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CLINICAL PRACTICE | NON-PEER-REVIEWED | MEETING REPORT

CATCH 2024 meeting summary: Collaborate & Address Treatment Challenges in Haemophilia

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Greater treatment choice and the associated flexibility in regimens has necessitated new conversations with people with haemophilia about their personal goals. Innovations in haemophilia treatment drive the need for innovation in care service delivery. Supported by Sobi™, CATCH (Collaborate & Address Treatment Challenges in Haemophilia) is an annual, non-promotional, medical education meeting that brings together members of the haemophilia multidisciplinary team from across the UK and Ireland to discuss all aspects of haemophilia care and management. This report summarises the key issues that were explored and discussed during the CATCH 2024 meeting, including understanding the personal motivations of people with haemophilia and how these influence treatment choices and support; facilitating behaviour change to improve outcomes; reviewing the practicalities and possibilities for eliminating bleeds and new arthropathy in people with haemophilia; and developing new models of care to elevate haemophilia services.

Keywords: *Haemophilia, Patient care, Standard of care*

The ongoing evolution of the therapeutic landscape in haemophilia continues to bring greater treatment choice [1,2]. Combined with a greater focus on individualised, patient-focused care based on shared decision-making and flexible treatment regimens [3,4], this raises the potential for achieving normalised haemostasis in haemophilia A [2].

Against this background, there is a need for healthcare professionals (HCPs) to consider both what could be achievable for people with haemophilia (PWH) and how they, as treaters, can provide appropriate services and support to ensure optimal outcomes based on individual needs and preferences. Innovations in haemophilia treatment necessitate new conversations with patients about their personal goals and drive a need for innovations in care delivery, treatment pathways, outcome measures, and the role of the wider multidisciplinary team (MDT) [3,5,6]. In short, innovations in haemophilia treatment drive a need for innovations in care service delivery.

Supported by Sobi™, CATCH (Collaborate & Address Treatment Challenges in Haemophilia) is an annual, non-promotional, medical education meeting that brings together members of the haemophilia MDT from across the UK and Ireland, to discuss aspects of haemophilia care and management and share best practice.

CATCH 2024 was the fifth iteration of this meeting. Held in Birmingham from Friday 29th to Saturday 30th November 2024, it was designed and delivered by a steering committee and faculty of independent haemophilia treaters and patients, chaired by Dr Kate Khair and facilitated by Haemnet. This report summarises the key issues that were explored during the CATCH 2024 sessions and workshops. Unless otherwise referenced, content should be considered speaker opinion or summarised audience discussion.

CONQUERING YOUR PERSONAL MONT BLANC: WHAT EVERYONE CAN LEARN FROM THE PEAKS AND TROUGHS OF EXPEDITION PLANNING

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The opening session of CATCH 2024 focused on the climb of Mont Blanc, the highest peak in Western Europe, by a group of people with bleeding disorders [7]. Though mostly unknown to each other, participants in the Mont Blanc challenge shared the experience of having overcome personal challenges linked to having a bleeding disorder. Clive Smith and Panagiotis (Panos) Christoforou reflected on this from the viewpoint of living with severe haemophilia A, and how this had equipped them with the motivation and resilience to tackle Mont Blanc.

Clive and Panos were both were diagnosed with severe haemophilia A in early childhood and received prophylactic treatment. They both had brothers with the same diagnosis, and both had no prior family history of haemophilia. Both had experienced lots of bleeds in childhood but remained determined not to be defined by haemophilia. They both described how building up their own confidence and networks of 'supporters' had enabled them to pursue their career goals, overcome professional struggles, and enjoy physical challenges.

Clive reflected on having been determined to succeed academically and how flexible support from his care team had helped this. Academic achievement helped to build his confidence, and he went on to pursue a successful career in law. However, balancing living with haemophilia and its associated challenges with working in a high-pressure environment meant he continued to need to draw on the resilience he had developed. He also described his interest in exercising and training to succeed in endurance races, and how this also involved both balancing risk and countering negative attitudes.

