on users.

A key objective of the NHD Online 2 programme is to create a single, modern platform that supports all core NHD functions, and provides improved visibility of data held. Over the coming year, development will focus on completing the migration and redevelopment of the remaining functionality currently held within the legacy NHD Online system. This will enable the retirement of the older platform and the consolidation of services within NHD Online 2, simplifying support and maintenance, improving user experience, strengthening integration with related systems and providing a scalable foundation for future innovation across the bleeding disorders community.

Adverse Event Reporting and EUHASS Integration

The National Haemophilia Database (NHD) adverse event reporting system has continued to mature following its successful implementation, with further enhancements introduced to support more comprehensive national surveillance and reduce the reporting burden on treatment centres. During the year, the adverse event framework was expanded to accommodate emerging treatment pathways, including the introduction of a new adverse event category for gene therapy-related events. These additions ensure that the reporting system continues to evolve alongside advances in clinical practice and emerging safety monitoring requirements.

The automated integration between NHD and the European Haemophilia Safety Surveillance System (EUHASS) has also been further developed, enabling these new adverse event types to be transferred seamlessly to EUHASS as part of the existing reporting workflow. This maintains the principle of reporting once through NHD, with data automatically shared with EUHASS where

appropriate, reducing duplication of effort for participating treatment centres while supporting both national and international safety surveillance activities.

Work has also been undertaken to explore and develop simplified mechanisms for the reporting of death events to EUHASS. By leveraging information already recorded within NHD, the intention is to automatically populate relevant elements of the EUHASS reporting process using existing data sources wherever possible. This approach has the potential to significantly reduce administrative burden on centres while improving the efficiency, consistency and completeness of reporting.

Alongside these developments, ongoing collaboration with EUHASS has ensured that the adverse event system remains aligned with changing surveillance requirements. This has included the introduction of additional data fields, new reporting options and updates to event classifications, ensuring that both NHD and EUHASS continue to capture the information required to support effective safety monitoring across the bleeding disorders community.

To further improve reporting completeness, new adverse event reminder and notification functionality has also been developed for treatment centres. These enhancements are designed to support the timely review and submission of adverse event information, helping to improve data quality, ensure important safety information is captured, and strengthen the overall effectiveness of national haemovigilance and pharmacovigilance activities.

Collectively, these developments continue to enhance the NHD's role as a central platform for adverse event management, providing treatment centres with efficient reporting tools while supporting national and international PwBD safety surveillance programmes.

Secure Power BI Reporting Infrastructure

During the year, significant work was undertaken to establish a dedicated local Power BI reporting infrastructure to support the delivery of secure, PwBD-level reporting within the National Haemophilia Database (NHD). The project involved the purchase and configuration of supporting server infrastructure, implementation of the required Power BI licensing model, and the development of a secure reporting environment designed to meet NHS information governance and cyber security requirements.

The new platform has been architected to enable authorised users to access interactive reports containing personal identifiable data (PID) within a controlled and secure environment. Extensive configuration and testing were undertaken to ensure appropriate authentication, role-based access controls, data segregation and audit capabilities were in place prior to deployment.

Integration with NHD has enabled reporting datasets to be securely refreshed and presented through interactive dashboards, providing treatment centres with improved visibility of their local PwBD populations, activity, outcomes and data quality metrics. By moving beyond traditional static reporting, users can explore information dynamically, apply filters, analyse trends and gain deeper insights relevant to their clinical and operational requirements.

The implementation of the local Power BI infrastructure represents an important step forward in enhancing access to timely and actionable information for haemophilia services. The platform provides a scalable foundation for future reporting developments and supports ongoing efforts to improve data quality, service monitoring and PwBD care across the bleeding disorders community.

System Integration and Interoperability

Enhancing Data Flow Across the Bleeding Disorders Digital Ecosystem

A key area of focus during the year has been the continued development of integration between the core systems that support the bleeding disorders community, including the National Haemophilia Database (NHD), Haemtrack, Haemophilia Centre Information System (HCIS) and EUHASS. These systems serve complementary purposes and collectively support PwBD care, treatment monitoring, surveillance activities and national reporting.

