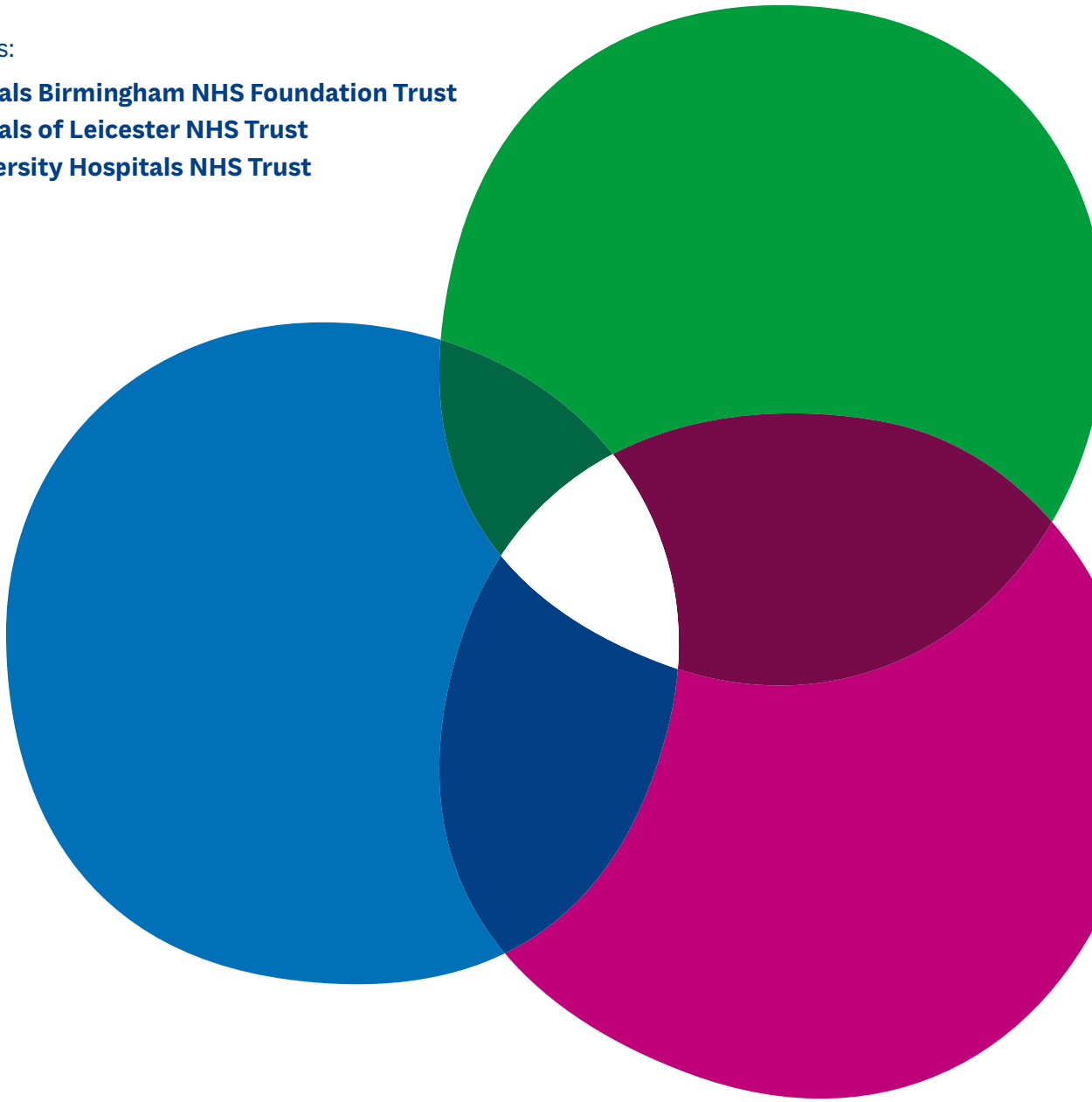
Bridging the Gap:

A Midlands-wide NHS service evaluation exploring treatment information needs in inherited bleeding disorders

Participating Trusts:

University Hospitals Birmingham NHS Foundation Trust
University Hospitals of Leicester NHS Trust
Nottingham University Hospitals NHS Trust

May 2026



Bridging the Gap

Supported by:

Roche CHUGAI Takeda

Acknowledgements

Steering Group

The Bridging the Gap initiative was guided by a multidisciplinary Steering Group comprising clinicians, allied health professionals and data specialists from the three participating haemophilia comprehensive care centres, together with two local patient representatives.

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Leicester:

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Project management and coordination was undertaken by **Laurence Woollard, MSc**, Director of On The Pulse Consultancy, with research support from **Dr Richard Gorman**, Assistant Professor in Ethics and Social Science at Brighton and Sussex Medical School. Both contributors bring lived experience of severe haemophilia, which informed the design and delivery of this work.

Graphic design throughout the project was undertaken by **Marc Avery Studio**.

Project governance and communication

University Hospitals Birmingham NHS Foundation Trust (UHB) served as the host organisation for this service evaluation, providing governance oversight, financial administration and communications support.

The Steering Group would like to acknowledge the contributions of colleagues across UHB and participating Trusts who supported different aspects of this evaluation.

UHB:

- **Ciara Brown** – Senior Management Accountant, R&D
- **Camillia Edmead** – Secretary to Haemophilia Consultants
- **Ben Harpwood** – Information Governance Manager
- **Nicky Kay** – Financial Management Assistant
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University Hospitals of Leicester NHS Trust:

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Nottingham University Hospitals NHS Trust:

- **Tom Harrison** – Digital and Design Communications Lead

Sponsor declaration

Roche Products Ltd. and **Chugai Pharma UK Ltd.** have provided financial support for the Pan-Midlands Service Evaluation Initiative and have had no involvement in the project.

Takeda UK Limited has provided financial support for the Pan-Midlands Service Evaluation Initiative and has had no involvement in the project.

Report information

Version: 1.1

Date: May 2026

Recommended citation: Woollard L, Gorman R, Lowe G, Millen E, Salta S, on behalf of the Bridging the Gap Steering Group. *Bridging the Gap: A Midlands-wide NHS service evaluation exploring treatment information needs in inherited bleeding disorders.* Birmingham: University Hospitals Birmingham NHS Foundation Trust; 2026.

Contents

Foreword

Across the Midlands, specialist multidisciplinary teams (MDTs) work closely with people living with inherited bleeding disorders (IBDs) and their families to provide lifelong care and support. Advances in treatment over recent decades, alongside changing models of care, have transformed outcomes for many individuals, enabling more effective bleed prevention, greater independence and improved quality of life. As the treatment landscape continues to evolve, the way information is communicated and understood becomes ever more vital.

Within our haemophilia comprehensive care centres (CCCs), supporting shared decision making (SDM) is a key responsibility and an essential part of high-quality care. This involves ensuring that patients and carers feel informed, supported and able to participate confidently in decisions about treatment, in ways that reflect their individual needs and circumstances – whether for themselves, a child or someone they care for.

The region we serve is home to a diverse and vibrant population, reflected in the wide range of people and communities who attend our clinics every week. This makes it especially relevant that the information we provide about treatment options is accessible, meaningful and responsive to the experiences and priorities of those we care for.

For this reason, we felt it was important to come together across the **Birmingham**, **Leicester** and **Nottingham** centres to undertake a coordinated regional service evaluation — what we believe to be the first of its kind for IBDs in the Midlands and possibly more widely within the UK. This collaboration, known as **Bridging the Gap**, set out to capture the perspectives of service users to better understand their perceptions, sources and expectations of treatment information.

Through the survey undertaken as part of this work, we heard that while many people feel confident engaging with their clinical team, there is more we can do to support individuals in critically appraising their treatment options. Given the strong preference for receiving information through our CCCs, this also highlights the responsibility on us as MDTs to ensure that information is communicated in a balanced, evidence-informed way, enabling people to participate effectively in SDM.

The recommendations outlined in this report coalesce around a number of interconnected themes, centred on building capacity within both MDTs and the people they support, developing more structured approaches to the decision-making process, together with improving the accessibility and inclusivity of treatment information across the care pathway.

They are intended both to support reflection within our own approaches to how treatment information is delivered and to offer the wider

> “There is more we can do to support individuals in critically appraising their treatment options.

network of stakeholders — including colleagues from different centres and Trusts, patient organisations, representative bodies and others involved in bleeding disorders care — insights that may help inform future practice.

We are grateful to all those who took the time to share their experiences as part of this evaluation. Fundamentally, this work is about embedding equity in how people are supported to engage in discussions about their treatment, ensuring that everyone — regardless of their background or circumstances — has the opportunity to understand the options available to them and participate meaningfully in decision-making. In doing so, we hope to take practical steps towards reducing — and ultimately bridging — the gap between access to information and its effective use in supporting treatment choices.

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About Bridging the Gap

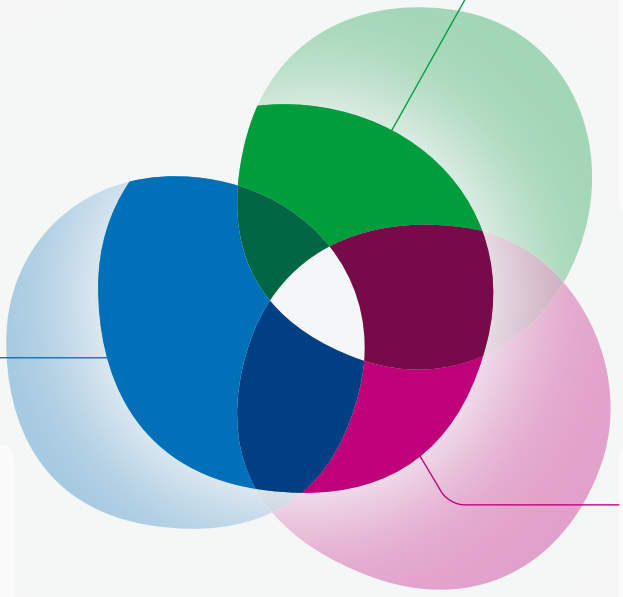
Bridging the Gap is the name given to this Midlands-wide NHS service evaluation, undertaken in partnership between the haemophilia comprehensive care centres (CCCs) in Birmingham, Leicester and Nottingham.

The initiative explored how adults living with inherited bleeding disorders (IBDs), along with parents and carers supporting children or adults unable to complete the survey independently, make decisions about treatment, the types of information they use and what support may help them engage more confidently in these discussions.

The visual identity developed for the project was inspired by the geography and heritage of the Midlands. Each element reflects the distinct locality of the three CCCs, while collectively symbolising the connection and collaboration that underpin this work (**Figure 1**).

By establishing a shared identity, Bridging the Gap sought to foster a sense of collective ownership among service users and multidisciplinary teams across the region, while reinforcing a place-based commitment to strengthening care for the IBD community.

Figure 1. **Bridging the Gap project logo.**



Nottingham
Forest Green

Reflecting the woodland and heathland landscapes of Nottinghamshire, most famously Sherwood Forest – associated with the legend of Robin Hood for more than 600 years.

Birmingham
Royal Blue

Inspired by Birmingham's association with royal blue, long reflected in the colours worn by Birmingham City Football Club since 1875.

Leicester
Regal Purple

Referencing Leicester's royal heritage, highlighted by the discovery of King Richard III's remains beneath a city centre car park in 2012.

Abbreviations and Terminology

Abbreviations

AI	Artificial Intelligence
BDUC	Bleeding Disorder of Unknown Cause
CCC	Comprehensive Care Centre
CPD	Continuing Professional Development
EHL	Extended Half-Life
HCP	Healthcare Professional
HLQ	Health Literacy Questionnaire
IBD	Inherited Bleeding Disorder
MDT	Multidisciplinary Team
PAM	Patient Activation Measure
SDM	Shared Decision Making
VWD	von Willebrand Disorder

Language and terminology

Throughout this report, we use a range of terms such as ‘people living with’, ‘individuals’, ‘patients’, ‘service users’ and, where relevant, ‘carers’. These are used intentionally and interchangeably to reflect different contexts within the healthcare system. The same applies to the terms ‘disorder’ and ‘condition’, which are both used in relation to recognised inherited bleeding disorder names as well as within the broader narrative.

We recognise that language can influence perceptions of a condition, how care is delivered and how people experience themselves and others; we have sought to use terminology that is respectful, person-centred and stigma-free, while acknowledging that no single term will reflect all preferences.

Terms shown in bold from Section 2 onwards are defined in the Key Terms section (pages 34–35).

