SIBDN

Scottish Inherited Bleeding Disorders Network

Annual Report
2025/26

The Network is supported by a dedicated programme team within Public Services Delivery Scotland (PSDS), consisting of:

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This document has been prepared by the National Services Directorate (NSD) of Public Services Delivery Scotland (PSD Scotland) on behalf of SIBDN. Accountable to Scottish Government, PSD Scotland works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. The SIBDN Network is a collaboration of stakeholders involved in the care of patients with bleeding disorders, who are supported by a PSD Scotland Programme Team to drive improvement across the care pathway.

Introduction

The Scottish Inherited Bleeding Disorders Network (SIBDN), a national managed clinical network, was formally designated in April 2016. It is commissioned by the National Services Division (NSD).

In people with bleeding disorders, the haemostatic (clotting) process does not work properly. As a result, people with bleeding disorders can bleed for longer than normal and some may experience spontaneous bleeding into joints, muscles, or other parts of their bodies.

These conditions are rare in the general population and most are genetically inherited. They include Haemophilia A and B, von Willebrand Disorder (vWD), other rare coagulation factor deficiencies and platelet disorders. Most bleeding disorders are treated by replacing the missing clotting factor.

Haemophilia care is provided by Haemophilia Comprehensive Care Centres (CCC) for Adults and Children in Glasgow and Edinburgh, and 3 Haemophilia Centres based in Aberdeen, Inverness and Dundee, which are linked to the Edinburgh CCC.

Factor replacement products are funded at the national level through an arrangement that is referred to as the Risk Sharing Scheme for Inherited Bleeding Disorders. This scheme pools funds for blood clotting concentrates and drugs for people with Haemophilia and rare bleeding disorders resident in Scotland. People who receive products from the scheme will be registered with one of the Haemophilia Centres. NSD administers the scheme on behalf of the territorial Health Boards in Scotland.

SIBDN aims to support the delivery of an equitable high-quality service across Scotland for patients with inherited bleeding disorders underpinned by evidence-based, professionally developed and agreed clinical pathways and guidance. It also strives to support good practice in multidisciplinary and integrated working both within the Network and its associated services.

SIBDN encompasses care for individuals born with an inherited bleeding disorder at all stages in the patient pathway from childhood through to adulthood. Specifically, all adults and children with the following diagnosis are covered by the Network:

- Haemophilia A (Factor VIII deficiency)
- Haemophilia B (Factor IX deficiency)
- Von Willebrand Disorder (vWD)
- Acquired Haemophilia and other related bleeding disorders
- Other rare forms of inherited bleeding disorders

Lead Clinician Update

During 2025/26, SIBDN has continued to push forward improving care throughout Scotland while promoting greater equity of access and outcomes. There have been regular meetings of the Steering Group and the Nursing, Data Manager, Physiotherapy & Psychology (NDPP) Sub-Group.

The Annual Education Event was held on 21st November 2025 in Edinburgh, which was well attended and well received. The opportunity for the clinical teams and stakeholders across the country to meet in person was invaluable. Work is currently underway in planning for the 2026 event.

Due to the Scottish Government review of National Networks business as usual was prioritised in 2025/26. However, with this a number of actions have continued to be taken forward by the group. These include:

- SIBDN patient experience questionnaire
- National guideline scoping
- Completion and agreement of a national transition guidance.

The SIBDN peer review and Infected Blood Inquiry sub-group have met to help take forward recommendations where appropriate for the Network. Audits for the remaining Haemophilia Centres are being planned across the Scottish teams.

With the review of National Networks now complete, SIBDN hopes to continue the current work and expand on further areas. These areas will be identified through the upcoming Strategic Needs Assessment.

Current position

Activity during 2025/26 reflected national prioritisation set during a period of review. Alongside evolving national planning arrangements, Managed Clinical Networks were asked to focus activity on a number of core priorities.

Looking ahead, and consistent with the direction set by the Health and Social Care Service Renewal Framework and Scotland's Population Health Framework (June 2025), and recognising that CEL 29 (2012) *Managed Clinical Networks: Supporting and Delivering the Healthcare Quality Strategy* remains the extant mandate for Managed Clinical Networks, SIBDN will build on its established approach by undertaking a Strategic Needs Assessment to inform the 2026/27 workplan and ensure priorities remain aligned to population need, current pathways, available data and stakeholder perspectives.