Significant progress has been made in improving the consistency, quality and flow of information between platforms. A major element of this work has been the standardisation of treatment product catalogues across systems, ensuring that new products introduced to the bleeding disorders community are represented consistently within NHD, HCIS and Haemtrack. This reduces duplication of effort, improves data quality and supports more accurate reporting and analysis across the national service.

Work has also continued to strengthen integration between NHD and Haemtrack through the adoption of common identifiers and enhanced data sharing mechanisms. This enables information captured within one system to be more effectively linked and utilised within another, reducing administrative burden on clinical teams while improving the completeness and value of data available for PwBD care, service management and national reporting.

Delivering these integrations presents a number of technical challenges, particularly as the systems operate across different network environments. NHD is hosted within the NHS HSCN network, while Haemtrack is delivered via an internet-facing infrastructure. To facilitate secure communication between these environments, dedicated interfaces have been designed and implemented. These services provide controlled and auditable methods for exchanging information while maintaining high standards of security, resilience and information governance.

This ongoing programme of interoperability work is helping to create a more connected digital ecosystem for bleeding disorders services. By reducing data silos and enabling information to flow more effectively between systems, these developments support improved data quality, greater operational efficiency and a stronger foundation for future digital innovation across the haemophilia community.

Artificial Intelligence (AI)

The rapid evolution of artificial intelligence (AI) continues to present significant opportunities to enhance the efficiency, effectiveness and innovation of digital health services. Over the past year, work has been undertaken to develop a formal AI strategy and policy framework to ensure that AI technologies can be adopted in a structured, responsible and secure manner across the National Haemophilia Database (NHD) environment. This approach has been designed to balance the considerable benefits of AI with the need to protect sensitive personal, clinical and organisational information.

Following evaluation of available technologies and associated risks, a decision has been made to adopt two AI platforms configured for protected organisational use. These services will be implemented within controlled environments designed to safeguard NHD data and information, ensuring that organisational data is not used to train public AI models and that appropriate security, governance and usage controls are maintained. The introduction of these tools will provide staff with

access to AI capabilities while remaining aligned with information governance, cyber security and data protection requirements.

The adoption of AI is expected to support a wide range of operational activities, including document preparation, information analysis, reporting, software development, knowledge management and administrative processes. By assisting with routine and time-consuming tasks, these technologies have the potential to improve productivity, enhance consistency and allow specialist staff to focus on higher-value activities that support PwBD, clinicians and stakeholders.

As AI capabilities continue to mature, ongoing monitoring and governance will remain a key component of our approach. The establishment of a formal policy framework ensures that AI is used safely, ethically and transparently, while providing a foundation for the future evaluation of additional use cases that could further benefit the NHD and the wider bleeding disorders community.

Cyber Security, Compliance and Resilience

Cyber security and information governance remain fundamental to the operation of the National Haemophilia Database (NHD) and its associated digital services. Over the past year, we have continued to strengthen our security, quality and operational management frameworks, building on the successful achievement of ISO 27001 certification. In addition to maintaining our information security certification, the organisation has now achieved certification to ISO 9001 for Quality Management and ISO 14001 for Environmental Management. Together, these internationally recognised standards demonstrate our commitment to delivering secure, high-quality and sustainable services while maintaining a culture of continual improvement.

Protecting sensitive personal and organisational data continues to be a key priority. Security controls are subject to regular review and enhancement to ensure they remain effective against evolving cyber threats. Our cyber security programme is supported by routine risk assessments, security audits, vulnerability management activities and regular governance reviews, enabling us to identify opportunities for improvement and respond proactively to emerging risks.

During the year, a number of additional cyber security technologies and services were implemented across the infrastructure supporting NHD and related systems. These enhancements have strengthened monitoring, threat detection, access control, endpoint protection and overall security visibility, providing additional layers of defence against increasingly sophisticated cyber threats. Security monitoring and incident response capabilities have also been enhanced to support the early identification and mitigation of potential security events.