SECTION 1

Executive Summary

1.1 Why was this evaluation undertaken

The treatment landscape for people living with inherited bleeding disorders (IBDs) has evolved significantly, with a growing range of therapies offering more personalised options for care. While not all individuals will experience equivalent progress, the emergence of new and novel therapeutic approaches – either in clinical development or approved for routine use – may mean that decisions about treatment involve greater complexity and consideration for some than in the past.

Shared decision making (SDM) is now central to IBD care, supported by access to clear, relevant and balanced information. However, effective participation in SDM depends not only on the availability of information but also on individuals' ability to understand, interpret and apply it in practice.

Within the Midlands – a region characterised by diverse populations and persistent health inequalities – there is a need to better understand how treatment information is accessed, experienced and used by people living with IBDs.

This service evaluation was undertaken through a multi-centre survey to explore treatment information needs and health literacy gaps across the Birmingham, Leicester and Nottingham haemophilia comprehensive care centres (CCCs), with a view to informing more tailored, accessible and effective approaches to information provision that enhance SDM.

1.2 Who responded

A total of 244 responses were received from individuals who consented to participate (from 264 responses overall), with 207 included in the final analysis. The majority were completed by adults living with an IBD (85%), with the remainder submitted by carers of children and young people aged under 16 or adults unable to complete the survey independently.

Respondents reflected a broad range of IBDs, with haemophilia A and B together accounting for 46% of the sample and von Willebrand disorder 33%, with the remainder comprising inherited platelet disorders and other rare factor deficiencies. A greater proportion identified as having mild severity (42%), with over half reporting on-demand treatment (56%). Participants were represented across all age groups, although most were adults aged 25–64 (59%). The sample was broadly evenly distributed by gender and predominantly White British (83%).

1.3 Key findings

The evaluation identified several key themes in how people living with IBDs access, understand and use treatment information:

- **High perceived capability but difficulty evaluating options**

  Most respondents reported confidence in understanding information and engaging with their clinical team (84%) but around one-third were uncertain or disagreed about their ability to weigh up treatment options (31%), with over a quarter reporting similar difficulty in explaining treatment options to others (27%).

- **Variation in decision-making roles beyond capability alone**

  While 71% described themselves as active participants in managing their care, around 30% reported more passive roles, indicating the importance of interpersonal communication and the quality of interactions with the clinical team alongside individual determinants.

- **Multidisciplinary team (MDT)-led communication remains dominant**

  Verbal explanation during clinic visits was strongly preferred (88%), with the MDT identified as the primary source of information by 73% of respondents and limited engagement with alternative sources, including social media (7%), patient organisations (6%) and peers (6%).

- **Strong demand for information on treatment developments**

  Two-thirds of respondents (67%) wanted to learn more about new and emerging treatments, alongside notable interest in side effects and safety (45%) and how different treatment options work (43%); these preferences were observed across all levels of self-reported involvement in decision-making.

- **Barriers are not widely recognised but affect a meaningful minority**

  Although most respondents did not report difficulty sourcing or accessing information, nearly a quarter (23%) reported or were uncertain about challenges, with barriers extending beyond specialist services into wider care pathways, including emergency care. Respondents also highlighted a need for more personalised information (30%) and simpler language (27%), with over half favouring receiving information at the earliest opportunity (51%) and during consultations (53%).

> While most people feel able to engage with their clinical team, a significant proportion remain uncertain when evaluating and explaining treatment options.

1.4 Recommendations at a glance

Optimise how clinical teams communicate and frame treatment information

Support MDT members through continuing professional development and reflective practice to enhance communication skills, including awareness of biases and power imbalances within SDM.

Support people to critically evaluate treatment options

Develop more structured, competency-based approaches to identify gaps in individuals' knowledge and comprehension, enabling tailored support and improving their ability to critically appraise choices.

Embed practical tools within routine care

Support SDM readiness and follow-up by integrating user-friendly, patient-centred tools, with protected time within consultations to facilitate their effective use.

Improve visibility and use of existing information resources

Better signpost and adapt established informational materials across the three CCCs, ensuring relevance to different conditions and real-world use.

Provide timely, accessible information on treatment developments

Deliver plain-language updates on new therapies – both within and across CCCs – that reflect variation in information needs between patient groups and modes of delivery.

Strengthen engagement with underrepresented communities

Further investigate barriers and facilitators to accessing and using treatment information within SDM among ethno-culturally diverse service users, to inform more inclusive and responsive approaches to care.

SECTION 2

Background

2.1 Evolving treatment landscape in inherited bleeding disorders

Inherited bleeding disorders (IBDs) are a group of rare conditions that affect how well the blood clots and are typically present throughout life. They are caused by a missing or reduced level of a clotting factor or by changes in how clotting proteins or platelets function. **Haemophilia A (factor (F)VIII deficiency)**, **haemophilia B (FIX deficiency)** and **von Willebrand disorder (VWD)** together account for the majority of cases. Other IBDs include **rarer coagulation factor deficiencies** and **inherited platelet disorders**.

Some individuals present with a clinically significant bleeding tendency but do not receive a diagnosis following standard investigations, often described as **bleeding disorders of unknown cause (BDUC)**. These cases were outside the scope of this evaluation, which focused on confirmed IBD diagnoses.

The severity and impact of IBDs can vary widely but many people experience symptoms such as prolonged bleeding, easy bruising or bleeding into joints and muscles. For this reason, ongoing access to effective treatment and specialist care is essential.

Over the past two decades, the treatment landscape for IBDs has evolved considerably.[1,2] Historically, treatment was centred on replacement of missing clotting factors, delivered either **on demand** (i.e. when a bleed occurs) or preventatively through regular **prophylaxis**. More recently, a broader range of options has emerged, including extended half-life (EHL) factor products, subcutaneous non-factor therapies that mimic the function of missing clotting factors, biologics designed to rebalance coagulation and gene therapies.

Clinical development continues to expand this landscape, with studies increasingly including a wider range of conditions and more diverse patient groups.[3] As a result, treatment is no longer "one size fits all" but is increasingly tailored to individual needs and preferences.

2.2 Importance of treatment information and shared decision making

As IBDs require lifelong management and bleeding can have serious consequences, people living with these conditions must be supported to make ongoing decisions about their care.

Shared decision making (SDM) has become a defining approach to care in IBDs.[4] It reflects a shift away from paternalistic models towards more collaborative relationships between individuals and healthcare professionals (HCPs), aligning with principles of person-centred care, patient autonomy and evidence-based practice.

This shift is also shaped by the legacy in which IBD care is situated. The **contaminated blood scandal** has had a profound and lasting impact on trust in HCPs and the NHS more widely,[5,6] reinforcing the importance of transparency, informed choice and meaningful involvement in decisions about treatment.

Access to clear, relevant and balanced treatment information is a key enabler of SDM. Individuals need to be able to understand available options, weigh potential benefits and risks and consider what matters most to them in the context of their daily lives.[7]

However, participation in SDM depends not only on access to information but also on an individual's ability to use it. This includes two closely related but distinct concepts: **health literacy** and **patient activation**.

Health literacy – the ability to access, understand and apply health information – is largely skills-based, whereas patient activation reflects the willingness and capability to take action. Individuals with higher levels of activation are more likely to seek out information and play an active role in decisions about their care.[8] In contrast, lower health literacy can act as a barrier to understanding information and is associated with more passive participation, including a tendency to defer decisions to HCPs.[9]

Taken together, these factors shape how individuals source, interpret and act on treatment information and the extent to which they are willing and able to deliberate their options with their healthcare team.

> Access to clear, relevant and balanced treatment information is a key enabler of shared decision making.

2.3 Regional context – Midlands haemophilia comprehensive care centres

Haemophilia **comprehensive care centres (CCCs)** provide specialist services for people living with IBDs, bringing together expertise across haematology, nursing, physiotherapy, psychology and other allied health professions to support diagnosis, treatment and long-term management. **Multidisciplinary teams (MDTs)** also address the wider physical, psychological and social aspects of living with an IBD, including patient education, reflecting a holistic model of care.[10]

This **service evaluation** focuses on three CCCs in Birmingham, Leicester and Nottingham. The Birmingham centre provides adult services, while Leicester and Nottingham deliver care across both adult and paediatric cohorts. Together, these centres serve large and varied populations across urban and rural areas, collectively supporting over 3,000 individuals living with IBDs with differing diagnoses, levels of severity and comorbidities.

The Midlands is one of the most ethnically and culturally varied regions in England, with several areas representing highly heterogeneous communities outside of London. This diversity is reflected in a wide range of languages, cultural norms and health beliefs, which can influence how individuals understand health information, interact with services and make decisions about their care. Evidence from across the region highlights persistent health inequalities, including differences in health outcomes, service access and communication.[11]

Within this context, there is a need to better understand how treatment information is experienced and used by people living with IBDs, with a view to strengthening approaches to information provision that enhance SDM across CCCs.

2.4 Aims and objectives

The aim of this service evaluation was to explore treatment information needs and health literacy gaps among people living with IBDs across the Midlands. Specifically, the evaluation sought to:

- Understand how confident people living with IBDs feel in discussing treatment options and making informed decisions.
- Explore preferences for treatment-related information, including format, content and source.
- Identify reasons why some information sources may not be accessed or perceived as helpful.
- Generate insights to inform the development of more tailored and accessible information approaches across CCCs.

SECTION 3

Methodology

3.1 Evaluation development

Bridging the Gap was developed as a collaborative, multi-centre initiative involving haemophilia CCCs in Birmingham, Leicester and Nottingham. It was designed and conducted as a service evaluation to generate insights at a regional level, reflecting the shared priorities of participating sites.

Development was guided by a multidisciplinary Steering Group comprising clinical, data and operational staff from each CCC alongside two local patient representatives with lived experience of IBDs.

Illustrative map showing the location of participating haemophilia comprehensive care centres within the Midlands region of England.

This group provided oversight throughout the design process, ensuring the evaluation was grounded in both clinical practice and service user insight.

The evaluation was coordinated by a patient advocacy professional and a social scientist, both living with IBDs, supporting an approach that integrated clinical, academic and experiential perspectives.

Survey content and supporting materials were developed iteratively, with input from Steering Group members and user testing to ensure clarity, inclusivity and relevance for a diverse population.

The evaluation was registered in line with local clinical audit and governance requirements at each participating Trust.

3.2 Eligibility criteria

The survey was open to individuals receiving care for an IBD at one of the participating CCCs in Birmingham, Leicester or Nottingham.

Eligible participants included the following:

- Adults (aged 16 years and over) living with an IBD, including haemophilia A or B, VWD, inherited platelet disorders and rare clotting factor deficiencies.
- Parents or carers of children and young people under 16 years of age with an IBD.
- Carers of adults with an IBD who were unable to complete the survey independently.

Participants were asked to complete the survey either for themselves or on behalf of the person they care for. Individuals not meeting these criteria were excluded from the evaluation through initial screening questions within the survey, including those without a confirmed IBD diagnosis (e.g. BDUC).

3.3 Survey design (21-item questionnaire)

The evaluation was conducted using a 21-item, anonymised survey developed for use across the three participating CCCs. The survey was designed to capture self-reported quantitative responses and qualitative perspectives on how treatment information is understood, accessed and used.

The questionnaire comprised a combination of multiple choice, Likert scale and free-text questions, organised across five sections: (1) respondent characteristics; (2) understanding and use of treatment information; (3) involvement in treatment decisions; (4) preferences for treatment information; and (5) perceived barriers and gaps.

Selected items were informed by established conceptual frameworks. Question 10 was adapted from the **Health Literacy Questionnaire (HLQ)**,[12] a validated instrument comprising multiple domains of health literacy and was used to capture aspects of how respondents access, understand and apply treatment information. Question 12 was informed by the **Patient Activation Measure (PAM)**,[13] using an adapted, non-proprietary format to reflect different levels of engagement and perceived role in treatment decision-making.

All questions were optional, with the exception of initial screening items used to confirm eligibility. The survey was designed to be completed in approximately 10 minutes and was available in both digital and paper-based formats, with translation and alternative formats available on request. Participants were provided with a detailed information page outlining the purpose of the evaluation and how their data would be used and protected. They were required to provide informed consent before completing the survey. Responses were submitted anonymously and thus did not affect their regular care.

3.4 Data collection period and distribution

Data collection took place over a 10-week period from December 2025 to February 2026.

The digital survey was hosted on Google Forms and made available alongside paper copies across the three participating CCCs. Paper-based responses were digitised and incorporated into the online records to enable a single, consolidated dataset for analysis. Each completed paper survey was assigned a unique identifier to support tracking and data management.

