UNDER SERVED OVER LOOKED

How our health systems are failing women and girls with a bleeding disorder

The Haemophilia Society

Contents

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Foreword by Kate Burt, Chief Executive of the Haemophilia Society

Three years ago, we set out to produce a comprehensive study of the quality of life, care and treatment for the 20,000 women and girls with a diagnosed bleeding disorder in the UK.

It quickly became clear that the evidence needed to produce this review was worryingly and unacceptably incomplete.

What also became apparent was how many women and girls feel overlooked and underserved by the current model of bleeding disorder care. Our report agrees.

Bleeding disorder care has struggled to break out of a financial and clinical mindset that often sees women and girls as secondary patients to men and boys with haemophilia.

Historically, we understand why. When the first dedicated haemophilia centre was set up in 1954, care was focussed on males with severe haemophilia who had no treatment and were at daily risk of life-threatening bleeds.

Today we live in a very different world. Bleeding disorder clinicians routinely treat a wide range of conditions affecting both men and women. Treatment options for some conditions, particularly haemophilia, have improved dramatically. But our report finds that a lack of clinical and scientific curiosity in women and girls has resulted in a service that has failed to fully understand and adapt to support their needs.

Quite simply, women's needs are different. They need to be treated differently. They are being left behind in an ever-changing treatment landscape, in part due to a lack of scientific research which could push forward improvements in care.

As well as making 19 far-reaching recommendations, this report unapologetically raises many questions, some of them uncomfortable. But it is only by plugging the gaps in our knowledge and confronting ingrained thinking that progress starts to be made.

We want this project to be a springboard for change. We hope it will start conversations in every haemophilia centre in the UK and beyond, resulting in meaningful and long-lasting improvements to treatment and care. This is not an easy task, but change is overdue.
This report could not have happened without the support of over a hundred women and girls with bleeding disorders who shared their experiences and the steering group who worked so hard to shape this important study.

We dedicate this report to Jess McLean (Page), a key member of our steering group, who died from acute myeloid leukaemia aged 29 in 2024. Jess was a passionate advocate for women and girls with a bleeding disorder whose warmth and compassion touched so many in our community. She will always be a treasured member of our Haemophilia Society family.

Executive summary

Women and girls make up over half of people with registered bleeding disorders in the UK but healthcare services are often failing to meet their needs.

This report finds that far too often women and girls with bleeding disorders are underserved by the NHS. They are fighting harder and for longer to get a diagnosis and effective treatment than men with a bleeding disorder.

Women are treated in the UK's network of haemophilia centres by clinicians with great expertise and dedication against a challenging backdrop of lack of resources and difficulties in recruitment.

But there is much work to do to ensure the service routinely offers women and girls the specialist care they need.

Women and girls' needs are different, and they should be treated differently, but services lack the flexibility and resources to embrace new models of care.

Although there are examples of ground-breaking great practice, most services have failed to adequately adapt and are not offering women and girls the best treatment and care.

Of the UK's 29 haemophilia comprehensive care centres, only eight offer joint haematology and gynaecology clinics. Fewer than half have a dedicated clinical lead for women and girls with bleeding disorders. In smaller treatment centres, the figures are much lower.

Women and girls are less likely to have access to specialist physiotherapists, sometimes having to return to their GP for a referral when the service should be available through their centre's multidisciplinary team.

Lack of research and inadequate data collection have hindered our understanding of the needs and experiences of women and girls with bleeding disorders and left many underserved by our healthcare system. Our conversations with over one hundred women and girls with a genetic bleeding condition have brought out numerous examples of genuine health concerns being ignored, overlooked or inadequately followed up.

16 years

On average, women are diagnosed with a bleeding disorder 16 years later than men.

50k

We estimate that up to 50,000 women live with an undiagnosed bleeding disorder and could be experiencing debilitating symptoms with no support, such as very heavy periods and frequent bruising.

Far too often women are being let down at primary care level because the complexities of testing for genetic bleeding disorders are not recognised. Testing, if it happens, is ineffective, sometimes resulting in women being told they don't have a condition, when the opposite is true.

Specific genetic and factor level testing needs to be done in secondary care by specialist clinicians. But even in specialist hands, testing policies vary considerably between haemophilia centres and should be standardised.

Women with a bleeding disorder are at increased risk of iron deficiency anaemia (IDA) which can have a serious impact on their quality of life. Yet our study found that iron deficiency is not well monitored, resulting in missed opportunities for early treatment that would prevent the development of anaemia.

The use of preventative treatment, also known as prophylaxis, which is standard care for managing moderate and severe haemophilia appears to be underused in women and girls, particularly those with von Willebrand disorder.

There is concern that although guidelines recommend long-term prophylaxis for heavy menstrual bleeding, this treatment option is frequently overlooked. More research is needed on the benefits of prophylaxis in the management of heavy menstrual bleeding, which could dramatically improve thousands of women and girls' lives.

Many women interviewed about their experiences felt their health concerns were not taken seriously by clinicians. The unwillingness of some clinicians to see women who have the haemophilia gene as anything other than 'just carriers' has been a barrier to effective treatment for too long.

Being dismissed by a healthcare professional or told to 'get on with it' can be devastating. Many women retreat until another health crisis forces them to try again. Some never do. We hope women can use the evidence in this report to leverage better conversations which lead to more appropriate treatment and care.