Panos had also been keen to study in order to pursue a career as a doctor. Travelling and living away from a protective home environment had been a risk in terms of his ability to manage his haemophilia. However, with the encouragement of a range of 'supporters', including family, friends, teachers and HCPS, he was able to achieve his ambition. This support, and the motivation to become involved in extra-curricular activities related to his studies and haemophilia, also gave him the confidence to pursue physical challenges

The challenges of climbing Mont Blanc included strategic planning around treatments to support safety and recovery during and after physical training for the expedition, and managing the combination of intense training and work commitments. Clive and Panos's resilience and confidence in their ability to recognise signs of a bleed, understand when to treat and judge risk were important factors in successfully completing the climb, and working with care teams to develop treatment regimens to support and enable physical

goals were key. However, these are also relevant to overcoming the challenges associated with living with haemophilia more broadly. Climbing Mont Blanc can be seen as an analogy for how to approach living better despite having a bleeding disorder.

While acknowledging that not all individuals with haemophilia will share their academic and physical achievements, Clive and Panos were clear that with the right support, particularly from HCPs, all PWH could be enabled – and have the confidence – to reach their personal goals, physical and otherwise. As a haematologist, Panos takes the view that if PWH come to him with a challenge, the response should be to discuss their treatment plan to facilitate their goals. HCPs need to support PWH to use treatment in the way that suits them best, and in the way that is most effective to enable personal goals to be attained and allow individuals to live in the way they want to – particularly at a time when treatment advances mean the prospect of achieving normalised haemostasis in haemophilia A is possibility.

To achieve their goals, PWH need positive supporters, facilitators and allies to enable the confidence to pursue opportunities and help them navigate haemophilia-related challenges. HCPs should engage with PWH to understand their individual challenges, physical or otherwise, to ensure they have the right treatment and guidance to protect themselves. Treatments are available to support PWH to undertake all kinds of challenges, and the full range should be used so that each individual patient has the potential to achieve the goals they set for themselves. Whether they climb Mont Blanc or not is immaterial.

THE JOURNEY TO NORMALISED HAEMOSTASIS: ELEVATING THE STANDARD OF CARE IN HAEMOPHILIA

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With significant innovation in treatment options for haemophilia over the past 50 years [1,8,9,10,11,12,13,14], treatment goals have evolved from preventing early death to achieving health equity. This includes freedom from spontaneous bleeds and associated morbidities [9].

In the real-world setting, regular prophylaxis does not prevent all joint bleeds

World Federation of Hemophilia (WFH) guidelines for the treatment of severe haemophilia A promote standard of care as prophylaxis with haemostatic products to protect against bleeds [11]. Prophylaxis is indicated for all patients with severe bleeding phenotype, regardless of lab- based severity, with a recommendation to target FVIII trough levels of 3–5 IU/dL or higher, equivalent to moderate haemophilia A [11,14]. Tailored dosing and scheduling based on weight and pharmacokinetic monitoring are also recommended to support the reduction of bleeding episodes and improved joint protection [1].

However, a UK expert consensus on the preservation of joint health in PWHA agreed that treatment should aim for a trough FVIII level of ≥15 IU/dL, with peaks up to normal levels, where there is no additional treatment burden [15]. They also agreed that maintaining a greater time with a FVIII level ≥20–30 IU/dL provides better bleed protection.

The need for higher trough levels has been further demonstrated in the real-world setting. In a UK observational study of people with severe haemophilia A on FVIII prophylaxis (N=237), 60% of adults and 33% of children were affected by joint bleeds [16]. Similarly, in a European survey of people with severe haemophilia A on FVIII prophylaxis (N=166) 39% had experienced a target joint [17].