The priorities for SIBDN in 2025/26 were:

Priority Action	Progress
Consider the recommendations included in the Infected Blood Inquiry (IBI) report and peer review reports and develop a plan for action/ monitoring where appropriate.	The Network continued to consider the recommendations arising from the publication of the IBI and Peer Review reports in 2024. To support this work, the Network established a Short Life Working Group to review the recommendations and identify priorities for implementation. The outputs from this group will inform the Strategic Needs Assessment planned for 2026/27.
Advise on developing and delivering a service for patients in Scotland eligible for etranacogene dezaparvovec.	Gene Therapy was approved by SMC in August 2024. This therapy can now be delivered in Scotland and is funded through the risk share scheme. The Network continues to provide advice as required to support the planning and delivery of etranacogene dezaparvovec in Scotland.
Undertake a “What Matters to Me” engagement exercise and incorporate priorities into the workplan.	Questionnaires and posters were circulated to teams across Scotland to distribute to patients and carers. The collation period was extended for a further 12 months to encourage additional responses. Feedback was reviewed at the Steering Group meeting on 25 March 2026 and will be included within the Strategic Needs Assessment planned for 2026/27.
Development of transition guidance.	Transition guidance endorsed at meeting on 29 October 2025 and is progressing through the NSD guidance approval process. The guidance will be launched in 2026/27.

Out of the 16 BAU objectives outlined in the 2025/26 workplan, 15 were successfully completed. The review of SIBDN guidance documents was paused to consider their ongoing requirement. This work will be progressed through the Strategic Needs Assessment planned for 2026/27. In the interim, the documents have been removed from the website pending evaluation of their continued need.

The Network continued to make use of technology and remote communications to progress work this year. This has continued to be effective, saving time on travel and promoting economic and climate-friendly practices.

Highlights

Annual Conference

The SIBDN education event took place at Westport Building, Edinburgh on 21 November 2025. 41 delegates attended the event and 15 (36%) provided feedback.

The objective of this event was to support the continuing education of staff looking after patients with bleeding disorders. 100% of people who completed the evaluation strongly agreed or agreed that the event had met this objective.

Additionally, all the presentations scored highly for content and delivery. Topics covered during the event included:

- Gene therapy in Scotland
- Managing bleeding disorders and menstruation
- Patient perspective: life with carrier status and diagnosis
- New drug update – Altuvoct – a clinical perspective
- New drug update – Altuvoct – a laboratory perspective

The graph below shows the extent to which attendees felt the learning from the event would change their practice.

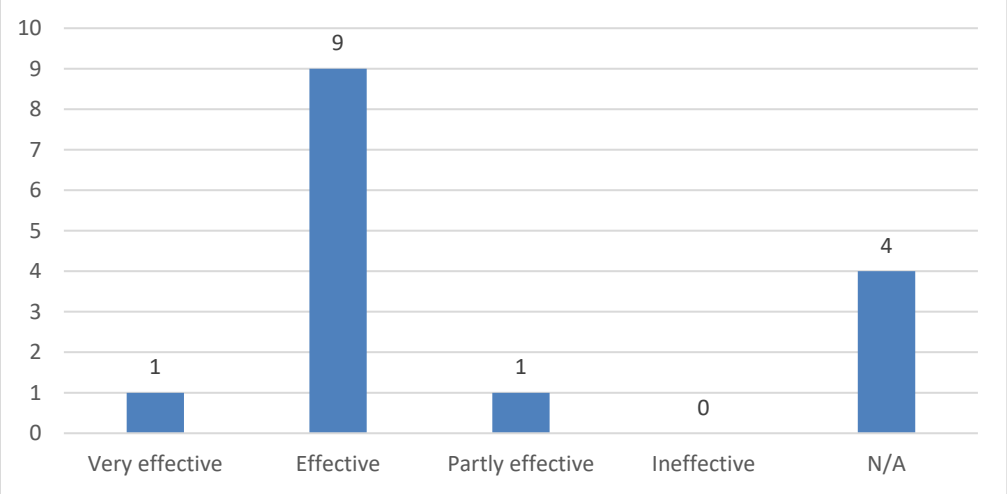

Figure 1: Feedback regarding effectiveness of event in changing practice

Comments on how their practice would change included:

- I will look at recordings/pro formats for girls attending haemostasis clinic
- Involvement in gene therapy MDM.
- The day helped me justify the investigations and extra support needed for girls with heavy menstruation.

15 respondents would recommend this event to their colleagues. 75% reported that the learning from this session would contribute to their CPD requirement for revalidation. The event provided 180 hours of CPD to healthcare professionals.

Members Annual Meeting - In summary

- Overall feedback indicated that the programme was very well received by attendees.
- Key themes included the positive impact of presentations on future practice, improved knowledge of menstrual bleeding disorders, and the need for further education around women with bleeding disorders. Ultimately supporting better patient experience and outcomes.
- The majority of delegates highlighted the value of this year's event noting especially the networking opportunities the event provided.

Development of guidance on transition from paediatric to adult services

The Network developed guidance on transition from paediatric to adult services for young people with bleeding disorders. This guidance aims to support healthcare professionals in NHS Scotland to deliver a consistent approach. The guidance was endorsed by the Steering Group in October 2025.