Diagnosing and managing women and girls' bleeding disorders well reduces time spent in A&E clinics and means there will be significantly less disruption to work, education and social lives. Feeling understood and well-treated also reduces the psychological impact of living with a bleeding disorder, which can be debilitating.

There are some signs of change, and we hope this report will accelerate the adoption of a new mindset within haemophilia centres and those who control their funding.

The new NHS service specification in England for bleeding disorder services, which is currently under consultation, includes far greater recognition of the needs of women and girls. In addition, the European Principles of Care for Women and Girls with Bleeding Disorders already provides a framework for equitable treatment. If these principles were realised across the NHS, significant improvements would follow.

The solutions are not easy or quick. Our work on this project has shown that the experiences of women and girls with bleeding disorders are so varied that it is impossible to clearly identify a small number of specific changes that would improve outcomes. Instead, this report sets out the wide cultural changes required alongside improved funding for haemophilia centres to ensure everyone can access the best treatment and care.

Women with bleeding disorders

Women make up over half of people with registered bleeding disorders in the UK but services are not tailored to suit their needs. Everyone with a diagnosed bleeding disorder should be treated at a haemophilia centre, but dedicated specialist care for women and girls is only available in a small number of centres so access to the best care is patchy.

Of the 30.4 million women in the UK, nearly 20,000 have a diagnosed bleeding disorder and make up over half of the National Haemophilia Database which records all people with a bleeding disorder in the UK.

We expect that there are additionally around 30,000-50,000 undiagnosed women and girls with a bleeding disorder and clinically relevant symptoms across the UK who could benefit from diagnosis and treatment.

While haemophilia is traditionally considered a male disorder, and in its severe and moderate forms it does still present predominantly in men, mild haemophilia does occur in women. Over 1000 women with haemophilia are registered in the National Haemophilia Database, making up over 10% of diagnosed people with haemophilia in the UK.

The most common bleeding disorder is von Willebrand disorder (VWD), which occurs equally in men and women, with higher diagnosis rates in women. Rarer factor deficiencies and platelet disorders account for over 40% of registered bleeding disorder diagnoses and are diagnosed disproportionately in women and girls.

Bleeding disorder care has traditionally focused on the needs of men and boys. Despite an ever-growing recognition of the needs of women and girls, there remains a gap in the level of treatment and care offered by some centres.

‘Many of the experiences described by women with bleeding disorders 20 years ago remain prevalent. Healthcare provision needs to change to offer them better treatment and support.’
Cinderella Study (2022)[1]

Particularly in haemophilia, mothers, daughters and sisters are often secondary patients to the man or boy with haemophilia. Family-wide care and diagnosis does not always take place and many are required to return to a GP for a personal referral. The Cinderella Study[1] demonstrated how women with the haemophilia gene have challenges getting a diagnosis, face a lack of awareness amongst clinicians, see poor communication from their centres and suffer stress and anxiety.

Within families there is often a normalisation of bleeding symptoms, for example comparing periods to other family members who may also have a bleeding disorder leading to higher bleeding tendencies being recognised late or not at all.

While this report focused on women and girls with bleeding disorders, it takes place in a context of wider challenges women and girls have in accessing care and getting the best outcomes in the NHS. The 2022 Women’s Health Strategy for England found that ‘there are disparities in women’s health across the country.’

Some findings in this report are specific to bleeding disorders and some are more widely applicable. Our intention is that there should be equity in access to care and treatment for all women and girls with a bleeding disorder.

‘51% of the population faces obstacles when it comes to getting the care they need. Although women in the UK on average live longer than men, women spend a significantly greater proportion of their lives in ill health and disability when compared with men.

Not enough focus is placed on women-specific issues like miscarriage or menopause, and women are under-represented when it comes to important clinical trials.

This has meant that not enough is known about conditions that only affect women, or about how conditions that affect both men and women impact them in different ways.’

Women’s Health Strategy for England (2022)

An introduction to bleeding disorders

The term ‘bleeding disorder’ covers a set of rare genetic diseases which affect the body’s ability to regulate blood clotting effectively. This is caused by a genetic defect which leads to a deficiency or dysfunction of certain cells or proteins in the blood.

Bleeding disorders include haemophilia A and B, von Willebrand disorder (VWD), also known as von Willebrand disease, rarer factor deficiencies and platelet disorders. These genetic conditions are rare in the general population, with just over 40,000 people in the UK registered as having a bleeding disorder, of which around a third require regular treatment.

Despite the relatively small number of patients, bleeding disorder treatment represents a significant cost to the NHS, and lifetime costs for people with severe bleeding disorders can easily run into millions of pounds.

As rare diseases, general healthcare professionals are often unaware of the implications that bleeding disorders can have, and even relatively minor injuries or treatments will require specialist attention if long-term damage is to be avoided.

If left untreated, or treated suboptimally, severe bleeding disorders can result in physical disability, and in extreme cases can be fatal. But if well managed, with the right treatment, many negative impacts of bleeding disorders can be mitigated and people with bleeding disorders can live well, although with slightly inhibited lives, into old age. All bleeding disorders can have a substantial impact on quality of life, particularly if poorly managed.