These data suggest that, despite regular prophylaxis, joint bleeds still occur [16,17,18,19,20], and that a shift towards normalised haemostasis could address remaining unmet needs [9]. This view was supported by audience voting, where 69% would aim for factor VIII levels over 50 IU/dL to prevent all bleeds. A further 26% said they would target factor levels above 30 IU/dL, thus improving haemostasis, reducing bleeds and enhancing patient-reported outcomes.

Normalising haemostasis to support patient goals

The Faculty noted that normalising haemostasis is akin to normalising life – i.e., supporting patients to develop the self-confidence they need to embrace life and achieve their goals. The journey would be different for each PWH, and the long-term impact of living with haemophilia without lifelong prophylaxis means achieving a 'haemophilia-free mind' [21] may not be possible for older generations of PWH. However, the ambition should always be to "reach the final destination with memories, not dreams".

In discussing how the MDT could support PWH, the Faculty extended the journey analogy. The ultimate

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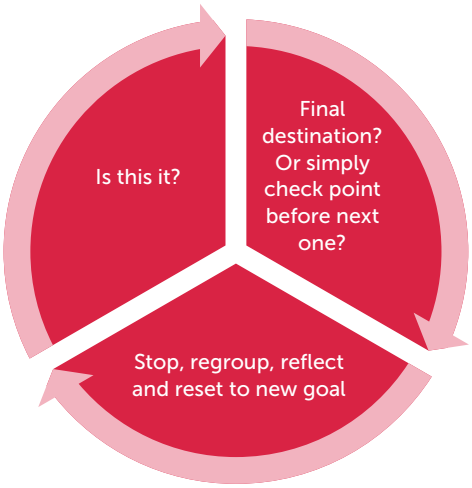
Figure 1. Cyclical goal planning



destination (goals) must be set by the patient, with the MDT considered as the SatNav helping to navigate the patient journey, and factor levels as 'the fuel in the tank'.

It is important that goal-oriented treatment plans are adaptable as situations change. A forward-thinking approach can help anticipate outcomes and barriers, and while momentum should be maintained, there must also be opportunities to pause, reflect, regroup, and reset to new goals in alignment with the patient's situation; i.e. treatment plans should consider cyclical goal planning (Figure 1). Reaching a goal should not mean stopping but prompt the question 'What next?'.

Chronic care and role adjustment

Highlighting a chronic care model that stresses the interaction between an informed activated patient and a prepared proactive team [22], the Faculty considered the role of nurses in facilitating the journey to normalised haemostasis.

The nurse assumes multiple, inter-related roles within the MDT, and is pivotal in education and coordination of care [23]. They are involved in making connections with different HCPs on behalf of patients, but with improvements in treatment and the prospect of normalised haemostasis, they may see PWH less frequently in clinic. If the nurse-patient interaction becomes less concerned with bleeding, then a shift in focus is required in terms of how best to deliver ongoing care. Increased focus on psychosocial elements and the patient's lifeworld may form part of this shift.

Elevating the standard of care for PWH should be a continual process and requires a two-way knowledge sharing process between PWH and the MDT, and also within the MDT. The ideal is to move to an environment where the MDT are facilitators, enablers and full partners in the care of PWH.

Elevating treatment goals for haemophilia

Dr Gary Benson summarised that elevating treatment goals for haemophilia A meant recognising that clinical and modelling studies show attaining zero bleeds may require FVIII levels of 15–50 IU/dL depending on the individual [24,25]. Maintaining sustained normalised haemostasis may lead to absence of spontaneous clinical and sub-clinical bleeding, long-term preservation of joint function, reduced pain and increased ability to enjoy an active life [24,25]. Sustained FVIII levels ≥40 IU/dL may be an appropriate treatment target in future [14,26].

To achieve these treatment goals in practice, routine assessments could consider monitoring objective measures of joint health (not just ABR) [27], enabling patients to articulate their anxiety and pain levels and make shared decisions with HCPs over treatment goals [11].