Distribution was primarily facilitated through real-time clinical interactions, with people living with IBDs and carers invited to participate during in-person and virtual appointments. NHS-branded posters and leaflets were used to promote the survey and were designed to meet accessibility standards, helping to establish trust in the evaluation. These included the survey URL and QR code to enable access. No incentives were offered to participants, as the evaluation was embedded within routine care and participation was voluntary.

In addition, at one CCC (Leicester), eligible individuals were contacted directly via an internal message system, facilitated by the centre's Data Manager and Improvement Programme Manager within the Trust, enabling distribution beyond in-clinic attendance.

To support delivery, site visits were conducted by the Project Manager in January 2026 to interact with local teams, clarify processes and address any queries. A small voucher-based reward scheme was also established to encourage staff engagement in raising awareness of the survey.

Distribution was limited to participating CCCs to ensure responses were obtained from individuals receiving care within the defined service setting, supporting the integrity and relevance of the dataset. No identifiable data were collected.

3.5 Data analysis approach

Descriptive statistics were used to examine quantitative responses across survey items.[14] This included reporting frequencies and proportions for different response options as well as summarising Likert scale ratings.

Initial analysis was undertaken independently by two members of the evaluation team. Findings were then compared and discussed to identify patterns and areas of convergence across related items. These patterns were used to inform the development of key themes that structure the presentation of results.

Photo: Site visit to the Leicester Haemophilia CCC, 13th January 2026.

Left to right: Dr Sandhya Munireddy (Consultant Haematologist), Sarah O'Connell (Haemophilia Lead Nurse), Laurence Woollard (Project Consultant), Pedro Goncalves (Data Manager), Dr Muhammad Anas Memon (Clinical Fellow), MaryJoy Agustin (Specialist Nurse).

Responses that did not meet eligibility criteria were reviewed and categorised to document reasons for exclusion, including incomplete consent, failure to satisfy inclusion requirements (i.e. not being a person living with an IBD or a carer or not receiving care at one of the participating CCCs) or absence of a confirmed IBD. Of note was that a number of paper-based responses were submitted without all consent fields ticked, reinforcing the importance of clear and robust consent processes in future survey delivery.

Qualitative data arising from free-text options were reviewed to identify any additional insights. An inductive approach was taken, with observations drawn directly from the data rather than being defined in advance.[15] Given the small number of free-text responses, these were used to provide illustrative context rather than formal thematic development.

Quantitative and qualitative findings were considered together to provide a more complete understanding of how treatment information is experienced by survey participants, bringing together both observed patterns and underlying insights.

The draft analysis was shared with the Steering Group to support interpretation and ensure alignment with clinical and service user perspectives.

3.6 Limitations

This service evaluation has several limitations which have been carefully considered in interpreting the findings and remain relevant to how they are understood.

The data are based on self-reported responses and are subject to both participation and response bias. Individuals who chose to take part may differ systematically from those who did not and responses may be influenced by differences in how survey questions are understood or a tendency to provide socially desirable answers.[16] Although participants were assured of anonymity, the relational nature of IBD care may have influenced how comfortable some individuals felt expressing critical views. Some survey items were informed by validated instruments such as

the HLQ[12]; however, responses still reflect individuals' perceptions of their ability to understand and use treatment information rather than objective measures of capability or behaviour.[17] Similarly, severity was recorded based on how the condition had been explained to respondents, which may not fully align with clinical classification or reflect variation in **bleeding phenotype** and treatment requirements.[18,19]

Aside from initial screening questions, all other survey items were optional. Consequently, the number of responses varied across questions and within response categories.

Distribution relied primarily on conversations during routine clinical interactions, with additional direct messaging at one centre. As a result, not all individuals receiving care across the participating CCCs will have had an equal opportunity to take part and the findings may represent the views of those more likely to engage with survey opportunities. The timing of data collection and the absence of a postal option may have further limited reach.

Responses relating to individuals under 16 years of age were provided by parents or carers, meaning the perspectives of children and young people may not be directly captured. All materials were produced in English, which may have limited accessibility for some individuals and the sample was predominantly White British, restricting the generalisability of findings. Moreover, in order to balance the inclusion of personal data with data governance and privacy considerations, socio-economic indicators such as education, employment or income were not collected, which restricts exploration of how these may relate to differences in engagement and involvement in decision-making.

The survey was designed to minimise participant burden and encourage completion by limiting the number of free-text questions.[20] Accordingly, qualitative insights provide contextual depth but should not be interpreted as formal thematic findings. A small number of paper-based responses were excluded due to incomplete consent documentation. Although the evaluation was supported by pharmaceutical sponsors through an unrestricted grant, sponsors were not involved in the design, delivery or analysis of the evaluation; nonetheless, awareness of sponsorship may have influenced perceptions of the activity among some individuals.

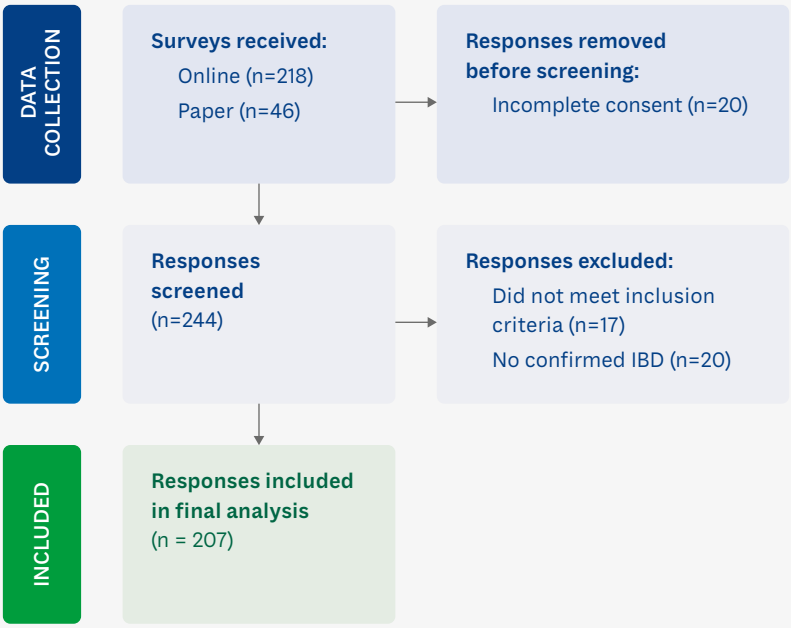
SECTION 4

Respondent Profile

A total of 244 responses were received from individuals who provided consent to participate. Following screening, 207 were included in the final analysis (**Figure 2**).

This section summarises the characteristics of respondents across key demographic and clinical variables.

Figure 2. **Flow of survey responses through screening and inclusion in the final analysis.**

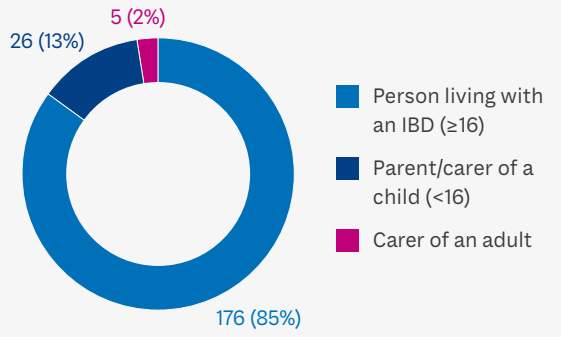


Note: Incomplete consent relates to paper-based responses, as the online survey required all consent fields to be completed before the questionnaire could be accessed. Responses classified as 'no confirmed IBD' include individuals who selected 'Not sure' or provided a response under 'Other' that did not indicate a diagnosed IBD; this group may encompass individuals with a BDUC.

4.1 Respondent type

The majority of responses were completed by individuals living with an IBD (n=176/207; 85%), with a smaller proportion completed by parents or carers on behalf of a child or dependent adult (hereafter referred to collectively as 'carers') (**Figure 3**).

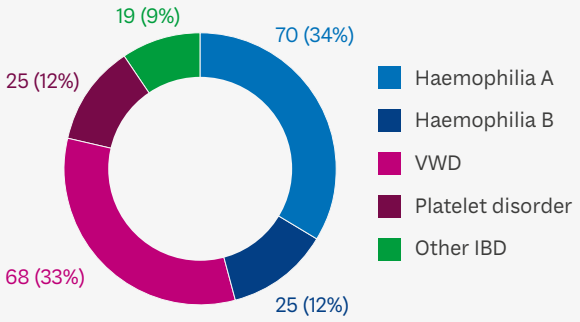
Figure 3. **Distribution of respondents by respondent type (Question 1 (Q1); n=207).**



4.2 Condition

Respondents reported a range of IBDs (**Figure 4**). The distribution broadly reflects known epidemiology, with haemophilia A more commonly represented than haemophilia B.[1,10] VWD and haemophilia A were similarly observed within the sample, despite VWD being recognised as the most prevalent IBD.[21]

Figure 4. **Distribution of respondents by inherited bleeding disorder (Q3; n=207).**

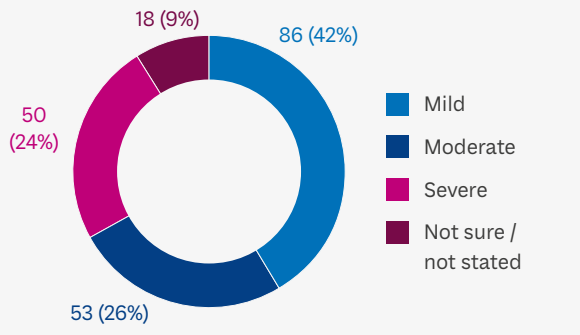


Note: Platelet disorders include Glanzmann's thrombasthenia and Hermansky-Pudlak syndrome. "Other IBD" includes rare factor deficiencies (e.g. FVII, FX, FXI) and combined conditions.

4.3 Severity

Severity was reported based on how respondents' IBD had been explained to them, either for themselves or on behalf of the person they care for (**Figure 5**). As such, it may not fully capture clinical variation in bleeding phenotype or treatment need. A greater proportion identified as having mild severity (n=86/207; 42%), with fewer reporting moderate or severe forms. This is particularly important in interpreting the findings, given potential differences in treatment experience and engagement across severity groups. This distribution may also reflect variation in exposure to condition-specific surveys and similar activities, with people living with milder IBDs traditionally less represented in research, while those with more severe forms may be more frequently studied and encounter research fatigue.[22,23]

Figure 5. **Distribution of respondents by severity (Q4; n=207).**

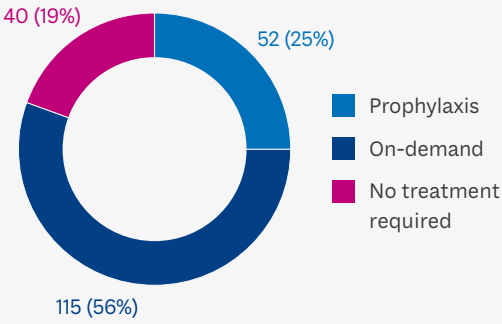


Note: Severity is self-reported based on respondents' understanding of their own condition or that of the person they care for. Percentages do not total 100 due to rounding.

4.4 Treatment approach

Treatment approach was indicated across the sample (**Figure 6**). Over half (n=115/207; 56%) reported being on an on-demand regimen, with a smaller proportion on regular prophylaxis or no current treatment. This aligns with the higher proportion of respondents identifying as having mild severity and may influence how individuals experience and engage with their care, including their level of interaction with healthcare services.

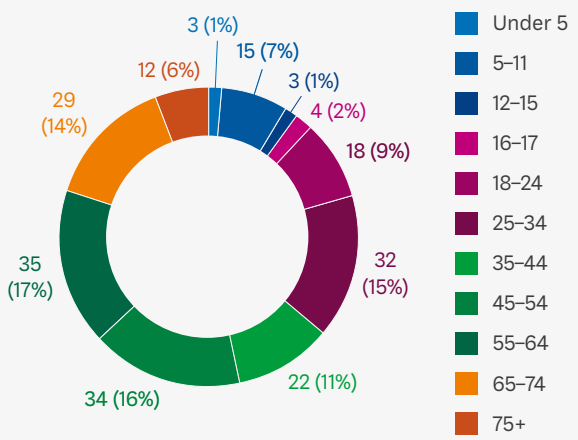
Figure 6. **Distribution of respondents by treatment approach (Q5; n=207).**



4.5 Age group

Respondents were represented across all age groups (**Figure 7**). Participation was concentrated among adults aged 25 to 64, while approximately one fifth of respondents (n=43/207; 20%) were aged under 25. Representation among those aged 12 to 17 was limited, despite this being a period of transition from paediatric to adult services and towards greater autonomy, self-management and involvement in treatment choices, during which access to treatment information becomes increasingly important.[24,25]

Figure 7. **Distribution of respondents by age group (Q6; n=207).**



Note: Percentages do not total 100 due to rounding.