There are currently no cures for bleeding disorders, although treatment options continue to improve. There are a range of potential treatments, depending on the severity and nature of the bleeding disorder. These range from intravenous factor replacement therapies to tranexamic acid, taken in tablet form, which blocks the breakdown of clots and helps to control excessive bleeding.

New products include extended half-life treatments, which are intravenous factor replacement treatments that can stay in the blood stream for up to a week, purer or new recombinant (synthetic) clotting factor concentrates and innovative non-replacement therapies. Gene therapy is pointing the way towards a possible functional cure for some bleeding disorders.

Types of bleeding disorders

Bleeding disorders are conditions where the blood doesn’t clot properly. Most are inherited and are caused by either a blood clotting factor or platelets not working correctly, being reduced or missing altogether. Clotting factors are proteins in the blood that control bleeding.

Most bleeding disorders are caused by clotting factor disorders or deficiencies. These are factor I (one) [fibrinogen], factor II (two) [prothrombin], factor V (five), factor VII (seven), factor VIII (eight), factor IX (nine), factor X (ten), factor XI (eleven), factor XIII (thirteen) or von Willebrand factor (VWF).

Factor VIII deficiency is known as haemophilia A and factor IX deficiency is known as haemophilia B.

Platelets are small cells in the blood that clump together to start the process of forming a clot. When this doesn’t work properly you have a type of bleeding disorder called a platelet function disorder.

Some people have bleeding disorder of unknown cause (BDUC), this means they have an increased bleeding tendency and bleeding symptoms, but it has not been found to be caused by a specific factor deficiency or platelet disorder.

Treatment for bleeding disorders

There are many different types of treatments for bleeding disorders. The most appropriate one will depend on the type of bleeding disorder, its severity and the bleeding symptoms to be managed.

Factor concentrates are often seen as the ideal treatment for a bleeding disorder as it replaces the missing or faulty factor. Unfortunately factor concentrates are not available for all bleeding disorders and need to be frequently readministered. These treatments are given into a vein, usually as an injection but sometimes as a drip (an intravenous infusion). Depending on the bleeding disorder and how severe it is, factor concentrates may be given to prevent bleeding (prophylactic treatment) or only after a bleed.

Factors I, VII, VIII, IX, X, XI and XIII are available in replacement factors for bleeding disorders. They can all be made from human blood plasma – the straw-coloured liquid that carries the clotting factors. The plasma is treated during the process to make sure it cannot spread viruses.

For bleeding disorders involving factors VII, VIII, IX and XIII there are man-made factor (‘recombinant’) concentrates available. These are made in a laboratory.

There is another factor replacement treatment called prothrombin complex concentrate (PCC). This is also made from human plasma and contains a mixture of factors II, VII, IX and X, although not all PCC products contain all of these. It is used to treat deficiencies of factors II and X, and inherited combined deficiency of vitamin K dependent factors (VKCFD).

If there is no specific factor concentrate available for a condition fresh frozen plasma (FFP), which contains a wide range of coagulation factors, can be used. It is frequently used as treatment for factor V deficiency.

Cryoprecipitate is a product made from blood plasma. It contains factor I, factor VIII, VWF and FXIII that are important for blood clotting. It is more concentrated than FFP, so it can be given in smaller volumes through the drip.

Platelet disorders can be treated with platelet transfusions. Platelets are small blood cells, which form clots and can be extracted from donor blood. Platelet transfusions are given through a drip into a vein and looks like blood plasma. Some people may need HLA (Human Leucocyte Antigen) matched platelets to prevent side effects.

Desmopressin, also known as DDAVP, is a manufactured hormone that boosts factor VIII and VWF levels in people with mild haemophilia, some forms of VWD and will raise FVIII in combined factor V and VIII deficiency.

Tranexamic acid (TXA) is a drug that helps to stop clots breaking down. It can be used before minor dental or other surgery or to treat minor cuts, nosebleeds or heavy periods. It can be used alongside factor replacement for other bleeding symptoms. It comes either as a tablet or liquid to swallow or given as an injection into a vein.

Fibrin glue can be used to treat an injury, rather than the underlying bleeding disorder. It is mostly used on open bleeding such as a cut or wound.

Hormonal treatments such as the birth control pill or mirena coil can be used to help control heavy periods.

Safiya and Zarina's experience

Safiya is 16 years old and has severe factor V deficiency, a rare bleeding disorder that affects less than 100 people in the UK.

She was diagnosed as a child when she had a fall and banged her head. Her mother, Zarina, took her to hospital, but they were sent home. They were told by the hospital that her daughter was fine, but she wasn't. This was a frightening time as Safiya's health continued to worsen and they had to return to hospital. Finally, she was admitted and a week later they had a diagnosis.

As a child she was treated very carefully, she remembers having to be carried into school. She felt like a test subject as they didn't know how best to treat her.

As someone with a very rare bleeding disorder, she has a very limited number of treatment options. She has developed an inhibitor to plasma which has further limited how bleeds can be prevented and managed.

At times Safiya finds it a burden to have a rare condition which very few people understand and which restricts what she is able to do. She said: 'I don't want to have to explain myself so much, to go into every detail of my life. I have to limit myself in life to stay fit and healthy there are things I can't do. It feels like I am missing out.'

