

CATCH 2023 Meeting Summary: Collaborate & Address Treatment Challenges in Haemophilia

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Access to treatment and healthcare services for people with haemophilia in the United Kingdom (UK) and Republic of Ireland ranks highly by international standards for contemporary haemophilia management. Collaborate & Address Treatment Challenges in Haemophilia (CATCH) is an annual Sobi™ medical education meeting which brings together multidisciplinary haemophilia treaters throughout the UK and Ireland to discuss all aspects of haemophilia management, including associated challenges and unmet need. This report summarises key issues explored and discussed during CATCH 2023, including 'raising the bar' in haemophilia care; haemophilia care for women and girls; changing haemophilia treatment paradigms to consider disease impact as well disease severity; bone health and haemophilia; and shared decision-making.

Keywords: Haemophilia, Patient care, Standard of care

INTRODUCTION

Haemophilia care in the UK and Ireland

Access to treatment and healthcare services for people with haemophilia in the United Kingdom (UK) and Republic of Ireland ranks highly by international standards for contemporary haemophilia management [1,2]. People with clinically severe haemophilia have access to prophylactic recombinant factor VIII and IX [3], and non-factor replacement

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therapies^[4], with gene therapy for haemophilia A and B licensed and expected in clinical care soon^[5,6]. Those with moderate or mild haemophilia are usually treated on demand with recombinant products. Genetic testing is available and allows identification of women who are carriers of the haemophilia gene. Women and girls who have low factor levels, and are thus clinically affected, are able to access the same treatment as their male counterparts^[7]. Care is delivered through comprehensive care centres where there is access to a full multidisciplinary team including medical and nursing care, physiotherapy and psychological support. With access to more effective treatment, people with haemophilia are living longer than before, are more able to participate in activities similar to their peers, and are encouraged to be active participants in decisions about their care and haemophilia management.

About CATCH

Collaborate & Address Treatment Challenges in Haemophilia (CATCH) is an annual Sobi™ medical education meeting which brings together multidisciplinary haemophilia treaters throughout the UK and Ireland to discuss all aspects of haemophilia management, including consideration of associated challenges and unmet need. CATCH 2023 was the fourth annual event in the CATCH series, two of which were run virtually due to the pandemic. CATCH 2022 was held face-to-face in London. All CATCH meetings have been non-promotional.

CATCH 2023 was held in Birmingham from Friday 29th to Saturday 30th September 2023. The agenda was designed by a steering committee, made up of haemophilia clinicians from the UK and Republic of Ireland, demonstrating all aspects of contemporary haemophilia care. The meeting opened with a debate exploring the topic 'Raising the bar in haemophilia care – what's left?', followed by four expert-led workshops about the care of women affected by haemophilia, bleeding in people with mild and moderate haemophilia, and the non-haematological impact of living with haemophilia, with a focus on bone health and shared decision making. Seventy-four delegates attended the overall meeting and each attended two workshops.

This report summarises the key issues that were explored and discussed during the CATCH 2023 debate and workshops. Unless otherwise referenced, content should be considered speaker opinion or summarised audience discussion.

OPENING DEBATE: THE BAR IS RAISED IN HAEMOPHILIA CARE – WHAT'S LEFT?

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Care standards in the management of haemophilia have progressed considerably in recent years, facilitated by therapeutic developments^[8]. In many respects, it could be argued that 'we have never had it so good' in terms of haemophilia care. On the other hand, there are still areas where care could be improved – so, should we be striving to raise the bar even higher? This was the subject of the opening debate at CATCH 2023. For the purposes of this discussion, the speakers were asked to present and argue diametrically opposed views. The views expressed were not necessarily representative of their true personal opinions.

All centres should be supported in meeting existing standards set for haemophilia care, before the bar is raised further

One side of the debate focused on whether a push to 'raise the bar' for haemophilia care in the UK and Ireland was appropriate. Despite the fact that the UK and Ireland rank highly internationally, *existing* standards of care are not yet being met^[9]. The overview report from the most recent peer review of care for inherited and acquired haemophilia and other bleeding disorders highlighted multiple areas of concern in haemophilia care, including staffing, staff training, and clarity and contents of treatment guidelines^[9]. Ensuring quality of care meets existing standards should perhaps be prioritised ahead of seeking to raise standards further^[10].

The report also demonstrated variance in the quality of care provided by different centres^[9]. As raising the bar has the potential to further increase the gap between higher-performing centres and lower-performing centres, there is perhaps a greater need to focus on meeting existing care standards and levelling out the standard of care provided between different centres. This should include addressing staffing and resourcing inequalities; for example, considering why certain centres have access to a dedicated

physiotherapist while others do not. In order to level out the standard of care provided by different centres, higher-performing centres could support other centres by sharing best practices.