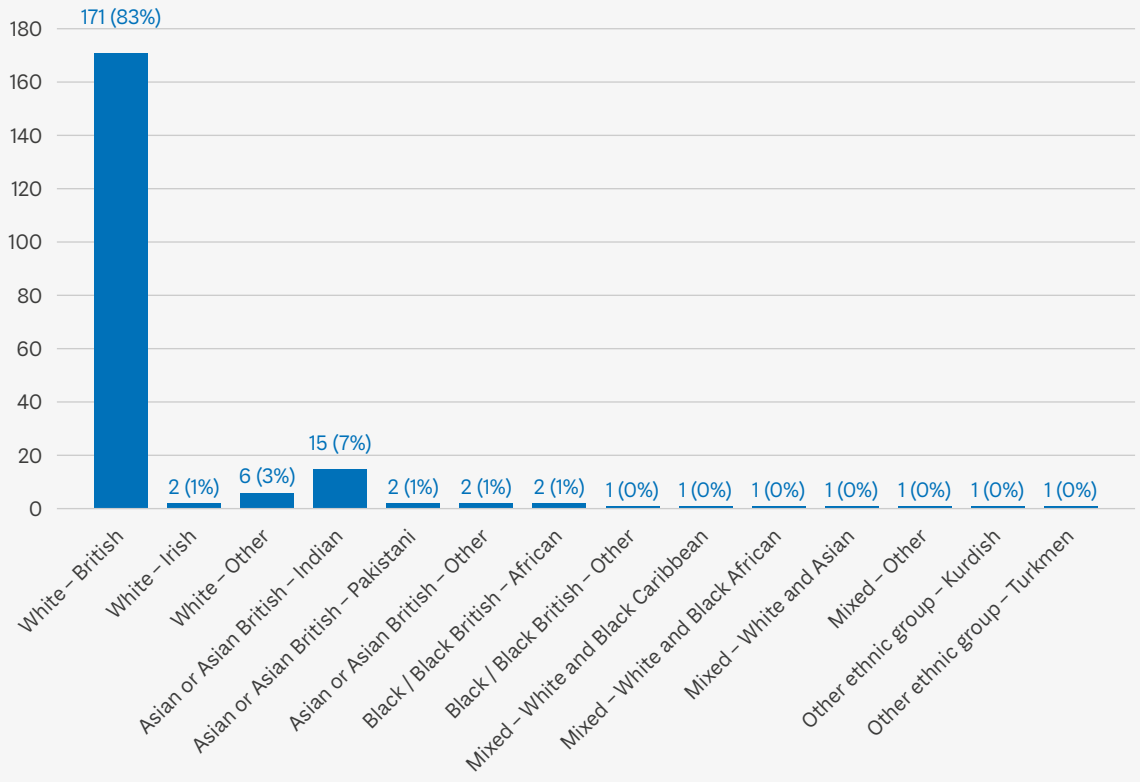
4.6 Gender

Respondents were broadly evenly distributed by gender (female: n=105/203; 52%, male: n=98/203; 48%). Additional response options were included to support inclusive reporting but were not selected. Of those identifying as female, a substantial proportion reported VWD (n=50/105; 48%), consistent with known patterns of diagnosis in which women are more likely to be identified due to specific bleeding challenges, notably those associated with menstruation.[21,25]

4.7 Ethnicity

Respondents were predominantly from a White British background (n=171/207; 83%), with the remaining responses distributed across 11 other ethnic groups (**Figure 8**). While this reflects some diversity within the sample, representation was concentrated within White ethnic groups. However, this corresponds with wider evidence highlighting the underrepresentation of ethnic minority groups in studies of long-term conditions, pointing to broader structural and systemic inequalities in participation, including within UK-based research.[26]

Figure 8. **Distribution of respondents by ethnic group (Q8; n=207), based on the England-specific classification recommended by the Office for National Statistics.**[27]



Note: Percentages do not total 100 due to rounding.

SECTION 5

Findings

This section presents the findings from the survey, drawing on both quantitative and qualitative data to explore how people access, understand and use treatment information. The analysis is structured across four themes: understanding and decision-making roles; sources and delivery of information; barriers; and interest in additional engagement and support.

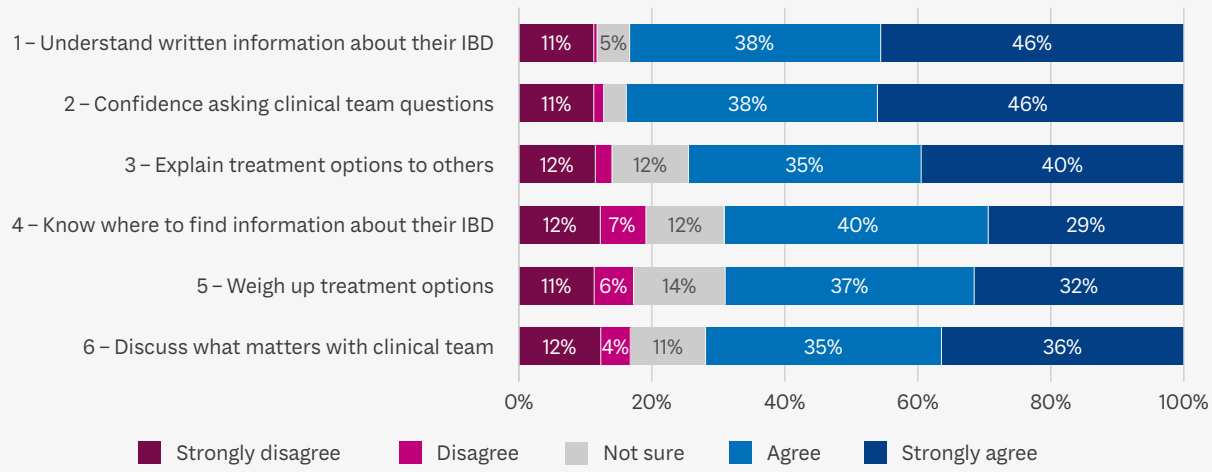
5.1 Understanding treatment information and decision-making roles

5.1.1 High perceived capability with challenges in more complex tasks

Across the survey, most respondents reported a high level of capability in engaging with treatment-related information (**Figure 9**). The majority agreed or strongly agreed that they were able to understand written information about their bleeding disorder (n=170/204; 84%), ask questions of their clinical team (n=171/204; 84%), know where to find relevant information (n=141/204; 69%) and talk about what matters to them (n=146/203; 71%). Considered together, participants appear able to access, comprehend and engage with information about their condition and treatment. At the same time, these findings do not indicate how or why these capabilities have developed or the extent to which they are shaped by individual initiative, experiential learning or the support provided by clinical services.

However, this capability was not consistent across all domains, with lower levels of agreement observed in relation to more complex tasks. Over one-quarter of respondents reported uncertainty or disagreement with their ability to explain treatment options (n=51/200; 27%) and nearly one-third in relation to weighing up different treatment options (n=63/203; 31%). While respondents generally perceive themselves to have advanced foundational skills in understanding and accessing information, capability

Figure 9. **Self-reported capability in engaging with treatment-related information across six statements (Q10; n=200-204 per item), adapted from the HLQ.**[12]



Note: n per item: 1=204; 2=204; 3=200; 4=204; 5=203; 6=203. Percentages are not shown for very small segments.

appears to decline when they are required to apply, evaluate or communicate treatment information.

Further exploration of responses suggests that this variation is not evenly distributed across the sample. Respondents reporting lower confidence in weighing up treatment options were more likely to be receiving on-demand treatment (n=37/63; 59%) or to have no current treatment (n=14/63; 22%), compared with those on prophylaxis (n=12/63; 19%). This cohort was predominantly composed of individuals reporting mild or moderate severity (n=46/63; 73%), with fewer reporting severe (n=9/63; 14%). A comparable trend was exhibited for confidence in explaining treatment options to others.

One possible explanation is differences in opportunities to develop and reinforce knowledge about treatment. Individuals with less intensive treatment exposure may have fewer routine interactions with specialist services or wider patient communities, reducing the likelihood of acquiring and retaining information over time.[28] This is evident in the following participant account from this cohort.

> "As my low platelets are stable I have been kept under the dept [sic] but… I haven't had an appointment in a couple of years."
>
> *(Participant BGT164, female, 55–64, mild platelet disorder, no current treatment)*

5.1.2 Variation in involvement beyond capability

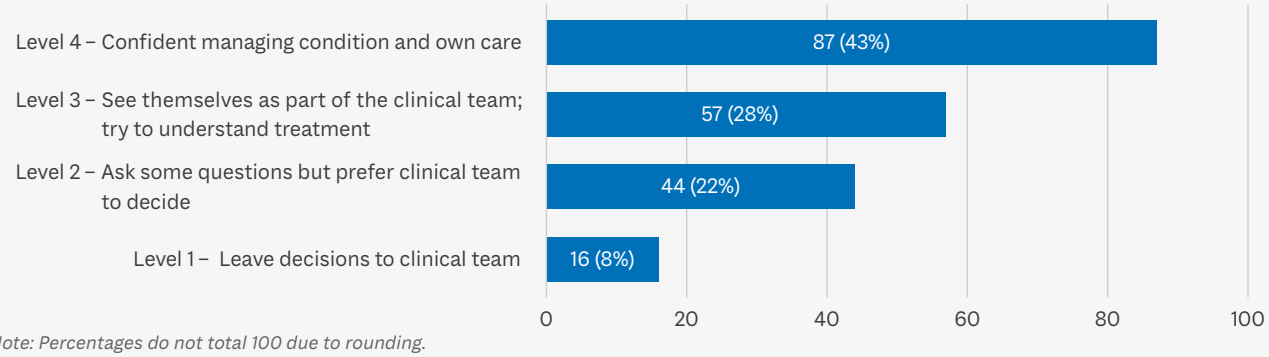
When considered alongside the health literacy ratings, a clear relationship emerges between perceived capability and role in decision-making, as captured by responses to the activation item (**Figure 10**).

Overall, 43% of respondents (n=87/204) reported a more active role in managing their condition, indicating that they feel confident in managing their care and know when to seek support (Level 4). A further 28% (n=57/204) described themselves as part of the clinical team and taking an interest in understanding and managing their treatment (Level 3). In contrast, around 30% suggested more passive roles, either leaving decisions to the clinical team (Level 1; n=16/204; 8%) or only occasionally asking questions while largely deferring decisions (Level 2; n=44/204; 22%).

Among respondents who expressed lower confidence in weighing up treatment options (Section 5.1.1; n=63), a similar underlying pattern is reflected in how they describe their role in decision-making. A greater proportion fell into more passive roles, with 45% (n=28/63) in Levels 1–2 of the activation item, compared with the full sample. Notably, a segment within this group (n=20/63; 32%) still described themselves as being at the highest level (Level 4). This points to a more nuanced relationship, where capability in evaluating treatment options does not always align with how individuals perceive their role in decision-making. In some cases, this may be shaped by relational factors such as rapport and trust with the clinical team, as articulated by one of the participants.

> "Any communication between myself and medics has always been easier with staff, docs [sic] or nurses, when there has been continuity of our relationship and there is knowledge of each other and trust."
>
> *(Participant BGT108, male, 55–64, severe haemophilia A, prophylaxis)*

Figure 10. **Self-reported role in managing and making decisions about care across four levels (Q12; n=204), adapted from the PAM.**[13]



Note: Percentages do not total 100 due to rounding.

This highlights the well-established importance of the therapeutic relationship in IBD care, where effective management is associated with active participation and ongoing interaction with clinical teams.[29] For some individuals, a predominantly passive role may also represent a preference for clinician-led decision-making, rather than disengagement. Yet these relational dynamics may be less developed among those with more limited contact with services, potentially influencing confidence in engaging with treatment decisions.

Taken together, these findings are broadly consistent with existing evidence suggesting that individuals who see themselves as active participants in managing their health are more likely to engage in treatment decisions.[30] They also indicate that this orientation is not shaped by knowledge or technical capability alone. A recent scoping review in haemophilia identified high-quality interactions between HCPs and patients as being paramount in influencing SDM and among the most modifiable factors for improvement, reinforcing the importance of interpersonal communication alongside individual determinants.[31]

A sub-analysis of responses from people living with haemophilia further examines the health literacy and activation items (see **Box 1**).