Her family has to spend so much time explaining her bleeding disorder. They feel doctors need more education and understanding in how to treat and care for her.

'It was awful in the beginning trying to be heard,' said Zarina. 'Doctors don't know what factor V deficiency is so when we go to A&E I have to tell them and teach them about what my daughter has.'

She still often has painful bumps and bleeds, her bleeding disorder isn't under control. What she really needs is to have better treatment options so she can have regular preventative treatment with a synthetic factor V product. She is worried that if she had a serious injury her life would be at risk.

"I have to limit myself in life... It feels like I am missing out."

Bleeding in women with bleeding disorders

A recent study[2] compared bleeding symptoms in women with the haemophilia gene to women without the haemophilia gene and found that over 70% had frequent bruising compared to less than 10% of the general population. This remained the case even when factor VIII levels were in the normal range.

While heavy menstrual bleeding (HMB) is not uncommon in the general population it is around twice as likely in women with bleeding disorders. After bruising and heavy menstrual bleeding the third most common symptom for women is mouth bleeds.[3]

The increased bleeding tendency in women with bleeding disorders can lead to serious bleeds which can be life-threatening. This is particularly likely to occur post-surgery or post-partum when women with bleeding disorders are particularly at risk of complications if undiagnosed or without an appropriate care plan.

In our focus groups and working groups many women mentioned the major impact of their bleeding disorder on work life, social life and educational opportunities. A bleeding disorder can also complicate people's sex lives and make intimacy more difficult.

In the UK cohort of the PIVOT-vWD Study (a cross-sectional, multi-country study co-developed by DHT.health, The Haemophilia Society, and key opinion leaders within the vWD community)[4] among those who had gastrointestinal (GI) or gum bleeds, women reported a higher average number of events in the last 12 months. A greater proportion of women also reported experiencing bruising during that time.

The impact of living with a bleeding disorder on women and girls is still not well understood. Better data on treatment and care outcomes could be collected to help us understand the level of unmet need.

Recommendation 1

People with bleeding disorders should have equitable access to good quality bleeding disorder care irrespective of sex and gender and regardless of where they live in the UK.

Recommendation 2

Funding should be provided to centres and the National Haemophilia Database to collect more patient relevant outcome data to better measure quality of life in women and girls with bleeding disorders and support more research on the lived experience of women and girls with a bleeding disorder.

Recommendation 3

Women and girls with bleeding disorders should be offered frequent monitoring for anaemia and ferritin levels with treatment and referral as required.

The UKHCDO (the UK haemophilia doctors' organisation) working group on women and girls recommends that additional information should be collected including data on demographics, referral and diagnosis, menstrual health, obstetric health, gynaecological health, iron status and treatment.[5]

A common impact of living with a bleeding disorder is iron deficiency anaemia (IDA) which was reported at a 25% higher rate in women compared to men in the PIVOT-vWD UK Study.

Women with heavy menstrual bleeding saw even higher rates of iron deficiency anaemia. Currently, iron deficiency is not being sufficiently well monitored for many women and girls with a bleeding disorder so that they can be effectively treated earlier to prevent the development of anaemia.

Due to the complexity of presentation and diagnoses in women and girls with bleeding disorders, clinical judgement of specialist clinicians should be relied upon in establishing the most appropriate care and treatment plan.

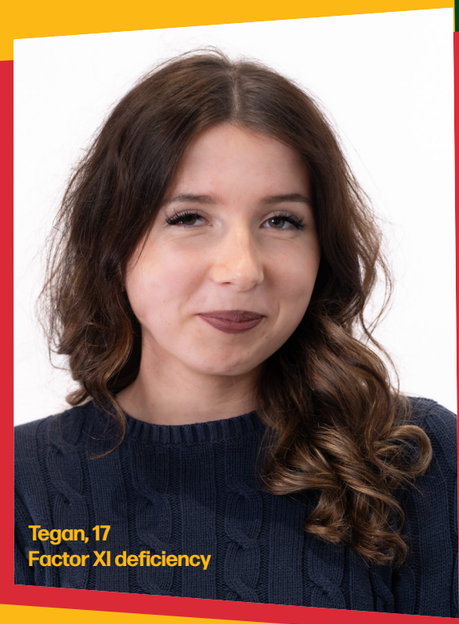
Tegan's experience

Tegan is 17 years old, she and her mother Nicola have factor XI deficiency. Her grandmother and great grandmother also had the condition.

Because her mother had a diagnosed bleeding disorder, she was transferred to a hospital linked to a bleeding disorder centre during pregnancy. A pregnancy and delivery plan was put in place. After Tegan was born however, they were told that they couldn't test her for a bleeding disorder until she was five years old as her factor levels may change.

She had a lot of bruises as a child and if she cut herself, it was hard to stop bleeding.

Tegan said: 'As a child I felt left out and ashamed of my bleeding disorder, my symptoms were dismissed as clumsiness.'



Tegan, 17
Factor XI deficiency

When she started her periods, they were very heavy. She also has occasional joint bleeds. The impact of her bleeding disorder has been that she was not able to do physical education at school and often could not go out with her friends.

‘Being a teenage girl with a bleeding disorder was a really isolating and upsetting experience. When I had my period, I didn’t want to go to school. It was really scary.’