It should also be borne in mind that the decision to raise the bar is not necessarily one that needs to be consciously made. Clinicians already 'raise the bar' every day as they strive to provide their patients with the best quality of care.

Continuously raising the bar enables delivery of an even higher quality of care

The opposing side of the debate argued that, while it is important to acknowledge that current care standards are not being met, better care comes from thinking beyond those standards. A recent study of people with haemophilia in European countries including the UK and Ireland found that less than half described their life as 'normal', which indicates a clear need for change^[10]. As haemophilia care changes, the goals of haemophilia care are becoming outdated^[11,12] – rethinking them would be of value in providing high-quality care to patients.

Understanding the true impact of haemophilia in different individuals could ultimately improve care. More detailed information on quality of life and lifetime cost of haemophilia is needed across all groups, especially in patients who typically struggle to access support and take part in studies^[13]. This information could allow development of a framework that assesses treatment value based on a more holistic view of patients' lives^[14], and which could support more personalised assessments and treatment decisions, as well as making cost-effectiveness assessments of treatment options easier. Today's research is tomorrow's standard of care, and focusing on the development of this framework could improve haemophilia care.

Another important part of raising the bar in haemophilia care is the ongoing movement towards more personalised prophylactic treatment. Patient expectations also need to change so that they understand prophylaxis should be part of the wider discussion around managing their haemophilia^[15].

During the closing vote of the debate, the audience majority shared their support for raising the bar. It was also acknowledged that current standards for haemophilia are not all being met. Raising the bar to meet the current standards is an important first step in pushing the bar even further and improving quality of care.

SETTING THE STANDARD IN HAEMOPHILIA CARE FOR WOMEN & GIRLS

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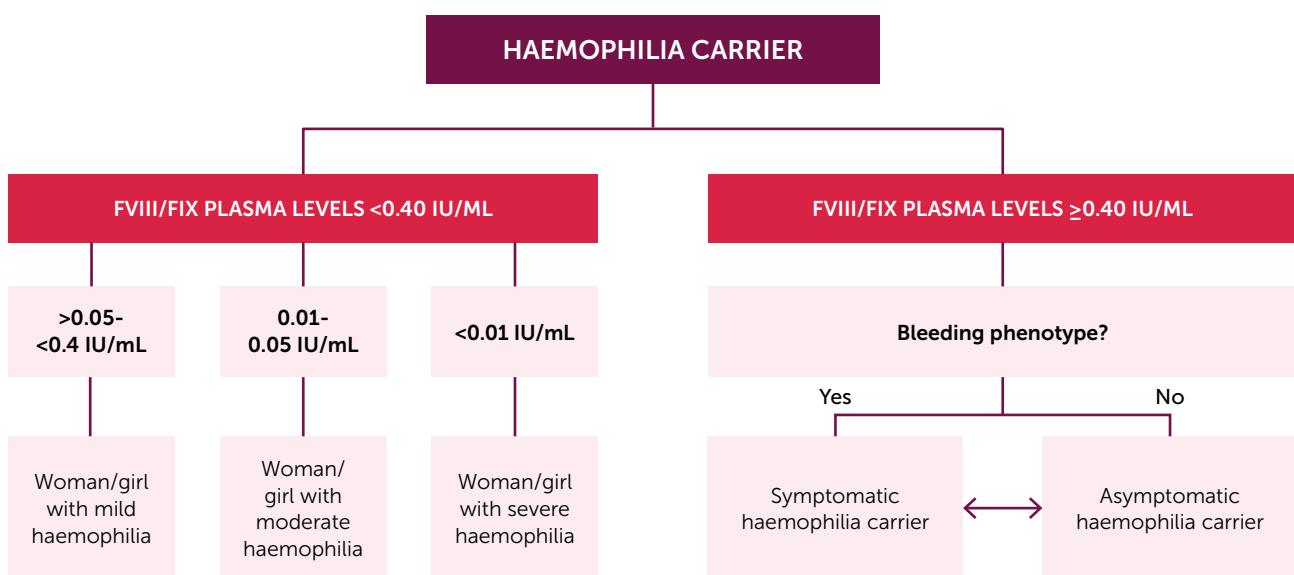
It is well known that haemophilia is a predominantly male disorder^[16]. That said, the statistics for women are underrepresented^[17]. Despite its prevalence in women, haemophilia care is currently organised around the needs of male patients, with timely diagnosis and appropriate management of female patients requiring improvement.