Links with Haemophilia Scotland

The Network has well-established links with Haemophilia Scotland, which provides tailored support, information and advocacy for people with bleeding disorders and their families. SIBDN and Haemophilia Scotland will continue to work in partnership to support patients through engagement activities, education, and the development of resources.

What Matters to Me

A "What Matters to Me" engagement exercise was extended during 2025/26 to identify what matters to people with bleeding disorders. Responses were received from 64 patients. Due to the age of some patients within the haematology service, some questionnaires were completed by patients and others by their parents or carers on behalf of the patient. It is therefore acknowledged that some responses may reflect parental or carer perspectives rather than the views of the child themselves. Common themes emerged from responses and are summarised below. These will be incorporated into the Strategic Needs Assessment planned by the Network during 2026/27.

What aspects of your care are you pleased with?

Staff support

- Friendly, caring & professional teams
- Approachable & knowledgeable
- Nurses highlighted for support, empathy & reassurance
- Good to have psychology support
- Strong MDT links within departments
- Improved pharmacy systems
- Long-standing trust in care team

Communication

- Easy access to advice via phone
- Prompt response from staff
- Clear explanations of results & next steps
- Patients feel listened to and taken seriously

Treatment

- Ability to be seen urgently if required
- Consultants clearly explain treatment plans
- Regular monitoring
- Patients feel safe, involved & well informed

What do you think could be done better?

Staff

- Would be good to see the same clinician each time
- Sometimes clinical reviews feel random

Treatment

- Improved medication delivery options
- More delivery days
- Improved communication between delivery staff and patients

Communication

- Better communication between departments
- Improved communication between annual reviews
- Clearer instructions about conditions and care pathways

Appointment/ waiting times

- Better waiting area facilities
- Long waits in clinic
- Delays between seeing different staff on clinic days
- Appointment times difficult for working parents/ carers
- More flexible appointments
- Text reminders of appointments

Out of Hours

- Improving OOH service responsiveness
- A&E staff need clearer guidance on haemophilia
- Access to haemophilia specialists during OOH

Specialist Services

- Direct contact with haematology instead of going via GP
- Access to specialist doctors and nurses
- Better pathways for gynaecology & women with bleeding disorders
- Specialist dental care for haemophilia patients

Suggestions to improve services in local area:

Access to local & convenient care

- Clinics closer to home/ more satellite clinics
- Group appointments together to limit amount of time in hospital and away from work/ school

Emergency & Out of Hours Experience

- Better haemophilia training for emergency & transport staff
- Easier access to out of hours care
- Easier parking during emergencies and out of hours attendance
- Return to using wards during OOH instead of having to go through A&E

Communication & contact with care team

- More structured communication with families, e.g, diagnosis and treatment
- Keep clinic appointments running on time to avoid disruption to work and school schedule

Awareness, understanding & education

- Better understanding of bleeding disorders in healthcare services (A&E, GP practices, maternity services).
- More community awareness to reduce the need for patients to explain their condition.
- More knowledge and support for women who are haemophilia carriers.

Psychosocial & peer support

- Annual psychologist appointment or, at minimum, annual mental health screening.
- More structured opportunities for parents to meet one another.
- Support during transitions (children to adults).

Care pathways, MDT & specialist access

- Improved gynaecology care pathways; gynae involvement in MDT; more patient involvement in planning.
- Access to physiotherapist as part of MDT.
- Direct access to haemophilia-experienced physiotherapist without referral.
- Need another doctor or specialist nurse to provide full-time service.
- Smooth child-to-adult transition with linked services (e.g., psychology).

Patient numbers

Haemophilia Centre	Haemophilia A	Haemophilia B	Other
NHS GGC (Adult)	84	18	14
NHS GGC (Children)	32	<5	TBC
NHS Grampian	25	6	<5
NHS Highland	10	<5	<5
NHS Lothian	61	8	10
NHS Tayside	23	6	<5

Figure 2: Approximate number of severe patients by Haemophilia Centre

Looking forward – 2026/27

The Network will undertake a comprehensive Strategic Needs Assessment to inform its workplan over the next 3 to 5 years. This will enable the Network to agree clear, evidence-based, and measurable outcomes. As part of this process, we will assess the needs of the patient population to guide and strengthen future patient engagement activity.

The Network will continue to support the Nurse, Data Manager, Physiotherapist, and Psychologist sub-group, facilitating regular meetings that provide opportunities for peer support, shared learning, and professional collaboration.

The transition guidance developed during 2025/26 will be published on the SIBDN Network website and disseminated to all relevant teams. Audit of this guidance will be incorporated into future workplans to support continuous improvement and assurance.

Education will remain a core focus for the Network, delivered primarily through the Annual Education Event, ensuring ongoing professional development and the sharing of best practice.

Finance

The Network is funded through Public Services Delivery Scotland and operated within its approved budget during 2025/26.