In preparation for her first period, she spoke to her mother and was seeing her consultant regularly. But when it arrived unexpectedly while she was at school, her bleeding was so bad that she had to go home.

She began tracking her periods in a bleeding diary and at times experienced almost constant bleeding. There was little awareness in her school and that made it hard to prepare and respond when she was bleeding. She would take tranexamic acid to school, but this was not always well supported and sometimes she found it difficult to get the treatment when she needed it.

As she has got older, she feels that she understands her bleeding disorder better and is more able to advocate for herself, but she is afraid that if she goes to university and moves centres she will need to start again. As well as managing her periods she also has problems with her joints and is now waiting for surgery on her knees. Now that she is at an adult haemophilia centre she feels it is harder to get heard and to get referrals when she needs extra specialist support.

Tegan said: ‘Going to my centre, I felt like an outsider as the only girl in with a bunch of boys.’

Testing

To understand, diagnose and properly treat and care for people with bleeding disorders good and frequent access to testing is required.[6] The approach should be to test early and often. Then to test and test again as levels can change . Many of the tests are specialised and so women and girls with bleeding symptoms or a familial history of bleeding disorders need to be referred to a specialist bleeding disorder centre for these tests.

As well as testing for bleeding time and factor levels, genetic testing can indicate bleeding disorders not picked up through other tests. For many women tests may come back normal or near normal despite an increased bleeding tendency. This may be due to near normal levels still leading to clinically relevant bleeding symptoms in women because of their increased haemostatic challenges or because multiple mild bleeding disorders occurring together will create an increased bleeding tendency.

There are four main types of tests for bleeding disorders. These will start with bleeding assessment tools (BATs) that ask people questions about their bleeding history and score their bleeding tendency. These can be easily available self-assessments such as the Haemophilia Society’s online symptom checker (haemophilia.org.uk/checkyoursymptoms) or assessment tools that can be used by GPs in a primary care setting.

There are non-bleeding disorder specific tests such as the activated partial thromboplastin time aPTT which measures clotting time. These can be done by non-specialist clinicians but will not pick up all bleeding disorders, do not indicate what type of bleeding disorder someone has and may be normal despite an increased bleeding tendency and the person having a bleeding disorder.

Inherited bleeding disorders can also exist in the absence of abnormal test results. An increasing number of people are being diagnosed as having a bleeding disorder of unknown cause (BDUC). All women and girls with bleeding symptoms should be diagnosed and registered in the National Haemophilia Database.

More specific tests need to be conducted and interpreted in secondary care by specialist clinicians. This means that anyone suspected of having a bleeding disorder, anyone with bleeding disorders in their family and anyone with an increased bleeding tendency should be referred to a haemophilia centre.

These tests include factor level testing and analysis of platelets as well as genetic tests. Often a combination of these tests will be required to come to a clear diagnosis and prepare a treatment and care plan. Genetic testing should be more widely available and can become standard practice in diagnosis of bleeding disorders.

Guidelines from the UKHCDO[7] encourage genetic testing in symptomatic adults and children where a genetic test will improve care or aid in diagnosis. In practice it appears that an overly cautious approach is taken.

Even in people with normal or near-normal levels genetic testing will show the presence of bleeding disorder genes and may be indicative of an increased bleeding tendency. In our interviews and focus groups, many women complained of a lack of time taken to explain test results and what it might mean for their treatment and care.

Recommendation 4

Girls with a familial history of bleeding disorders or an increased bleeding tendency should have access to testing for factor levels, platelet aggregation and clotting screens from birth with tests repeated throughout childhood.

Recommendation 5

Where relevant for diagnosis or treatment genetic testing should be offered to girls with bleeding disorders and girls with a familial history of bleeding disorders as part of routine practice.

Recommendation 6

Improved referrals from primary care would be supported by development of a specific bleeding assessment tool for women and girls. Bleeding disorder clinicians and patient groups should work to develop guidelines for primary care in relation to use of BATs and appropriate referrals to specialist services.

Delays in diagnosis

Women and girls with bleeding disorders see long delays in diagnosis. On average, women will be diagnosed with a bleeding disorder 16 years later than men. It has been suggested that this is due to differences in the severity of bleeding disorders between men and women but this gap persists even if you control for bleeding disorder severity.[7]

This finding has been supported in other studies including the PIVOT-vWD UK Study which has found that the median age of diagnosis was 10 years later in women compared to men.

There are likely a number of factors that lead to this discrepancy. In our focus groups one mother described how her daughter's factor levels weren't tested but her son's were. In her case with a bleeding disorder, von Willebrand disorder (VWD), that occurs equally in women and men this suggests a misunderstanding in the sex and gender split in different bleeding disorders. From our project it seems that many clinicians think that VWD and the rarer bleeding disorders are also more likely to have clinically relevant symptoms in men and boys, when, as this report has laid out, the opposite is true.

Being rebuffed in their diagnosis journey can put women off seeking a diagnosis. In our project people told of the mental and physical challenges to build themselves up to see a doctor to discuss their bleeding symptoms. However, if they then get ignored and dismissed, the impact of their bleeding on their quality of life downplayed, they won't raise it again.

A survey by the Haemophilia Society of women who used the online symptom checker found that six months later of those whose symptom checker results suggested an increased bleeding tendency and gone to see their GP none had been able to get a referral to a specialist centre for bleeding disorders.