Published in 2021, the European Principles of Care for Women and Girls with Bleeding Disorders (WGBD) offers guidance on the management of haemophilia in female patients^[7]. Unfortunately, it is not utilised to its potential. Data shared from the Oxford Haemophilia Centre demonstrates that only 10% of women had all 10 principles of care fulfilled^[18].

Haemophilia significantly affects women and girls in physical and psychosocial domains^[19-23]. Unfortunately, there are many barriers that stand between women and girls which prevent them from receiving good haemophilia care. These include the normalisation of bleeding symptoms^[20,21], lack of education around haemophilia, and uncertainty around when and how to access care. Being a carrier of haemophilia can impact on everyday life, particularly in association with reproductive life and guilt about passing on the haemophilia gene^[22,23], but also through missed school, work days and social events resulting in isolation, anxiety and depression^[20,21]. In addition, there are broader systemic issues, such as staffing and service capacity problems. There was a consensus amongst the group that standards of care for women varied between comprehensive care centres.

Furthermore, the terminology used to describe haemophilia does not necessarily reflect the reality of how female patients experience the disease, and thus may benefit from reconsideration. For example, women are commonly referred to simply as 'carriers', regardless of the severity of the bleeding that they experience^[7]. Moreover, the language used may also be exclusionary to transgender patients. This can result in a significant delay in diagnosis and appropriate management of bleeding symptoms^[20,22].

Figure 1. New nomenclature for haemophilia carriers and women and girls with haemophilia
Adapted from van Galen et al., 2021^[24].



FVIII/FIX: Factor VIII/IX

IU/mL: International units per millilitre

A new nomenclature has been defined with input from haemophilia experts, patients, and the International Society on Thrombosis and Haemostasis (ISTH) community. The new nomenclature accounts for personal bleeding history and baseline plasma FVIII/IX level^[24].

There are many avenues that can be explored in improving and raising the bar for haemophilia care in women and girls. The focus should be on improving equity of access to services, individualising care across patient lifetimes, educating women and their families, and optimising management of heavy menstrual bleeding. It is crucial that women's voices are heard, and women with haemophilia should be involved in research, registries, and the future direction of their care.

As part of improving services, it could be beneficial to develop dedicated services, such as heavy menstrual bleeding clinics, and joint clinics, such as obstetrics and gynaecology clinics for haematology patients. In terms of addressing the issues with delayed diagnosis, the general population should be educated on haemophilia, and when to consider seeking help for menstrual bleeding. To better improve care overall, more research in women and girls with haemophilia will play an important role. Regarding terminology, a shift towards inclusive yet sensitive language could benefit people with haemophilia. For example, avoiding the term 'Women's clinic' would be more inclusive of transgender patients.

CHANGING PARADIGMS – TREATMENT FOR PEOPLE WITH HAEMOPHILIA WHO BLEED, REGARDLESS OF SEVERITY

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The way patients interpret the severity of their haemophilia impacts their confidence in daily life, and their approach to treatment. Patients who perceive their disease to be of significant severity may feel restricted in their ability to live their normal lives^[10]. On the other hand, patients may be more likely to engage in care if they view their disease severity as significant. It is a balance: patients need to feel empowered enough to live their normal lives, whilst understanding that their disease is severe enough to necessitate good engagement with care. As such, it is important that the language used by healthcare professionals respects this balance. The labels of 'mild' and 'moderate' can hold different meanings for patients and healthcare professionals (HCPs).

Historically, advice focused on telling patients what they 'should not do', due to associated risk. Good management should focus on supporting patients in living their lives with limited restrictions. This starts with

establishing what their expectations are, thus ensuring adequate treatment.

Patients should be educated on the implications of their diagnosis, and how certain activities and choices pose additional risks to their health. For example, educating patients that certain sports may increase the risk of joint bleeds. The general population take risks every day – people with haemophilia should also be permitted to take risks in activities important to them. Educating patients on risk empowers them to make their own decisions, limiting their sense of impairment and giving them confidence to live as normal lives as possible.

The way haemophilia is classified affects management decisions, specifically with regards to prophylaxis. Rigid criteria around disease severity does not always include bleeding phenotypes, meaning that patients with 'moderate' haemophilia may not receive prophylaxis. This approach is restrictive, as disease classification may not accurately reflect the impact of the disease on the patient. For example, evidence shows that patients with 'moderate' haemophilia may experience worse joint disease scores than patients with 'severe' haemophilia [25]. Providing patients with prophylactic treatment, even if their disease is not defined as severe, could offer quality of life improvements through the physical effects of treatment, as well as through the confidence that comes from being on prophylactic treatment. The focus should be on treating patients based on their individual disease experience, and the risk posed to them by the activities in their normal lives.

