Scottish Inherited Bleeding Disorders Network (SIBDN)

Annual Report
2023/24

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Introduction

The National Managed Clinical Network for Inherited Bleeding Disorders or Scottish Inherited Bleeding Disorders Network (SIBDN) 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.[1]

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.

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[1] Service agreements are in place with NHS Greater Glasgow and NHS Lothian (on behalf of all East Coast Haemophilia Centres). Both health boards manage funds to buy and distribute blood clotting factors and other bleeding disorders drugs. The list of funded products is determined by NHS National Services Scotland (NSS) National Procurement contracts.

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

Current position

Following on from the strategy day held and lead clinician recruitment in March 2023, there has been a lot of work to regenerate the network during this year. Steering group meetings are back up and running and the subgroups have also been rejuvenated. Coming into the year there were significant concerns about the financial sustainability of the psychology service that has now been resolved. It was expected that the Infected Blood Inquiry would report this year but it has been delayed and we now know that it will report on 20th May 2024.

The network achieved 13/13 (100%) of its business as usual objectives and 7/8 (88%) service delivery objectives. Work on the patient pathway is still ongoing and will carry forward to 2024/25.

Highlights

Service Mapping

To build on the information collected at the strategy event in March 2023 and to re-establish relationships, discussions were held with the teams in centres across Scotland. Information was collected around activities at the various centres, some key elements are summarised below.

Centre	Haemophilia A	Haemophilia B	Other
NHS GGC (Adult)	58	12	9
NHS GGC (Children)	37	<5	0
NHS Grampian	25	5	<5
NHS Highland	9	<5	<5
NHS Lothian	50	10	5
NHS Tayside	22	<5	0
Total	**201**	**33**	**18**

Figure 1: Approximate number of severe patients by centre and condition at time of visit

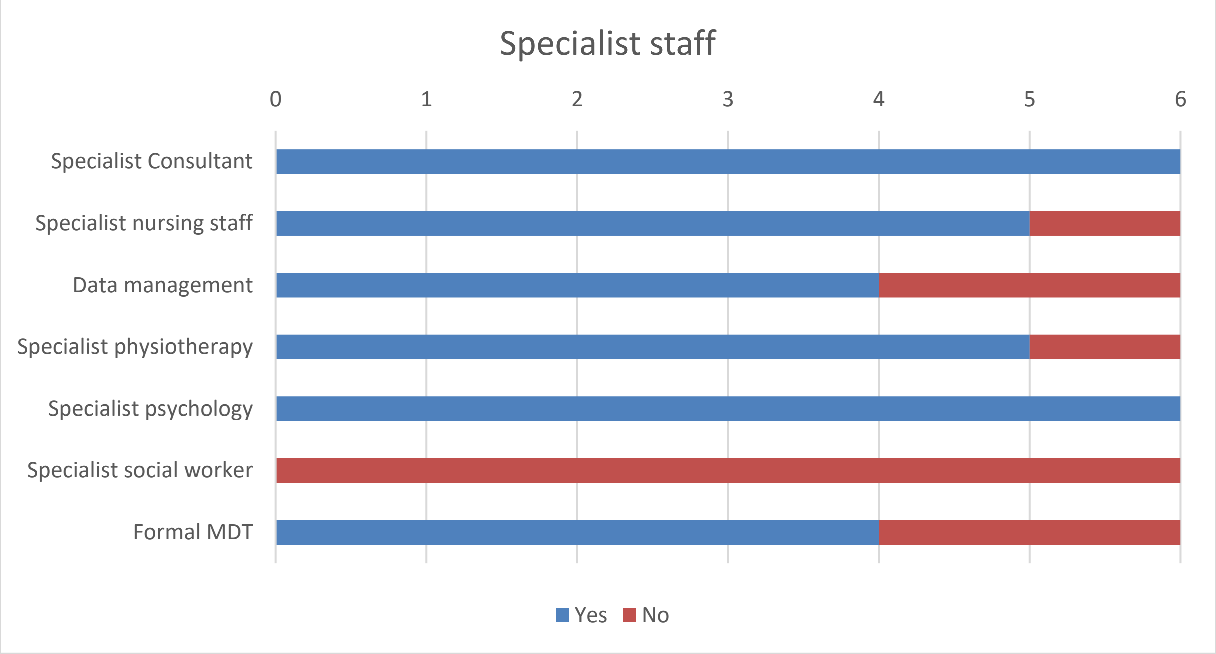


Figure 2: Number of services with specialist staff by discipline. Only notes availability of specialist staff, does not indicate capacity

In addition the discussions covered planned service developments and gaps which identified some key areas for the network to consider, including:

- Transition
- Psychology service
- Education, particularly for nursing staff
- Engaging with emergency departments and SAS