Project participants reported that even though women bleed every month, instead of their doctors trying to manage it they may be told to 'get on with it'. Some people talked about getting referrals for tests but in many cases, GPs were not doing the right tests or did not have the ability to ask for the right tests.

This led to them being told they definitely did not have a bleeding disorder when in many cases they did. They would like to see more honesty from clinicians about what they know and don't know and acknowledge mistakes when they happen.

In the PIVOT-vWD UK Study lower average satisfaction with primary care was reported in women compared to men.

The use of hormonal treatments for heavy menstrual bleeding or for contraception can lead to further delays in diagnosis by treating the symptoms but not leading to identification of the underlying bleeding disorder cause.

Val's experience

Val was 57 when she was diagnosed with type 2 von Willebrand disorder (VWD), despite showing symptoms of a bleeding disorder for more than 40 years.

From the onset of heavy periods at the age of 10, Val struggled with bleeding and with frequent bruising. As an adult, her bruising was so bad that her colleagues feared she was experiencing domestic abuse.

Val even underwent major surgery, including a hysterectomy at the age of 37, and still her bleeding disorder went undetected. It was when she was due to have surgery on a slipped disk in her neck that a consultant sent her for testing, having not been satisfied with the reasons behind her excessive bleeding.

After her diagnosis, Val's 35-year-old son, her grandson, sister and niece were all diagnosed with the genetic condition.

Val, 71
von Willebrand disorder

Val said 'Women with bleeding disorders are treated differently to men – they're ignored. Nobody listened to me for 50 years. After I was diagnosed, my mother's GP refused to refer her for tests because he said she was too old, so it 'wasn't worth it'. And that was the attitude.

'I nearly died on the operating table because I bled out while they were doing the hysterectomy. I went into shock and still nobody did anything to look at why or what my bloods were like.'

Val believes more questions need to be asked about women's bleeding with a far greater awareness about what 'normal' bleeding is. She is concerned that women are being put at risk because their bleeding is being treated without full investigations as to its underlying cause.

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Nicola, 51
Factor XI deficiency

‘Even medical professionals told me I couldn’t have haemophilia **because I’m a female**’

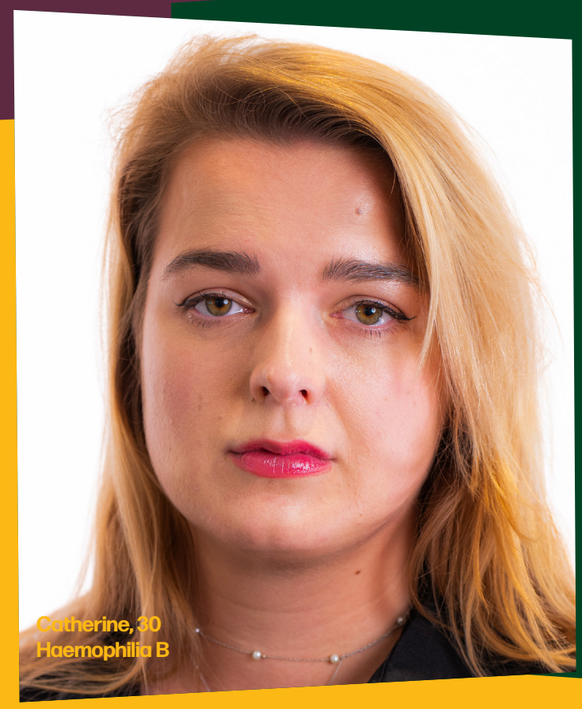

Imaan, 9
Glanzmann thrombasthenia

There are an estimated **50,000** women and girls with an undiagnosed bleeding disorder in the UK

On average, women are diagnosed with a bleeding disorder **16 years** later than men.


Hannah, 31
von Willebrand disorder

‘It would be nice to be **taken seriously**’


Catherine, 30
Haemophilia B

Continue the conversation at
haemophilia.org.uk/underserved-overlooked

Obstetrics and gynaecology

Women and girls with bleeding disorders need specialised obstetric and gynaecological care, delivered ideally through joint clinics with haematologists. Joint clinics are rare across the UK and there are only a small number of gynaecologists with a specialism in bleeding disorders.

Heavy menstrual bleeding is often the first symptom that women and girls with a bleeding disorder experience. UK guidelines for the gynaecological management of women and girls with bleeding disorders exist but the extent to which they can access those services varies wildly across the UK.

A draft report by the UKHCDO's Girls and Women with Bleeding Disorders Working Party[9], found that only eight out of the UK's 29 comprehensive care centres offered joint haematology and gynaecology clinics. Only 12 have a dedicated clinical lead for women and girls with bleeding disorders.

In smaller treatment centres, the figures are much lower. However, despite a lack of joint clinic services, two thirds had a named gynaecology consultant link with whom patient care could be directly discussed, which is considered good practice.

Joint clinics, like those at the Royal Free Hospital in North London and at Sheffield Haemophilia Centre show what best practice might look like. Fostering joint working and mutual respect between disciplines allow for gynaecologists to understand and share the latest things in their specialism while haematologists will be able to bring their expertise in bleeding disorders. They should work together to ensure the best outcomes.