Normalisation of haemostasis may appear aspirational, but expectations of new haemophilia A treatments offer the opportunity to continue the journey towards normalising life for all PWH.

WORKSHOP 1: FACILITATING HEALTH BEHAVIOUR CHANGE AS A MULTIDISCIPLINARY TEAM

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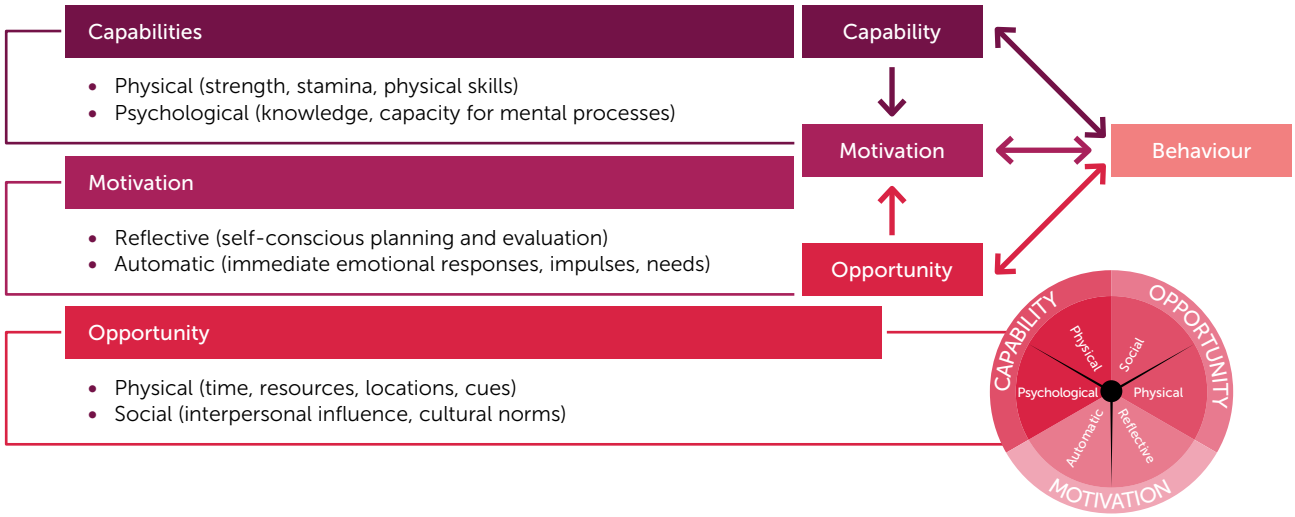
Health behaviour change refers to influencing the overt behavioural patterns, actions and habits that relate to patients' health maintenance, restoration and improvement [28]. A variety of behaviours fall within this definition, including smoking, alcohol use, diet, physical activity, sexual behaviours, physician visits, and medication adherence.

Evidence points to the positive impact that changing health-related behaviours can achieve. However, health behaviours are deeply embedded in individuals' physical, psychological, social, and cultural circumstances, and changing them can be challenging. As such, it is important to consider interventions that address the determinants of health behaviour in order to induce and sustain change [29].

There are multiple models, methods and theories around approaches to health behaviour change,

Figure 2. The Behaviour Change Wheel [30]



but no agreed strategic approach on how best to implement them [28]. This offers an opportunity to utilise different approaches that may positively impact patient expectations, attitudes, self-efficacy, and avoid relapse into negative behaviours.

The Behaviour Change Wheel is one method for characterising and designing interventions (Figure 2) [30]. Establishing core conditions of capability, motivation, and opportunity, it provides a framework for recognising barriers and ways to overcome them. The model identifies whether capabilities are influenced by psychological or physical barriers; whether motivations are based on reflective thought or more emotional automatic responses and habits; and whether opportunities are determined by physical or social influences. This deeper understanding of the core conditions enables targeted interventions that may incorporate education, training, incentivisation, enablement, providing models to aspire to or imitate, or environmental restructuring that changes a person's physical or social situation, e.g., Post-it note reminders [30].