BEYOND HAEMOSTASIS, BEYOND HAEMATOLOGISTS

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Currently, management of haemarthrosis in haemophilia focuses on prevention, and supporting patients with the clinical sequelae arising from these bleeds [3]. Looking to the future, management could focus more on limiting the joint damage that occurs following joint bleeds. Blocking inflammatory effects that occur secondary to joint bleed, could improve treatment outcomes [26]. Potential therapies for preventing or lessening joint damage may include

iron chelators, intra-articular cytokine injections and bisphosphonates [26].

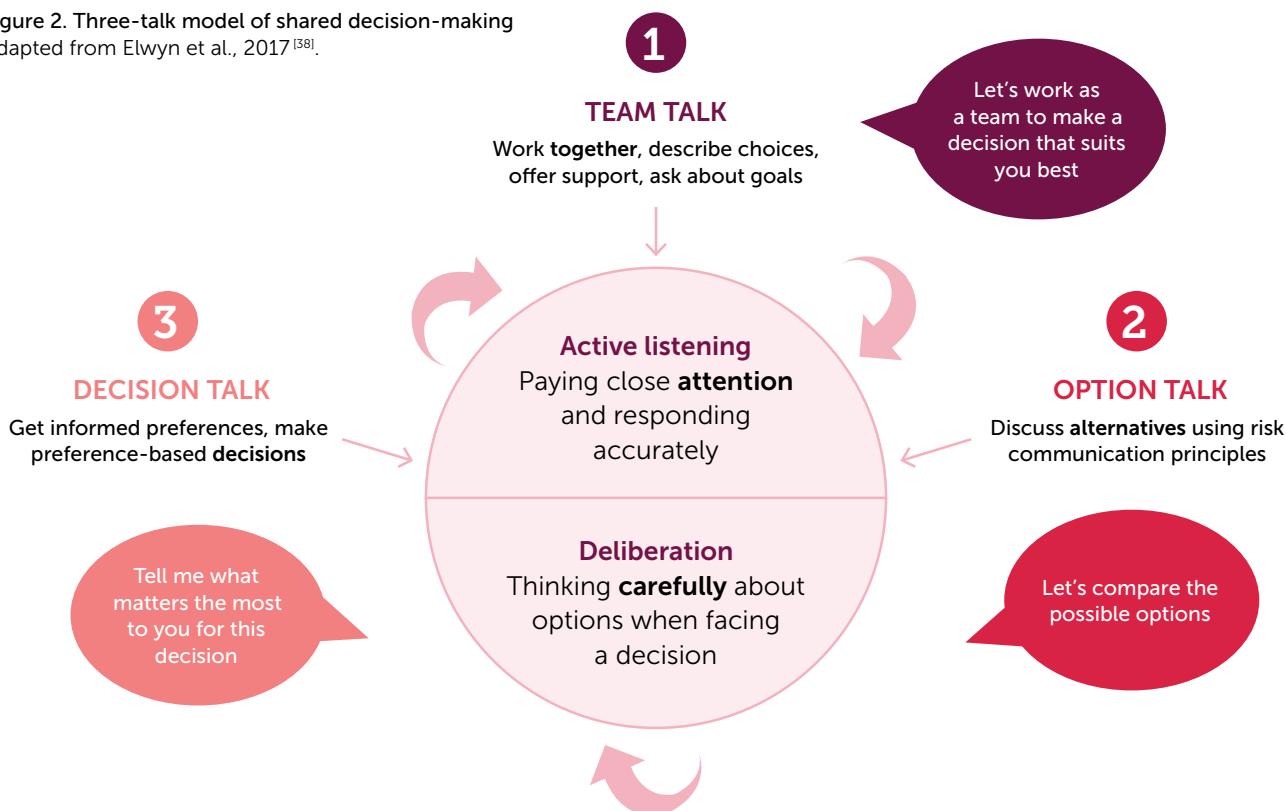
Another area of bone health that would benefit from further exploration is the phenomenon of microbleeds, a recognised phenomenon in other conditions [27]. It is postulated that in the phenomenon of microbleeding, patients may experience 'invisible bleeds' in which there is asymptomatic leaking of small amounts of blood into a joint [27]. It is not clear whether the joint changes seen in patients with haemophilia are significant, or simply the a result of 'wear and tear' as would be seen in the general population.