This care needs personalisation but the system is overwhelmed and there is not sufficient capacity to provide joined-up care.

Options for management of heavy menstrual bleeding will depend on the individual's current or future wishes to have children but will include[10] :

- Monitoring with replacement iron therapy
- Tranexamic acid
- Hormonal therapy including Mirena coil/Jaydess coil
- DDAVP or Replacement Clotting Factor Therapy
- Pain relief/anti-inflammatory drugs
- Surgery

Recommendation 7

Hospital trusts should fund more gynaecologists and facilitate improved links between haemophilia centres and gynaecology services. All regional bleeding disorder networks should include gynaecologists in the multidisciplinary team and haemophilia centres should run joint bleeding disorders/ gynaecology clinics for patients that need them.

Recommendation 8

Haemophilia centres, working with patient groups should ensure girls with bleeding disorders have better access to information on what is normal menstrual bleeding and what their treatment options are. Haemophilia centres should ensure menstrual bleeding management plans are in place before a girl with a bleeding disorder has her first period.

Many women and girls normalise their bleeding symptoms. People most often talk to their mum, aunt or sister about periods and with bleeding disorders as conditions that often run in the family this can make it seem normal to have heavy periods which can last longer than a week, having to get up in the night and use multiple products. Tools such as knowyourflow.ie can help women and girls to recognise if their periods are heavier than normal which can be sign of a bleeding disorder.

Preventative treatment (prophylaxis)

Factor prophylaxis is the standard of care for managing moderate and severe haemophilia but appears to be underused in women and girls with other bleeding disorders, particularly von Willebrand disorder (VWD).

In the PIVOT-vWD UK Study a higher proportion of men were on von Willebrand factor (VWF) prophylaxis compared to women. This finding was reflected in the Haemophilia Society's focus groups including one example of a woman with VWD whose son with the same condition has been offered factor prophylaxis while her daughter, despite bleeding complications, has not.

Women with VWD often experience heavy menstrual bleeding (HMB), leading to complications like iron deficiency anaemia (IDA) and decreased quality of life. Despite guidelines recommending long-term prophylaxis for those with severe HMB, it remains under-utilised.

In the Rates and Predictors of Prophylaxis in Women with Von Willebrand Disease and Heavy Menstrual Bleeding Study[11] a retrospective cohort of 168 women diagnosed with VWD, showed that 86% experienced HMB, commonly managed with tranexamic acid (TXA) and hormonal therapy, while only 8% received VWD prophylaxis. Surgical interventions for HMB were frequent, including hysterectomies and endometrial ablations. Our focus groups showed that some women were being offered hysterectomies when other options should have been available and hysterectomies could have been avoided if HMB was managed better earlier.

Surprisingly prophylaxis rates were similar for women with severe and non-severe HMB in the study which concluded that while there was a notable uptake of DDAVP prophylaxis, VWF prophylaxis was significantly under-utilised. The lack of demonstrated impact of prophylactic therapies on severe HMB may have been a factor. The findings of that study suggest a need to better understand barriers to prophylaxis use and encourage earlier intervention to reduce bleeding complications and reliance on intrusive therapies.

As recommended by the Infected Blood Inquiry's report in 2024, recombinant factor products should be offered in preference to plasma-derived products where clinically appropriate.

Recommendation 9

Women and girls with bleeding disorders should receive better information on access to and use of tranexamic acid, and this should be included by centres in care plans as standard. When clinically indicated, women and girls should have equitable access to factor products and non-factor therapies, including as prophylaxis.

Recommendation 10

Funding should be sought for studies on the benefits of prophylaxis with factor products and other agents such as desmopressin in women and girls, particularly in management of heavy menstrual bleeding.

Jenny's experience

Jenny was diagnosed with type 2M von Willebrand disorder (VWD) at birth. Her late grandmother had the condition, as does her father, older brother, auntie and nephew.

Jenny, 31, is treated on demand, mainly using tranexamic acid. Her haemophilia centre in London treats her intravenously with Wilate, a plasma-based factor replacement therapy, if needed. In 2024 she became the first woman in Europe to be dosed on a clinical trial for VGA0349 made by Vega Therapeutics, which could offer a prophylactic treatment option for VWD.

VGA0349 is a human monoclonal immunoglobulin, also called an antibody. The drug is an antibody directed against a specific protein in the blood called Protein S that plays a key role in regulating bleeding tendency.

Jenny, 31
von Willebrand disorder

The trial is in its early stages, but offers hope to Jenny and her family that a more flexible treatment option may be on the horizon which could change the way they live their lives.

Jenny said: 'It was really important for me that I took part in this trial and I hope others will too, because having a prophylaxis treatment option would really open up new opportunities.

"Men with severe haemophilia who have access to prophylaxis can have a relatively normal life. They can do most sports and get tattoos and piercings. I don't have the treatment cover to do those things, so my lack of treatment options limits what I can do in life."

Jenny has struggled mentally and physically with her bleeding disorder, particularly with its visible signs, such as severe bruising. She traces this back to primary school when a classmate announced in the lunch hall: 'my mummy says her parents are beating her up'.

Jenny said: 'My parents were more upset than I was, but it did make me aware that people were speculating about me and there was a level of stigma.'