Alongside technical security improvements, considerable emphasis has been placed on operational resilience. Regular business continuity and disaster recovery exercises are undertaken to validate recovery procedures, test organisational preparedness and ensure critical services can continue to operate effectively in the event of a disruption. These exercises provide valuable assurance that systems, processes and personnel are equipped to respond to a range of operational and cyber security scenarios.

Through continued investment in security, compliance and resilience, we remain committed to safeguarding personal information, maintaining stakeholder trust and ensuring the ongoing availability, integrity and confidentiality of the services that support the bleeding disorders community.

User Authentication – NHS Care Identity Service

Over the coming year, the National Haemophilia Database (NHD) will continue its work towards implementing NHS Care Identity Service 2 (CIS2) authentication. CIS2 is the NHS national identity and access management platform and will provide a modern, secure method for authorised healthcare professionals to access NHD systems using their NHS credentials.

The introduction of CIS2 forms part of our ongoing commitment to strengthening security, improving user experience and ensuring alignment with NHS digital standards. Once implemented, CIS2 will enable users to benefit from a streamlined authentication process while supporting enhanced identity verification and modern multi-factor authentication capabilities.

Preparatory work has been undertaken to assess technical requirements, develop integration plans and ensure a smooth transition for users. The implementation programme is being carefully managed to minimise disruption and to ensure that access to NHD systems continues to meet the needs of clinical teams and organisations across the bleeding disorders community.

The move to CIS2 will further support the security of personal information, simplify user account management and align the NHD with wider NHS digital initiatives. This investment will provide a strong foundation for future integration with national NHS services and help ensure the NHD remains a secure, resilient and trusted platform.

Integration with NHS Personal Demographics Service (PDS)

In addition to CIS2, work is planned to introduce integration with the NHS Personal Demographics Service (PDS) across the National Haemophilia Database (NHD) ecosystem. PDS is the national NHS service that provides access to key demographic information associated with a person's NHS number, including details such as name, date of birth, gender and registered GP practice. Integration with PDS will support the continued improvement of data quality, PwBD identification and operational efficiency across NHD and associated systems.

The introduction of PDS will enable demographic information to be validated and updated directly from the NHS national demographic record, reducing the need for manual data entry and helping to ensure that personal information remains accurate and consistent. This will support improved person matching, minimise duplicate records and reduce the administrative effort required by treatment centres to maintain personal details across multiple systems.

PDS integration will also strengthen interoperability between NHD, HCIS, Haemtrack and other connected services by providing a more robust and consistent approach to person identification. Access to authoritative NHS demographic data will help improve data quality for clinical care, national reporting, research and surveillance activities, while supporting compliance with NHS data standards.

In addition to the benefits for data quality, the introduction of PDS will simplify a range of operational processes, including PwBD registration, demographic updates and record validation. By reducing manual processes and improving accuracy at source, treatment centres will be able to spend less time managing PwBD records and more time focusing on PwBD care.

The implementation of PDS forms part of the wider strategy to modernise and integrate the bleeding disorders digital infrastructure, supporting a more connected, efficient and resilient ecosystem for PwBD, clinicians and healthcare organisations.

Conclusion

The past year has seen significant progress across the NHD digital ecosystem, with continued investment in platform modernisation, interoperability, security, reporting capabilities and PwBD-centred services. From the ongoing development of Haemtrack, HCIS and NHD Online 2 to advancements in adverse event surveillance, secure analytics, system integration and cyber security, these initiatives collectively strengthen the foundations that support clinical care, national data collection and research. Looking ahead, the introduction of technologies such as CIS2 authentication, NHS PDS integration and responsible AI adoption will further enhance security, efficiency and connectivity across the bleeding disorders community. We remain committed to delivering innovative, resilient and user-focused digital services that support PwBD, clinicians and stakeholders, while ensuring that the NHD continues to evolve in line with the future needs of haemophilia and bleeding disorders care.

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October 2026