5.2 Sourcing and receiving treatment information

5.2.1 MDT-led communication remains central to how information is shared and received

Respondents reported clear preferences in how they would like to receive information about treatment options (**Figure 11**). Verbal explanation during a clinic visit was by far the most commonly selected format (n=182/207; 88%). Around half also indicated a preference for printed materials (n=101/207; 49%) and email communication (n=90/207; 43%). Conversely, selection of digital formats was low, including websites or mobile applications (n=30/207; 14%), video (n=20/207; 10%) and infographics (n=20/207; 10%), with less interest in peer-to-peer channels (n=15/207; 7%) and minimal selection of AI tools (n=3/207; 1%).

Box 1. Evaluating treatment options and decision-making roles in haemophilia.

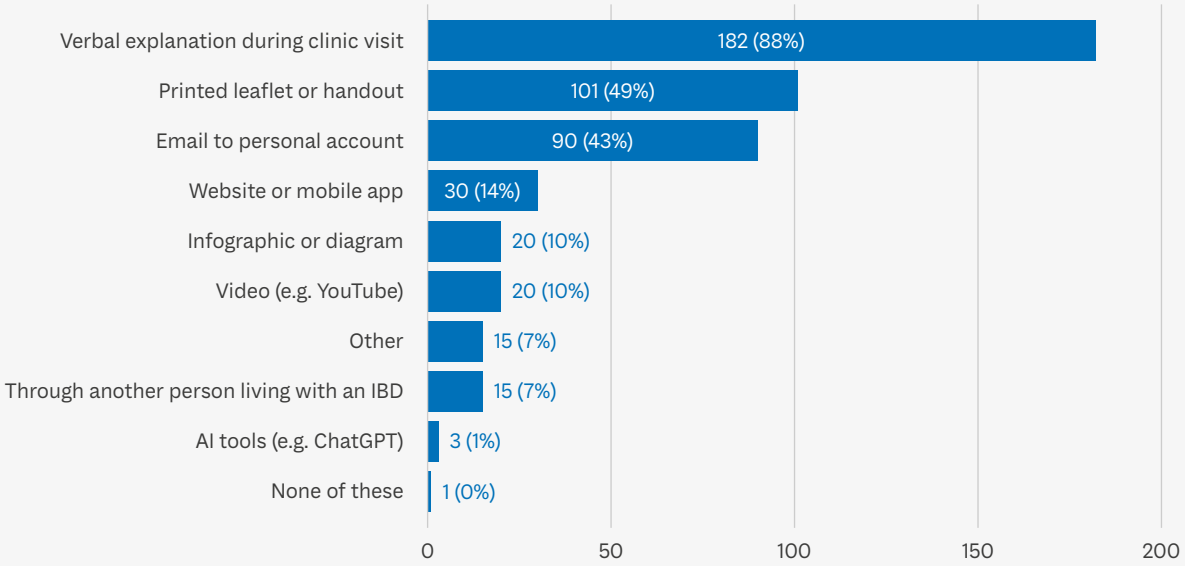
Among people living with haemophilia (n=95/207; 46%), 32% of respondents (n=30/94) reported being uncertain or disagreed that they were able to weigh up different treatment options, as indicated by the health literacy item (Figure 9). Within this group, 63% (n=19/30) identified as having mild or moderate haemophilia.

In relation to involvement in decision-making, based on responses to the activation item (Figure 10), 43% (n=41/95) described themselves as taking ownership and control over their care (Level 4) and 29% (n=28/95) as working in partnership with the clinical team (Level 3), while a quarter (n=24/95; 25%) reported a greater degree of passivity (Levels 1–2). Notably, passive involvement was more frequently reported among those with mild or moderate haemophilia (n=16/24; 67%) and those receiving on-demand or no treatment (n=17/24; 71%), with substantial overlap between these groups.

Collectively, differences in individuals' ability to evaluate treatment options and in how they position themselves in decision-making are evident across this haemophilia cohort, including among those receiving more regular treatment.

Nearly **one in three** people living with haemophilia (32%) reported **uncertainty** in their ability to **weigh up treatment options**

Figure 11. **Preferred formats for receiving information about treatment options (Q14; n=207).**



Note: Respondents could select more than one option.

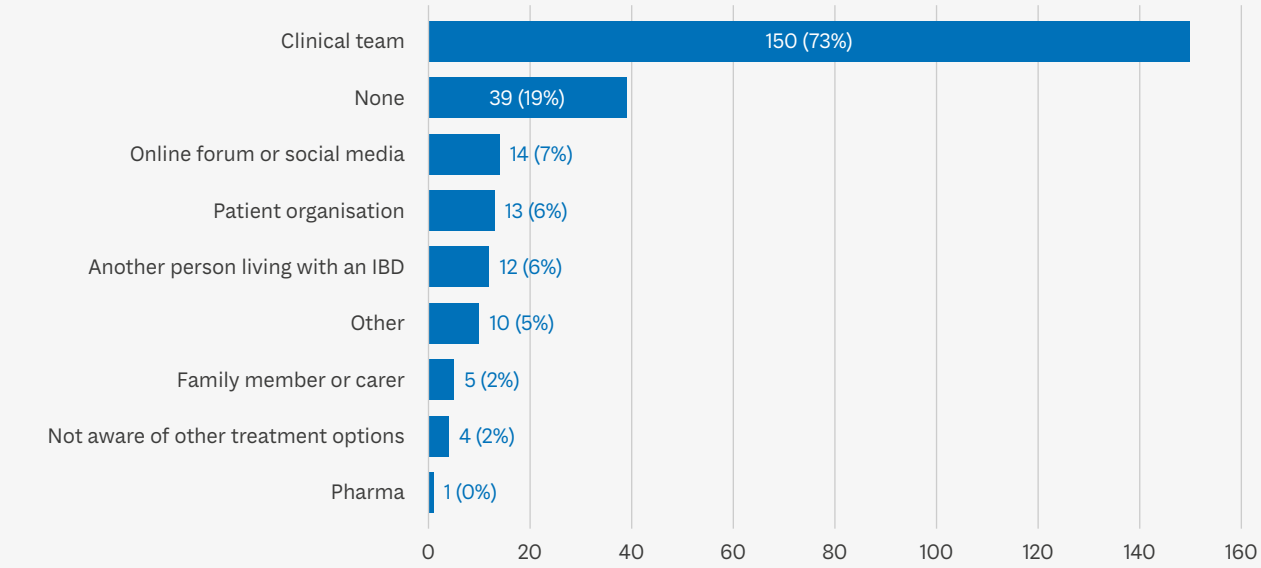
To explore variation across the sample, responses were examined by age group. Among those relating to children and adolescents (0–17; n=25), which were primarily provided by carers, verbal communication was universally preferred (n=25/25; 100%), with digital formats appearing as a secondary addition. Around half selected printed materials (n=12/25; 48%) and email communication (n=12/25; 48%), while smaller proportions selected websites or mobile applications (n=5/25; 20%), video (n=4/25; 16%) or infographics (n=3/25; 12%). This contrasts with wider evidence from UK media use and attitudes research indicating high uptake of video-sharing platforms among younger audiences, such as YouTube, although such use is typically oriented towards entertainment rather than health-related information.[32] It may partly reflect the use of carers as proxies for respondents under 16 and/or a relative lack of age-appropriate, IBD-specific content online.

Among younger adults aged 18–24 (n=18), verbal communication remained highly prevalent (n=16/18; 89%) but a broader mix of formats was observed. This included printed materials (n=13/18; 72%) and email communication (n=9/18; 50%), alongside digital options such as websites or mobile applications (n=4/18; 22%), infographics (n=4/18; 22%) and video (n=3/18; 17%). For those aged 25 and over, verbal communication continued to dominate (~85–95%), although patterns varied by age. For example, respondents who were 25–44 years old were more likely to adopt a multi-format approach, whereas those aged 65 and over showed a stronger concentration around verbal and printed formats, with very limited selection of digital options (<5%).

The strong preference for verbal communication within clinical settings is reflected in reported sources of information about treatment options (**Figure 12**), with the majority of respondents identifying their MDT as the primary source (n=150/205; 73%). This again reaffirms the central role of the therapeutic relationship within IBD care but perhaps also exposes a reliance on clinician-led communication – raising the question of how much information is actually retained in practice, given often-cited estimates that 40-80% of medical information shared in consultations is forgotten immediately.[33] Such observations therefore suggest opportunities to innovate through the development of communication approaches to augment information exchange within the consultation itself.

All other sources were selected by fewer than one in ten respondents, including social media (n=14/205; 7%), patient organisations (POs) (n=13/205; 6%) and peers (n=12/205; 6%). A small proportion of respondents reported receiving treatment information from family or friends (n=5/205; 2%) and almost none from pharmaceutical companies (n=1/205; 0%), with no reported use of AI tools such as ChatGPT. Additionally, nearly a fifth of respondents (n=39/205;

Figure 12. **Sources of information about treatment options (Q15; n=205).**



Note: Respondents could select more than one option. "AI tools (e.g. ChatGPT)" was included but not selected by any respondents.

19%) indicated that none of the listed sources were relevant. This group was predominantly composed of individuals reporting mild or moderate severity and receiving on-demand or no current treatment, aligning with earlier findings relating to more limited treatment exposure (see Section 5.1).

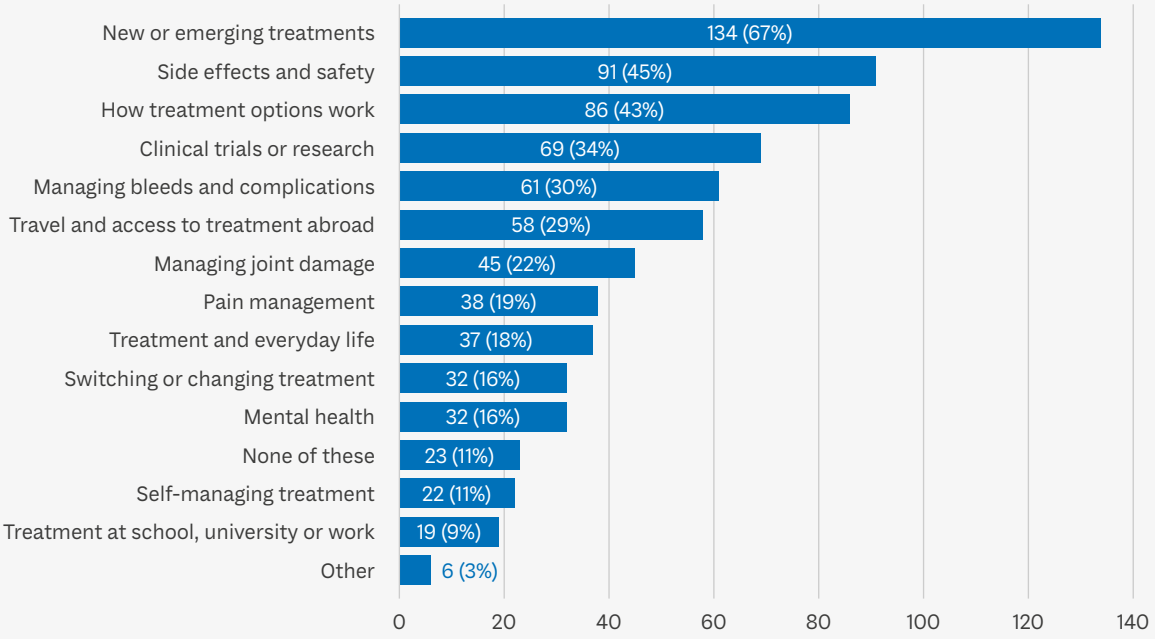
On the whole, within this sample the mode and delivery of treatment information remain strongly mediated through the MDT, with minimal engagement via alternative or supplementary sources. The findings correspond with research in haemophilia populations, where treatment centres are endorsed as the most important and trusted source of information,[34,35] although the extent to which this generalises across other IBDs remains less clear. Moreover, few respondents identified pharmaceutical companies or POs, despite their respective roles in supporting and developing patient-facing materials,[36,37] which may reflect the extent to which such inputs are facilitated via the MDT. Similarly, while artificial intelligence (AI)-enabled tools are emerging as educational resources,[38] their negligible selection suggests they are not yet established as standalone reference points for people living with IBDs, potentially influenced by the rarity and complexity of these conditions, together with wider variation in trust in digital health information.[32,39] However, this may evolve over time, as these technologies become more embedded in how individuals seek and locate specialised health knowledge.[40]

5.2.2 Ongoing information needs highlight gaps in current provision

Respondents identified a distinct set of priorities in relation to the types of information they would like to learn more about (**Figure 13**). The most frequently selected topics were new or emerging treatments (n=134/201; 67%), side effects and safety (n=91/201; 45%) and how different treatment options work (n=86/201; 43%), with clinical trials or research studies also selected by around a third of respondents (n=69/201; 34%). The four topics together highlight a strong demand for information that supports understanding of therapeutic advances and their implications, both in clinical development and in routine care.