Common health behaviour-related issues encountered by the haemophilia MDT include lack of engagement, the enduring influence of paediatric care on lifestyle choices, and addressing patients' reluctance to change. Highlighting the impact of inheritance on haemophilia and on patient beliefs, understanding a PWH's background can shape how the MDT approach conversations to positively influence health behaviour change. The Faculty stressed the importance of adopting a non-hierarchical MDT model to support this; for example, accepting that some PWH will talk more openly with their physiotherapist than their consultant can offer an opportunity rather than raise concern. Insights gleaned from conversations with treatment centre receptionists, analysis from data managers, discussions with consultants and nurses all have the potential to influence health behaviour change.

Dr Will Lester summarised that regardless of models used, respect for each person within the MDT underpinned any meaningful change, and that overall patient goals should not become obscured due to differences in MDT perspectives.

WORKSHOP 2: COULD WE ACHIEVE NO BLEEDS AND NO NEW ARTHROPATHY IN FIVE YEARS?

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Based on a recent UK expert Delphi consensus on the preservation of joint health in people with moderate and severe haemophilia A, the Faculty posed the question of whether it was possible to achieve no bleeds and no new arthropathy in people with haemophilia A (PWHA) within five years [15].

The expert consensus agreed that prophylaxis should be initiated in all PWHA (including children) with baseline FVIII levels of ≤5 IU/dL, and that if there was no increased treatment burden they should target trough levels of ≥15 IU/dL. They further agreed that

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Table 1: Comparing Delphi consensus and CATCH 2024 delegate responses

STATEMENT	LEVEL OF AGREEMENT	
	DELPHI CONSENSUS	CATCH DELEGATES
All PWHA (including children) with factor levels below 5 IU/dL should be started on prophylaxis	80%	74%
If there is no increased treatment burden, prophylaxis trough levels should target at least 15 IU/dL	80%	77%
Maintaining a greater period with factor levels of 20-30 IU/dL should reduce the risk of bleeding	87%	84%
Effective prophylaxis may lead to improvements in joint disease (either symptoms or function)	100%	84%
Can we achieve no new bleeds and no new arthropathy in the next 5 years?	87%	13%

PWHA: People with haemophilia A

maintaining a greater period of time with factor levels ≥20-30 IU/dL can be beneficial [10,15].

Looking into the future, the expert consensus agreed that by 2027 treatment goals for PWHA should include zero spontaneous bleeds and no development of haemophilia-related arthropathy when on prophylaxis [15]. They concluded that a future clinical treatment goal should be that all PWHA should maintain normalised FVIII levels of 50–150 IU/dL [15].

On testing the assertions of the expert consensus, the Faculty found that CATCH 2024 delegates agreed that:

- All PWHA (including children) with factor levels below 5 IU/dL should be started on prophylaxis
- If there is no increased treatment burden, prophylaxis trough FVIII levels should target at least 15 IU/dL
- Maintaining a greater periods with FVIII levels of 20-30 IU/dL should reduce the risk of bleeding
- Effective prophylaxis may lead to improvements in joint disease (either symptoms or function)

However, while the expert consensus promoted the possibility of achieving no new bleeds and no new arthropathy in the next five years as a treatment aspiration, delegates were less optimistic (Table 1). Delegates felt that as people with severe haemophilia engage in more physical activity, which is a positive development, consensus at the meeting was that the higher risk of injury may mean achieving no new bleeding and arthropathy was less likely to be achievable, despite precautions being taken. Additionally accidental trauma, falls, or other injuries can still lead to bleeds, regardless of prophylaxis. Even if subclinical bleeds are prevented, there may still be subtle, subclinical changes in the joints over time that could eventually contribute to what might be considered "new" arthropathy, even if not directly linked to a significant bleed. The definition of "no new arthropathy" can be challenging to measure precisely.