Furthermore, there are also knowledge gaps in the effects of coagulation factors outside of the vessels. Research into the role of extravascular coagulation factors could provide more information about the relationship between haemophilia and bone health [28,29].

In terms of other impacts of haemophilia on bone health, there is a well-established link between haemophilia and osteoporosis [30,31]. This may be related to the extravascular function of coagulation factors, reduced physical activity, steroid use and genetics. Bone health is important for all ages. Children and young people with haemophilia should be supported in reaching a healthy and appropriate peak bone mass, like their peers. Adults with haemophilia should have their bone health optimised to minimise fracture risk, whilst acknowledging the complexities and limitations of weightbearing as a bone health strategy when living with painful joint arthropathy. Osteoporosis in people with haemophilia should be detected early, but this is challenging as there are often multiple competing priorities in haemophilia management. People with haemophilia should have their functional ability assessed and monitored, with any changes noted and investigated appropriately [32]. It may also be beneficial to consider bone health screening in people with haemophilia as a baseline screen and include fracture risk (using Fracture Risk Assessment Tool (FRAX) scoring) as appropriate. This may also need to be considered especially prior to starting steroids [33], but further consideration would need to be given to who to screen and when to screen them, and which medical specialty should take overall responsibility for this process [34].

Osteoporosis management in people with haemophilia could be improved by developing stronger working relationships between haematologists, rheumatologists, endocrinologists, osteoporosis services, and physiotherapists. Furthermore, there should be a focus on improving education around haemophilia and bone health within these groups.

Figure 2. Three-talk model of shared decision-making
Adapted from Elwyn et al., 2017^[38].



Rehabilitation programmes should be offered to people affected by osteoporosis, with an emphasis on fracture prevention^[35]. An example of a rehabilitation programme currently in operation is the Salford Osteoporosis Rehabilitation Programme, a four-week programme of education and exercise for people with osteoporosis and osteopenia. It is clear that further research is needed to determine the feasibility and acceptability of current weightbearing exercises approaches for osteoporosis and how people with haemophilia may benefit, especially given the presence of lower limb, multi-joint arthropathy. Moving forward, the potential roles of nurses and physiotherapist in the long-term surveillance and management of bone health in people with haemophilia should be considered.

SHARED DECISION-MAKING SKILLS – PARTNERING WITH PATIENTS

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Haemophilia care is complex, and decision-making is subject to bias. As such, the decision-making process may lead to misdiagnosis and a lack of appropriate

intervention^[36]. Good haemophilia care requires a collaborative approach between the patient and healthcare professionals. Patients can bring expertise in their illness experience, social circumstances, and attitudes to risk, whilst HCPs bring expertise in diagnosis, prognosis and treatment^[37]. Shared decision-making (SDM) is important for several reasons, including the facilitation of a therapeutic partnership, and improved experience of care.

Patient involvement in care can be facilitated by taking steps to check patient understanding of options, providing summaries, and allowing sufficient time for processing and making decisions. A key focus of patient involvement should be on respecting patient values and preferences.

There are a number of models for SDM. An example of such a model is the Three-talk model of shared decision-making, which involves a team talk, an option talk, and a decision talk^[38]. The steps of this model are outlined in Figure 2.

There are also tools clinicians can access which can support decision making. The World Federation of Haemophilia (WFH) has developed an interactive SDM tool to support discussions about treatment options in haemophilia A or B. This can be used by patients, caregivers and the healthcare team, and will be updated as new research and information becomes available^[39]. Tools such as these have a valuable role to play in the SDM process.

CLOSING CEREMONY: THE BAR MAY BE RAISED, BUT THERE IS STILL LOTS TO DO

Dr Kate Khair
Director of Research, Haemnet, London

In the closing ceremony, Kate Khair concluded that today's research is tomorrow's standard of care. Thanks to research, we have raised the bar, and we continue to strive to deliver the best possible care, but we can raise it further. We can acknowledge when standards are not being met consistently across all UK centres, and make a conscious effort to ensure cost-effectiveness is appropriately assessed.

We need to think more broadly to tackle the issues of today. How do we provide comprehensive, individualised haemophilia care that addresses pregnancy, and issues specific to women? How do we change paradigms to achieve better management and prophylaxis for all patients who bleed regardless of severity? How do we look beyond haematology at issues such as bone health, and expand the specialities we involve in our multidisciplinary team?

Ultimately, we have an opportunity to change expectations around normality by engaging in shared decision-making with patients, and empowering them to play an active role in their care. Patients are the experts, and we can improve our services by asking them what kind of care they want and how it should be delivered. We should optimise patients' perceived expectations around their health and strive to support them in leading as normal lives as possible.

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