Further analysis of the data shows that interest in new treatments was observed across the full range of self-reported roles in decision-making, including among respondents who described more passive involvement in managing their condition (see Section 5.1.2). This suggests that demand for information is not limited to those who are already highly engaged or confident but extends to individuals who may be less active in decision-making. In line with the patient activation framework,[8,30] this speaks to the importance of ensuring that information and support strategies are accessible to individuals across the activation spectrum, rather than disproportionately serving those who are already seeking out treatment updates.

Figure 13. **Topics respondents would like more information about (Q17; n=201).**



Note: Respondents could select more than one option.

Nearly a third of respondents selected managing bleeds and preventing complications as a topic they wished to learn more about (n=61/201; 30%). Interest in this area was expressed across all IBDs, with similar representation among people living with haemophilia A and B combined (n=25/61; 41%) and VWD (n=25/61; 41%). A broad distribution was also seen across condition severity, including mild (n=25/61; 41%), moderate (n=16/61; 26%) and severe (n=15/61; 25%). Within the haemophilia cohort (n=25), responses spanned the life course and were more weighted towards higher severity, among whom 40% (n=10/25) reported prophylaxis use. This implies that the need for information on bleeding and its complications persists, despite expectations of improved haemostatic control and progression towards normalisation associated with newer therapies,[41] although the survey did not account for treatment modality.

Other topics included joint health (n=45/201; 22%) and pain management (n=38/201; 19%), both closely related to bleeding and its complications. There was substantial overlap between respondents selecting both options (n=30), the majority of whom were living with haemophilia A and B (n=18/30; 60%) and – consistent with the pattern observed for managing bleeds – reported moderate or severe presentations (n=16/30; 53%). Within this subgroup, responses were weighted towards mid–late adulthood, with 75% (n=12/16) aged 35–74, suggesting cumulative burden over time. Chronic pain is a complex comorbidity of haemophilia associated with joint arthropathy[42]; both may worsen with age.[43] This represents an ongoing and potentially under-addressed informational need alongside regular bleed prevention. Moreover, given the growing prominence of these issues within the haemophilia literature, this would appear to constitute a knowledge-action gap.

A sub-analysis of responses from people living with VWD further illustrates how these information priorities may vary across patient populations (see **Box 2**).

5.3 Barriers to accessing and using treatment information

5.3.1 Barriers are not widely recognised but affect a meaningful minority

Respondents were asked whether they had ever struggled to find or understand information about treatment options (Q18). While the majority reported no difficulty (n=156/202; 77%), nearly a quarter either reported challenges directly (n=24/202; 12%) or were uncertain (n=22/202; 11%). This suggests that, although overt barriers may not be widely recognised,

Box 2. Information priorities among people living with VWD.

Responses from people living with VWD (n=68) reflect a distinct but related set of information requirements, characterised by a combination of interest in therapeutic innovation and self-management. The majority of respondents identified as female (n=50/68; 74%). This is significant given that, although VWD is inherited equally by men and women, women are disproportionately affected by bleeding due to physiological factors (such as menstruation and childbirth) and may experience barriers to recognition and care, including underappreciation of symptoms and delayed diagnosis.[44,45]

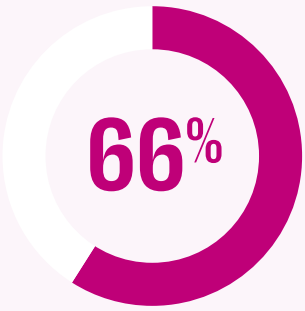
Consistent with the wider sample, preferences for information about new treatments came out on top (n=45/68; 66%), followed by side effects (n=34/68; 50%) and how treatments work (n=30/68; 44%).

The co-selection of topics relating to information about managing bleeds (n=21/68; 31%), joint health (n=13/68; 19%) and pain management (n=9/68; 13%) highlights the interconnected nature of these experiences. However, unlike the haemophilia-weighted observation in the main analysis, where joint and pain-related concerns were more closely associated with moderate or severe condition, responses from people living with VWD were more evenly distributed across severity and treatment groups, suggesting that these topics are not limited to those with more intensive treatment regimens (see Section 5.1).

In addition, around one in five respondents selected travelling and accessing treatment abroad (n=15/68; 22%), likely underscoring the wider impact of VWD on daily life and the additional planning and uncertainty associated with activities that may otherwise be considered straightforward by non-affected peers.[21,44,45] This also presents opportunities for cross-IBD learning: advances in treatment have made travel increasingly achievable in haemophilia,[46] with more established guidance and provision,[10] demonstrating the need for greater parity for those living with VWD.

Two-thirds

of people living with VWD (66%) prioritised **information on new treatments**, alongside ongoing needs related to bleeding and daily life



a meaningful proportion of respondents report or perceive some level of difficulty in accessing or interpreting treatment information.

Examining responses from those who reported difficulty (n=24) indicates that these challenges are not confined to any single subgroup and are observed across both condition types and levels of self-reported severity. In terms of the former, responses were distributed across all IBDs, with a slightly higher representation among people living with VWD (n=9/24; 38%). This may partly reflect the slower pace of therapeutic innovation in VWD relative to other IBDs, principally haemophilia.[2] Although VWD was first described over a century ago,[47] many unmet needs remain in its clinical management, further compounded by the heterogeneity of bleeding symptoms and as discussed previously, the under-recognition of its impact on quality of life.[21,44,45] These factors may, in turn, contribute to gaps in the availability and delivery of information to patients.

> "I haven't had any [treatment information]... ever!"
>
> *Participant BGT034, female, 45-54, VWD, prophylaxis*

When considered alongside earlier findings, it might be expected that respondents with lower capability in understanding and evaluating treatment options

(see Section 5.1.1) and those taking a more passive role in decision-making (see Section 5.1.2) would be more likely to report difficulty in accessing or interpreting treatment information. However, this is not that straightforward. For the 23% of respondents (n=46/202) who reported or were uncertain about difficulty, their responses to the health literacy and activation scales spanned the full range, including those indicating health-promoting behaviours at the highest level. While firm conclusions cannot be drawn, these insights reinforce the importance of avoiding assumptions of homogeneity within demographic or clinical groups in how individuals engage with treatment information, as such assumptions may be counterproductive when designing interventions to support improvements in health.[8]

5.3.2 Barriers extend beyond specialist services into wider care pathways

Qualitative responses further point to information-related challenges beyond haemophilia services, particularly in non-specialist and emergency care settings.

> "Total ignorance by [HCPs] outside the bleeding disorders centre."
>
> *Participant BGT086, female, 55–64, platelet disorder, on-demand*

> "[Accident and Emergency] need to be more aware of the complications of haemophilia and how urgent treatment needs delivering promptly..."
>
> *Participant BGT141, carer of an adult aged 18–24, haemophilia A, prophylaxis*

Recent guidance from the UK Haemophilia Centre Doctors Organisation (UKHCDO) Task Force on Emergency Care[48] recounts suboptimal patient experiences in acute settings and emphasises the importance of readily available treatment information to support rapid assessment and decision-making, recognising that people living with IBDs and carers can contribute meaningfully when appropriately supported and empowered.

Similar issues were noted in relation to coordination of care across services, particularly where procedures are delivered in community settings, such as dental care. Some respondents described the inconvenience of communicating information about their condition and arranging appropriate haemostatic protection, influencing decisions around disclosure.

> "I carry a card for [VWD]... (i)t's tempting not to say anything [to the dentist]... having to travel 20 miles to get the treatment... is quite ridiculous."
>
> *Participant BGT149, female, 55–64, VWD, on-demand*

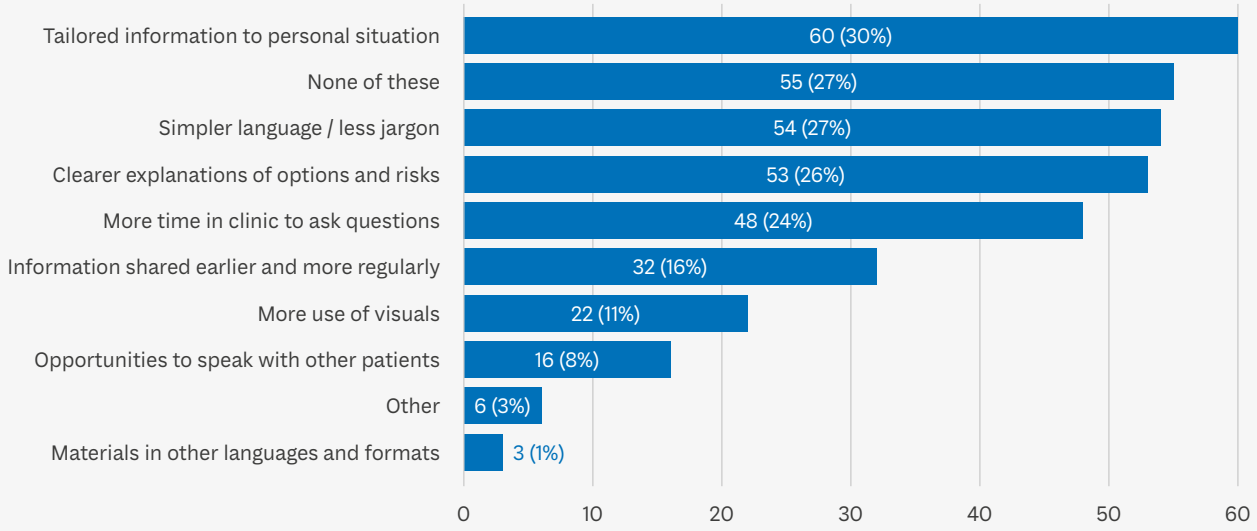
In the UK, people registered with the National Haemophilia Database – the primary registry for IBDs – are issued with a bleeding disorder alert card to be carried at all times to help ensure safe management in non-specialist contexts,[48] although its recognition and use in practice may vary. Alongside this, patient-centred tools have been developed to facilitate access to and sharing of treatment information, including a haemophilia centre-specific mobile app[49] and a rare disorder patient passport.[50] While these approaches show promise, considerations remain around perceived legitimacy and sustained user engagement.

5.3.3 Improvements centre on clarity, personalisation and continuity of information

While challenges in accessing or understanding treatment information were not widely reported (see Section 5.3.1), several areas for improvement in information provision were nonetheless identified (**Figure 14**).

Requests for tailored information (n=60/201; 30%), simpler language (n=54/201; 27%) and clearer explanations (n=53/201; 26%) signal a need for information that is both accessible and responsive to individual circumstances. Nearly a quarter of respondents (n=48/201; 24%) also indicated a desire for more clinic time, suggesting that constraints within consultations may limit opportunities for discussion and clarification. This is particularly relevant in the context of investigational and emerging therapies, where discussions around risks, benefits and uncertainty require time to support informed SDM,[4,51] even as time pressures within clinical settings remain a recognised constraint to its implementation.[31] Evidence also portrays how historical harms, distinctly the contaminated blood scandal, continue to shape risk perception and treatment decision-making within the IBD population.[52]

Figure 14. **Areas identified by respondents to improve the information they receive about current or future treatments (Q19; n=201).**



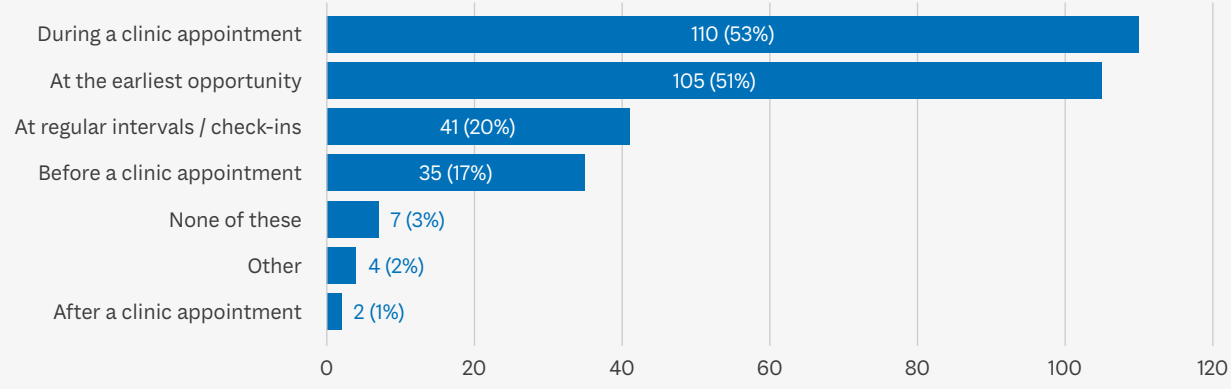
Note: Respondents could select more than one option.