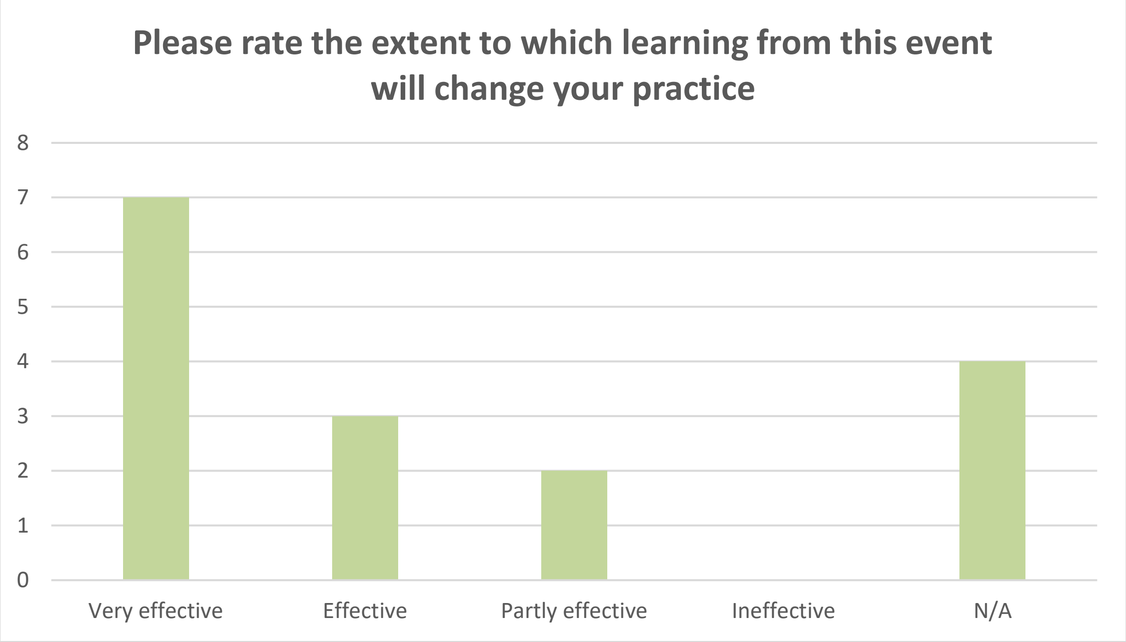
These topics are picked up in the annual or strategic workplan. Contact details have been collated for all centres to facilitate further engagement.

Education event

The SIBDN education event took place as a hybrid event on COSLA on 3rd November 2023. There were 36 people attending.

100% of people who completed the evaluation strongly agreed or agreed that the event had met its objective. Additionally, all the presentations scored highly for content and delivery.

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



In particular people highlighted the need to access physiotherapy for this patient group, a major topic from the day, and attendees intended to take this forward locally using some evidence and innovative approaches discussed.

Stakeholder Survey

A stakeholder survey was shared in March 2024 to gather feedback from people who currently work within, are involved in, or are impacted by the network. There were 6 responses and a lot of positive feedback was received and highlights the value added by the network:

- 83% responses ‘strongly agreed’ or ‘agreed’ that the network makes a positive difference to patients.
- 67% responses ‘strongly agreed’ or ‘agreed’ that the network makes a positive difference to staff.
- 83% responses ‘strongly agreed’ or ‘agreed’ that the network provided a structure to make service improvements in haemophilia or IBD care.
- 67% responses ‘strongly agreed’ or ‘agreed’ that the networks service development activity adds value to haemophilia or IBD care.
- 100% of applicable responses ‘strongly agreed’ or ‘agreed’ that the networks education offering adds value to haemophilia or IBD care.
- 67% responses ‘strongly agreed’ or ‘agreed’ that the networks audit and continuous quality improvement activity adds value to haemophilia or IBD care.

The survey was also an opportunity for stakeholders to share feedback on network strengths, network challenges, areas for improvement and the priorities for the next few years. The responses are summarised below:

Strengths	**Improvements**
• Patient representation • Education • Fostering a common approach • Willingness by stakeholders to contribute and the expert knowledge contained within Steering Group	• Improved audit and data processing • By having new faces and getting everyone involved • Perhaps even more education workshops or events throughout the year to help increase knowledge or gather ideas.
Priorities	**Challenges**
• Requesting revisiting of the funding model for clinical services • Increasing access to clinical trials and physiotherapy • educational days ,helping with funding of certain posts -physio making a business case • Collecting relevant data to compare • New treatment options; improvement in physiotherapy access, maintaining face to face contact with patients. • Ensure annual education days are maintained. Improvements to areas such as education and communication implemented. Information on new medicines and pathways clearly made for network to communicate.	• The current funding model - there is no guarantee that health boards will provide the necessary funding for clinical services • Staffing in areas to allow people to attend • Cost of making improvement and getting agreement from Health Boards. • Continued funding within is a concern

The network will consider the responses to the survey and identify any action required.

Looking forward – 2024/25

Priorities will include:

- Consider recommendations included in the Infected Blood Inquiry report and develop a plan for action/ monitoring where appropriate
- Advise on developing and delivering a service for patients in Scotland eligible for etranacogene dezaparvovec to inform planning if it is approved by SMC
- Undertake an engagement exercise to identify what matters to people with haemophilia and incorporate priorities into the SIBDN workplan
- Deliver commitments outlined in the education strategy
- Work with the psychology service to identify opportunities to ensure equity of access
- Scope transition between paediatric and adult services to identify areas for improvement
- Contribute subject matter expertise to support the procurement process for haemophilia products

Finance

The network spent £2,083 on the costs of the strategic planning event which fell at the end of March 2023 and the education event in November 2023.

Risks and issues

There is a risk that the recommendations from the Infected Blood Inquiry report create challenges for the network.

There is a risk that the network is unable to make full use of data due to the gaps in data management resource in the services.

There is a risk that appropriate staff are not released for SIBDN education events due to staffing issues.