From the patient perspective, Adam Jones raised the notion that effective shared decision- making includes understanding patient preferences, history, and ambitions, and the key goal of treatment for PWH should perhaps be more focused on normalising quality of life.

In this respect, the Faculty suggested that 'elevating the standard of care' could be brought about through the MDT focusing on elevating patient choice and decision-making capabilities, particularly at a time when new treatment choices are becoming available.

WORKSHOP 3: ELEVATING HAEMOPHILIA SERVICES: ADVANCING COMPREHENSIVE CARE

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Current and future treatments for haemophilia A will likely enable higher factor level targets. HCPs, including the wider haemophilia MDT will need to adapt models of care to support this development.

The breadth of specialties involved in the care and management of PWH suggests care has already moved away from a consultant-led model in many instances. The haemophilia treatment centres represented by CATCH 2024 delegates all include a consultant, nurse and physiotherapist in the core MDT; some also include psychologists, social workers, laboratory and research

Figure 3. Multidisciplinary team members at haemophilia treatment centres represented by CATCH 2024 delegates
Word cloud created by delegates in response to the question 'What does your current multidisciplinary team structure look like?'

staff, data managers, play therapists, and other roles (Figure 2).

The current models of care at delegates' treatment centres were identified as primarily consultant-led but also broad in scope, with evolving multidisciplinary input in the care model. Delegates were also challenged to identify, from experience, the most important aspects of haemophilia care from the patient perspective. Core themes included continuity of care, individualising care and shared decision-making.

With such a broad variety of models identified, models of care may need to be adapted and enhanced to ensure delivery of patient care needs remains effective. The Faculty showcased the Advanced Nurse Practitioner (ANP)/Physiotherapist model of care developed at the National Coagulation Centre, Dublin. PWH are seen annually in clinic for a comprehensive assessment by the ANP and physiotherapist, followed by a telephone or video review six months later. The intention is to establish a therapeutic relationship based on continuity of care. Alongside the scheduled core clinic and six-monthly reviews, the model incorporates fluidity to allow for unscheduled care and referral to additional services such as pain clinics, dental clinics and orthopaedic clinics. This enables a proactive rather than reactive approach where needs can be anticipated, facilitating timely tests and access to specialists, and supporting efficiency without risk to patient safety or satisfaction. Assessments include health outcomes and goal setting, social circumstances and activity level, aiming to maximise quality of life and health outcomes.

Delegates were tasked with planning and designing a comprehensive care service for PWH with a 'blue sky' approach and no restrictions. This was then refined to a realistic model of care that could be delivered within the next five years, and which may be achievable for care teams to implement. Suggestions for such a service included access to social workers, patient-initiated follow-up services, greater awareness of patients' emotional wellbeing, patient access to home ultrasound, and processes to bypass Accident and Emergency services when accessing out-of-hours care.

While there are potential financial and organisational barriers to implementing change, approaches to overcoming these may be available. Charitable funding may support specific purchases (e.g., gym equipment). Aligning initiatives to national strategies beyond haematology may help secure funding (e.g., successful ageing, women's health). Appealing to the interests of non-haematology organisations or individuals may spark joint research funding (e.g., bleeding disorders and obstetrics/gynaecology).

CLOSING CEREMONY

Dr Kate Khair
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In the closing ceremony, Dr Kate Khair concluded that PWH have demonstrated their desire to overcome challenges, and that the tools now exist to help gain greater confidence, access more opportunities, and attain higher achievements. With HCPs offering coordinated solutions through dedicated MDTs a continued elevation of the standard of care will allow for the targeting of normalised haemostasis in PWH.

The interactivity, commitment, and innovation displayed during CATCH 2024 demonstrates the willingness to implement changes that have a lasting impact, in designing new models of care, facilitating health behaviour change, and striving for a future where no bleeds and no new arthropathy in PWH becomes a reality.

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