> "Clinicians should be mindful that after infected blood some in my community have a wariness and reticence towards treatment options. This is clearly linked to the trauma of what has happened in the past – yet is given very little regard by clinicians. Again, our holistic care should be considered when receiving treatment… and changes [sic]."
>
> *Participant BGT126, male, 45–54, haemophilia A, prophylaxis*

A smaller proportion of respondents indicated a preference for patient peer support (n=16/201; 8%), aligning with earlier findings on the limited but present role of peer-to-peer channels in how information is received (see Section 5.2.1). This may also reflect variable exposure to – or integration of – peer support within routine care, potentially constraining awareness of its value as a complimentary source of information and support.[53] Similarly, relatively low selection of other languages or formats (n=3/201; 1%) likely reflects the demographic composition of the sample (see Section 4.7) and almost all respondents reporting English as their main language (Q9; n=203/207; 98%).

Interest in receiving information earlier or more regularly (n=32/201; 16%) aligns with preferences for when information is most helpful within the care pathway (**Figure 15**). Over half of respondents

Figure 15. **Preferred timing for receiving information about treatment options (Q16; n=207).**



Note: Respondents could select more than one option.

indicated the earliest opportunity (n=105/207; 51%) and during consultations (n=110/207; 53%), while a fifth favoured ongoing check-ins (n=40/207; 20%). This is complementary, suggesting that improvements in information provision may lie not only in the content itself but also in how and when it is delivered, with a need for greater continuity and reinforcement throughout the patient journey. While this evaluation did not explicitly examine how the characteristics of those providing information influence its reception and use, research does show that individual clinician factors, including experience, attitudes and communication behaviours, can shape the effectiveness of information exchange and contribute to insufficient understanding.[54]

5.4 Additional engagement and support

5.4.1 Interest for some is driven by unmet needs and gaps in care and research

Given the Midlands focus of this evaluation, respondents were asked whether they would be interested in attending a local or regional event to learn more about treatment and available support, with a mixed level of demand observed (**Figure 16**). While 45% of respondents expressed a willingness to attend an event in some format (in-person: n=37/204; 18%; online: n=25/204; 12%; both: n=31/204; 15%), a substantial proportion were either not currently interested (n=80/204; 39%) or unsure (n=31/204; 15%).

Among those for whom attending an event held appeal (n=93/204; 45%), responses were seen across condition types, levels of severity and age groups, with no clear concentration in any single subgroup. This is consistent with earlier findings that information needs are widely distributed and not limited to specific populations (see Section 5.2.2). Further qualitative insight from this cohort highlights a range of underlying motivations, including a desire for greater access to treatment options and opportunities to hear about and participate in research, reflecting a perceived lack of studies and clinical trial opportunities in some conditions, particularly rarer IBDs.[55]

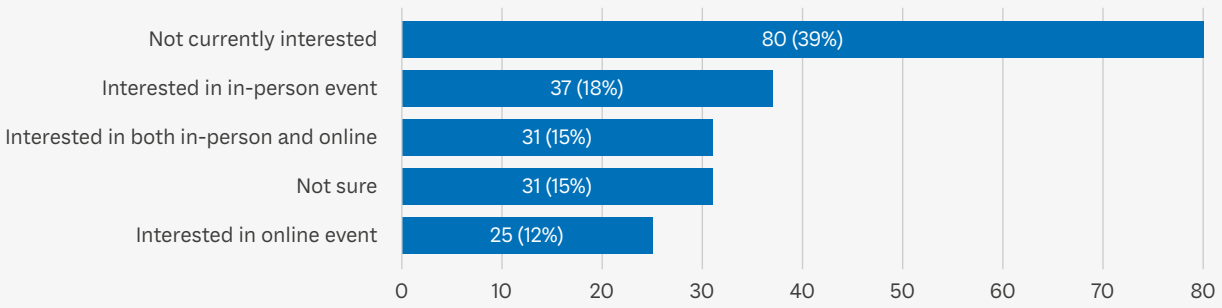
> "For rare bleeding disorders… it would be great to have more active research opportunities to take part in/hear about."
>
> *Participant BGT178, female, 25–34, platelet disorder, on-demand*

Some respondents described the need to actively advocate for appropriate treatment, particularly in less severe populations, alongside concerns about long-term outcomes:

> "I have noticed that because my boys are mild/moderate the treatment options are limited and I have to advocate for them to have the right treatment… I sometimes feel that mild/moderate haemophiliacs are forgotten about…"
>
> *Participant BGT139, carer of a child under 5, haemophilia B, on-demand*

This sense of being overlooked is echoed in the literature, where individuals living with mild or moderate haemophilia may experience clinically meaningful burden but have received comparatively less attention than their severe counterparts in treatment and care pathways.[56,57] As the findings here suggest, this may extend to greater reliance on self-advocacy in navigating care.

Figure 16. **Interest in attending a local or regional information event on treatments and support (Q20; n=204).**



Note: Percentages do not total 100 due to rounding.

5.4.2 For others, existing information and support is considered sufficient

Qualitative responses from the over half of respondents (n=111/204; 54%) who were unsure or not interested in attending an event suggest that, in many cases, existing information and support are already meeting expectations – reducing the perceived value of additional engagement opportunities.

This is evident in respondents' descriptions of positive communication with their clinical team.

> "Discussions about 'gene therapy' and moving to 'subcultaneous injections' [sic] were easy, straightforward and incredibly informative and positive... The [MDT] have always been fantastic with their... reassuring support."
>
> *Participant BGT117, male, 65–74, haemophilia B, prophylaxis*

> "My team has always been very helpful in answering questions about my treatment... I am very happy... and have no issues."
>
> *Participant BGT187, female, 25–34, haemophilia B, on-demand*

Others indicated that they had consistently received appropriate information when required.

> "The hospital I visit have always been very good at explaining what treatment I needed..."
>
> *Participant BGT084, female, 75+, VWD, on-demand*

> "I've always found my treatment information top notch."
>
> *Participant BGT202, male, 45–54, haemophilia A, on-demand*

This cohort similarly spans a broad range of clinical and demographic characteristics, suggesting that lower interest in additional engagement via an event is not confined to a particular condition or subgroup. Responses to the activation item (see Section 5.1.2) give weight to this interpretation, with the full range of involvement levels represented, including a clear majority (n=79/111; 71%) who describe themselves towards the higher end of the scale (i.e. taking an active role in managing their IBD). Ultimately, the limited interest expressed here does not necessarily signal disengagement but may instead speak to the strength of the patient–MDT relationships that underpin SDM, as depicted in this sample.

SECTION 6

Discussion

This service evaluation, conducted as part of the Bridging the Gap initiative, set out to explore treatment information needs and health literacy gaps among people living with IBDs across three haemophilia CCCs in the Midlands – Birmingham, Leicester and Nottingham – to inform approaches to information provision that enhance SDM. The survey findings present a unique regional picture of current access to treatment information, how it is appraised and preferences for how it is received, shaped by both self-reported capability and the relational dynamics in which care is delivered. Respondents (n=207) were predominantly adults reporting mild or moderate conditions, with many treated on-demand or receiving no current therapy. As a result, their interactions with the CCCs may be more intermittent than those with more intensive treatment regimens, although perspectives across the IBD and severity spectrums are captured. Within this broader context, there is a high level of perceived capability in engaging with treatment information but greater difficulty in evaluating treatment options and a more nuanced picture of how people position themselves in decision-making. This occurs within an information-seeking environment that remains strongly clinically mediated.

Analysis of responses reveals a more complex interplay between information literacy skills, extent of involvement in SDM and the sources through which people learn about treatment options than might be anticipated. While most respondents agreed or strongly agreed with statements reflecting their capacity to engage with treatment-related aspects of their care, including understanding written text and asking questions of their clinical team, this does not extend to explaining or weighing up treatment options, with around one-quarter and one-third respectively reporting uncertainty or disagreement. At the same time, a clear majority describe themselves as taking an active role in managing their condition and feeling responsible for decisions about their care, suggesting that their perceived ability and motivation to participate in SDM is not solely contingent on technical understanding. This tension sits alongside a significant reliance on clinical teams as the primary gatekeepers of treatment information, whether by design or default, with 88% of respondents preferring verbal explanations in clinic and 73% identifying their MDT as their principal point of reference for information on newer or less familiar therapies.

These observations raise important considerations for how treatment information is delivered and comprehended in practice. While MDT-led communication remains both highly trusted and widely relied upon, it may also contribute to a model of information exchange that is episodic, subject to framing effects (e.g. how risks, benefits or uncertainty are presented)[52] and difficult for people living with IBDs to retain. Against this backdrop, the ability to ask questions and engage in dialogue does not necessarily equate to confidence in interpreting or applying treatment information independently. Rather, it portrays a process in which understanding is often constructed within the consultation itself, influenced by the way information is shared, contextualised and reinforced by the MDT. This places significant individual and collective responsibility on clinical teams as both conduits of information and key determinants of how that information is internalised and acted upon over time – recognising that treatment decisions are not made in isolation and may be susceptible to inherent power differentials within patient-clinician interactions.[31] Possibly compounding the issue is a discordance between clinicians' perceptions of patient understanding and patients' actual comprehension, with implications for health outcomes.[58] There is thus a need for HCPs to be mindful of these power imbalances and the high esteem in which they may be held by people living with IBDs, while also reflecting on and, where appropriate, challenging their own assumptions about patients' health literacies.

Taken together, these factors help explain why, on the one hand, most respondents describe themselves as playing an active part in treatment management,

> Understanding of treatment options is often constructed within the consultation itself, influenced by the way information is shared, contextualised and reinforced by the multidisciplinary team.

a pattern observed across the full sample and within condition-specific subgroups. On the other hand, they continue to depend on clinician-led input to make sense of treatment options. This apparent contradiction aligns with what has been described as an 'activated patient paradox', whereby individuals are encouraged to participate in SDM, yet do so within systems that continue to centre clinical expertise and are strongly influenced by underlying expectations and norms.[59] Alternatively, it could also be viewed as a strength of established care models in which people living with IBDs in the Midlands are participating on equal ground with HCPs, reinforcing a sense of trust and collaboration that has been deeply undermined in the past.[5,6]

Building on this, fewer than one in ten respondents identified POs, peers or digital platforms as relevant sources of treatment information, with negligible use reported for pharmaceutical companies and emerging technologies such as AI. Clearly, such a trend is indicative of treatment knowledge being largely disseminated through the MDT. This is not to suggest, however, that SDM support tools, including **decision aids**, are not being utilised during clinical encounters, as recommended within broader approaches to information provision.[7] For example, decision aids have been shown to increase activation levels and support more informed, values-congruent choices.[30,60] Rather, it may reflect how patient-facing materials are developed and delivered in practice, with POs and pharmaceutical companies contributing to their development within a regulated, non-promotional framework, ultimately leading to these resources being channelled via clinical teams.[36,37] As a result, they may be less visible to people living with IBDs as distinct or independent outputs.

Nearly all respondents (n=201/207) identified areas where they would like to learn more, with greatest demand for knowledge about new and emerging treatments (67%), followed by side effects and safety profile, how different treatments work and participation in clinical trials or research studies. Notably, interest in new treatments was observed across the full range of self-reported roles in decision-making, including among those describing more passive involvement. Therefore, these priorities converge around therapeutic innovation and its implications, while simultaneously underscoring the need for information and support strategies that are accessible across the activation spectrum.[8,30] This is further reflected in requests for tailored information, simpler language and clearer explanations, signalling a desire for information that is both user-friendly and responsive to individual circumstances. Moreover, in the VWD sub-analysis (n=68), priorities spanned both therapeutic innovation and self-management, with nearly a third identifying managing bleeds as a topic of interest, alongside wider matters such as the ability to travel. The majority of the VWD cohort identified as female, who experience a disproportionate impact of bleeding due to physiological factors, illustrating the effect of symptoms on daily functioning and areas that have historically received less attention compared with haemophilia.[44,45] Collectively, this suggests that current approaches to information provision may not fully align with the breadth and diversity of patient needs, pointing to a potential knowledge–action gap.

Finally, the limited ethnic diversity within the sample warrants mention. While some variation was observed, respondents were predominantly from a White British background, echoing longstanding underrepresentation in research involving people living with long-term conditions.[26] This is particularly pertinent in the Midlands context, where enduring discrepancies in the inclusion of ethnic minority and underserved groups in health and social care research have been documented, driven by a combination of structural, sociocultural and practical barriers to participation.[11] These challenges have implications not only for the generalisability of the evaluation findings but also for how effectively services and interventions, including the provision of treatment information, are designed in a way that accounts for diverse cultural groups. Strengthening engagement with underrepresented communities will therefore be critical to ensuring that future work in this area does not inadvertently reinforce existing inequalities.

SECTION 7

Recommendations

Overall, this service evaluation highlights the need to strengthen how treatment information is delivered and applied in practice across the three haemophilia CCCs in the Midlands. While current models of care are characterised by meaningful therapeutic relationships and a high level of trust, including reliance on the MDT as the primary source of information about treatment options, they also reveal important opportunities to better support individuals in engaging with new and emerging therapies. This involves weighing treatment trade-offs based on individual preferences and applying knowledge to manage their condition and participate effectively in SDM.

The following recommendations draw on the findings presented in Section 5 and are intended to enable more consistent, accessible and responsive approaches to treatment information across the region. For clarity with regards to terminology, reference to people living with IBDs includes, where appropriate, carers and family members involved in supporting the care and decision-making of children under 16 years of age and adults who are unable to do so independently.

1 Recognise and optimise the role of clinical teams as mediators of treatment information

Many interactions around treatment information are episodic and centred on the consultation itself, underscoring the importance of how information is communicated, framed and reinforced, particularly when introducing new or less familiar therapies. Members of the MDT should be supported through existing continuing professional development (CPD) and reflective practices to consider how treatment options are presented and interpreted. This may enhance the implementation of SDM and contribute to higher-quality patient–clinician interactions. There may also be scope to align with existing competency frameworks and key skills training within IBD care – including those developed for specialist nurses, where communication and patient support are recognised as core domains of clinical practice[61] – while remaining sensitive to implicit biases and power imbalances inherent in healthcare relationships.

2 Empower people living with IBDs to critically evaluate treatment options, not just be presented with them

While many respondents reported confidence in engaging with their clinical team, this did not always extend to explaining treatment options or weighing up different approaches when making decisions. Empowering people living with IBDs to interpret, compare and apply treatment information may help address this disconnect, particularly for those with milder conditions or less frequent contact with CCCs. This includes supporting individuals to make sense of trade-offs, articulate their understanding and feel better equipped to determine what is right for them or the person they care for. Practically, this may involve developing a more structured, competency-based approach to identifying gaps in individuals' knowledge and comprehension, enabling clinical teams to tailor support accordingly, as has been demonstrated in other long-term conditions.[9] This may help improve individuals' ability to evaluate treatment options and facilitate more personalised approaches to care, building on the strong relational foundations reported within the evaluation.

3 Embed practical tools to support preparation, discussion and follow-up within routine care

Given the MDT's role as principal mediators of treatment information, there is scope to consider how people living with IBDs are supported to prepare for, engage in and reflect on these discussions.

Embedding practical tools within routine care that enhance readiness to participate in SDM may help reduce barriers to knowledge acquisition and create a more enabling environment for learning and self-efficacy. This could include simple prompts to facilitate preparation ahead of appointments, approaches to guide discussion during consultations and mechanisms to reinforce key information afterwards. Such approaches have been implemented in other settings and have been shown to be most effective when informed by empirical evidence derived from service users, rather than assumptions held by researchers or clinicians about what is likely to work.[62] Consideration should also be given to how these tools can be integrated into existing clinic workflows, including allocating protected time within consultations to aid their effective use, so that they augment rather than add burden to routine care.

4 Broaden access to and visibility of complementary information provision

There was limited preference for sources of treatment information beyond the clinical team, with most respondents favouring verbal explanations in clinic and printed materials and relatively low engagement with digital platforms, POs or other external formats. This suggests that existing information provision may not be sufficiently visible or accessible. Attention should therefore be paid to how established resources and SDM tools – including those developed at an international level for application across different healthcare settings[4,31] – can be more effectively signposted and adopted by the three CCCs to maximise their use and avoid unnecessary duplication of effort. This may require exploring how these tools can be adapted for local implementation, with direct input from people living with IBDs to ensure real-world relevance and utility, particularly where they are condition-specific (e.g. haemophilia) rather than inclusive of all IBDs.

5 Respond to the demand for information on treatment developments

There is a clear preference for information about new and emerging treatments, alongside a desire to better understand how different options work and their potential risks and benefits. Notably, this interest was observed across the full spectrum of decision-making styles, including among individuals describing more passive involvement. As such, the CCCs – both within and across centres – should be proactive in providing timely updates on therapeutic advances and their implications in both clinical development and routine care, ensuring that content reflects plain-language best practices.[63] This will require members of the MDT to be sufficiently aware of emerging therapies to engage in informed discussion, supported by timely access to up-to-date clinical trial data and relevant CPD opportunities. Moreover, there will be variation in information needs between patient groups that should be taken into account, alongside exploring different modes of delivery – including local or regional events – where there is demonstrable interest.

6 Address lack of engagement with underrepresented communities

The limited representation of ethnic minority and underserved groups within this evaluation reflects a persistent challenge in engaging and reaching these populations, despite the diversity of the region. Addressing this within IBDs will require more targeted approaches to engagement, including culturally appropriate communication strategies, collaborative working with system partners and, ultimately, co-produced interventions that are developed with and for the communities they are intended to serve. There is a unique opportunity across the CCCs to further investigate the barriers and facilitators to accessing and using treatment information within SDM among ethno-culturally diverse service users and to fully appreciate the implications for patient experience, satisfaction and other relevant outcome measures. This could complement evaluation undertaken on a regular (e.g. annual) basis, using structured approaches to track changes in health literacy, engagement and involvement in decision-making over time, enabling a more longitudinal understanding of whether changes in practice are having the intended impact and where further adaptation may be required.

Key Terms

Bleeding disorders of unknown cause (BDUC)

A clinically significant bleeding tendency where no underlying cause can be identified despite normal laboratory test results, typically based on a personal and/or family history of bleeding.[64]

Bleeding phenotype

The pattern, severity and frequency of bleeding experienced by an individual, reflecting how their condition presents in practice. For example, in haemophilia, bleeding phenotype can vary between individuals with similar factor levels and may be influenced by elements such as joint health, underlying biology and lifestyle.[10]

Comprehensive care

A coordinated, multidisciplinary approach to managing people living with **inherited bleeding disorders**, delivered through **comprehensive care centres**. It brings together clinical, nursing, laboratory, physiotherapy and psychosocial expertise to provide holistic, lifelong care, including prevention, treatment, rehabilitation and patient education.[10]

Contaminated blood scandal

A major public health tragedy in which thousands of people in the UK, including many living with haemophilia, were infected with blood-borne viruses through NHS blood and blood products during the 1970s and 1980s. The scandal has had profound and lasting impacts on individuals and families, including loss of life, long-term health complications and ongoing psychological and social effects.[5,6]

Decision aids

Tools designed to support **shared decision making** by helping people make informed choices about their healthcare. They provide information about available options and help individuals to consider what matters most to them, enabling values-based judgements in partnership with healthcare professionals.[7]

Glanzmann's thrombasthenia

A rare inherited platelet function disorder in which platelets are unable to aggregate effectively, resulting in impaired clot formation and a tendency to experience frequent or prolonged bleeding, particularly in the mucocutaneous area and heavy menstrual bleeding in women. This can have a significant and ongoing impact on quality of life, affecting physical health as well as emotional and social wellbeing.[65]

Haemophilia A

An inherited bleeding disorder caused by a deficiency of clotting factor VIII, leading to impaired blood clotting and a tendency to experience prolonged or spontaneous bleeding, particularly into joints and muscles. The severity and pattern of bleeding can vary between individuals, reflecting differences in **bleeding phenotype**.

Haemophilia B

An inherited bleeding disorder caused by a deficiency of clotting factor IX, resulting in impaired blood clotting and a tendency to experience prolonged or spontaneous bleeding, particularly into joints and muscles. It is less common than **haemophilia A** but presents in a similar way, with the severity and pattern of bleeding varying between individuals.

Haemophilia comprehensive care centre (CCC)

A specialist centre providing **comprehensive care** for people living with **inherited bleeding disorders**, bringing together expertise across clinical and allied health disciplines to support diagnosis, treatment and long-term management. Care is delivered through a holistic approach that addresses physical, psychological and social needs.[10]

Health literacy

The ability to access, understand, appraise and apply health information in order to make informed decisions about care. It reflects a person's knowledge and skills in using information to manage their health and wellbeing.[9]

Health Literacy Questionnaire (HLQ)

A validated questionnaire used to measure multiple aspects of **health literacy**, capturing how individuals access, understand and use health information and services across different domains.[12]

Hermansky–Pudlak syndrome

A rare inherited disorder that affects multiple systems in the body. It is characterised by reduced pigmentation of the skin, hair and eyes and a variable bleeding tendency due to platelet dysfunction, often presenting as easy bruising, nosebleeds or prolonged bleeding.[66]

Inherited bleeding disorders (IBDs)

A group of rare, lifelong conditions that affect how well the blood clots, caused by a deficiency or dysfunction of clotting factors or platelets. They are characterised by a tendency to bleed, which can range from mild to severe. Common IBDs include **haemophilia A**, **haemophilia B** and **von Willebrand disorder**.

Multidisciplinary team (MDT)

A group of healthcare professionals from different disciplines who work together to deliver coordinated care for people living with **inherited bleeding disorders**. This typically includes a haematologist, specialist nurse, physiotherapist, laboratory specialist and psychosocial support, with access to other specialists as needed depending on patient needs and local service provision.[10]

On-demand treatment

Treatment given in response to a bleeding episode, rather than on a regular schedule. Its aim is to control and manage individual bleeds when they occur.

Patient activation

A behavioural concept describing the knowledge, skills and confidence an individual has to manage their health and healthcare, including their ability and willingness to take an active role in decision-making and self-management.[8,30]

Patient Activation Measure (PAM)

A validated patient-reported measure used to assess an individual's activation. Individuals are often grouped into four levels – from low to high – to support tailored care and interventions based on their capabilities, beliefs and likely behaviours.[13]

Inherited platelet disorders

A group of rare inherited conditions that affect the number and/or function of platelets, leading to an increased tendency to bleed. These include disorders of platelet function and inherited thrombocytopenias, with examples such as **Glanzmann thrombasthenia** and **Hermansky–Pudlak syndrome**.

Prophylaxis

Regular treatment given to prevent bleeding episodes from occurring. This may involve clotting factor replacement or other haemostatic therapies administered at scheduled intervals.

Rare factor deficiencies

A group of rare **inherited bleeding disorders** caused by reduced or absent levels of specific clotting factors other than those affected in **haemophilia A**, **haemophilia B** or **von Willebrand disorder**, such as factors VII, X or XIII. These conditions can present with a wide range of symptoms, from mild or moderate bleeding to potentially serious or life-threatening haemorrhage.[67]

Service evaluation

A process of assessing the effectiveness or efficiency of how a healthcare service, or an aspect of it, is currently delivered, with the aim of generating information to inform local decision-making.[68]

Shared decision making (SDM)

A collaborative process in which a person and their healthcare professional work together to make decisions about care, based on clinical evidence and the person's individual preferences, values and circumstances. This involves sharing information and considering the risks, benefits and possible outcomes of different options and may include the use of **decision aids**.[7]

von Willebrand disorder (VWD)

The most common **inherited bleeding disorder** caused by reduced levels or impaired function of von Willebrand factor, a protein essential for normal blood clotting. It is typically characterised by mucocutaneous bleeding (such as nosebleeds and easy bruising), with heavy menstrual bleeding commonly affecting females. VWD can present with a range of symptoms and is classified into three main types: type 1 (typically mild), type 2 (variable severity) and type 3 (most severe).[21]

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Bridging the Gap

Understanding treatment information needs in inherited bleeding disorders across the Midlands