For many years Jenny would wear thick tights throughout summer to hide her bruising and avoided sports she enjoyed, such as swimming. After counselling, she was able to confront her complicated feelings of shame and self-consciousness around her bleeding disorder.

"'Psychological support was really important in helping me realise that the most important thing is that I can cope with my bleeding disorder and feel mentally strong. It doesn't matter what other people think. Having a bleeding disorder goes deeper than just physical symptoms and I think everyone would benefit from being able to talk about the psychological impact it has on their lives.'

Pregnancy and childbirth

Pregnancy and childbirth can be particularly challenging times for women with a bleeding disorder. Women with bleeding disorders are at increased risk of bleeding during pregnancy and prolonged or heavy bleeding during and after childbirth is common.

Bleeding disorders are not known to affect fertility but some, notably fibrinogen deficiency and factor XIII deficiency can increase the risk of miscarriage. For some bleeding disorders such as haemophilia A, factor levels can rise significantly during pregnancy while for others such as haemophilia B they do not. However, these rises if they occur, may not be sufficient to prevent bleeding given the nature of bleeding challenges presented during childbirth.

As well as specialised care more research is required into impact of bleeding disorders on fertility.

As genetic conditions there is also the risk of bleeding in the child during childbirth which can be managed through an effective childbirth plan and for some bleeding disorders genetic testing of embryos or sex testing can be offered to understand and plan for this.

In our focus groups and interviews, many women cited a lack of support and understanding when they wanted to get pregnant. There may be a need for more education for GPs to enable them to help planning in advance of pregnancy including use of progesterone in women with bleeding disorders.

World Federation of Hemophilia guidelines[13] recommend testing for people with haemophilia in order to establish if the women has the haemophilia gene and for testing during pregnancy to establish if the gene has been passed to their child if the child is boy. These guidelines could go further to make recommendations on testing in advance of the birth of a girl with the haemophilia gene.

Recommendation 11

Haemophilia centres should provide women with bleeding disorders with pre-conception genetic counselling and consultation to create a comprehensive management plan for pregnancy with all treatment and care options during pregnancy, childbirth and post-partum.

Menopause

Women with bleeding disorders need support in advance of and during the menopause.

There can be an assumption among health professionals that menopause reduces the impact of bleeding disorders on a women's quality of life but instead this can be a particularly problematic time. It can lead to increased physical and psychological needs which should be discussed and addressed.

Challenges in the perimenopause can include un-anticipated periods, stomach cramps and continued bruising. These need treatment and care and may not be resolved until the post-menopause period.

Additional factors that stigma and worry may lead to women not sharing their issues and concerns with professionals, partners and family.

Case studies presented by Christina Burgess of the Haemophilia and Bleeding Disorders Counselling Association (HBDCA) showed that there is a psychological impact of menopause including lack of confidence and a reduced sense of place in the world.

Menopause can impact on intimacy and relationships. These impacts are often not given sufficient consideration by healthcare professionals and centres. There needs to be greater understanding of the menopause by the multidisciplinary team and better tailored care and psychological support for women with bleeding disorders is required.

We need better information for healthcare professionals on the impact of the perimenopause and menopause on women with bleeding disorders. There are opportunities for educational workshops to better understand women's needs and give them the confidence to engage with women during the menopause, understand their challenges and offer better care.

Diagnosis matters at any age, if women have an increased bleeding tendency or a genetic heritage of bleeding disorders, they should be offered testing to establish a diagnosis regardless of age.

Recommendation 12

Haemophilia centres should improve the pathway for care for women with bleeding disorders during menopause through specialised clinics and improved internal referrals.

Louise's experience

Louise was first diagnosed with a bleeding disorder at the start of the menopause.

She had a history of longer periods but had not had any issues in major surgery although she did have bleeding after a dental surgery, which was severe enough for a blood transfusion to be discussed.

At 45 years old she had inflammation and was sent to rheumatology. She was initially treated with methotrexate for inflammatory arthritis, a powerful drug with serious side effects. After taking only two doses, Louise experienced bruising around her waist and bra area and prolonged bleeding from a cut.


Louise, 60
Delta platelet storage pool disorder

Louise was referred to haematology by her GP after a prolonged bleeding test and attended the department for two years. She was told there were no issues but had to keep returning for further appointments. A change of personnel at the hospital meant there was a different view and Louise was sent back to her GP asking for a referral to a haemophilia centre. After the centre did more specialised tests, a diagnosis was made.

She now knows she has delta platelet storage pool disorder. If she cuts herself, she has to be treated or care for the wound carefully. She takes particular care of her eyes which bruise very easily. She has to liaise with her bleeding disorder treatment centre regarding any medical procedures to ensure she has cover and that the correct protocols are followed. She always keeps tranexamic acid (TXA) with her but doesn't have many good treatment options.

The TXA does work for minor bleeds, but it gives headaches and makes her feel sick. If there is serious bleeding, she can have platelet transfusions. In the past this led to allergic reactions which are a serious complication. These days they should be 'matched', and she is given steroids and antihistamines to try and prevent side effects.

She does not expect anyone to know or understand her condition as it is very rare. But she wants to be taken seriously when she goes to hospital or needs care; She feels there is a lack of understanding of the causes and bleeding tendency in non-haemophilia bleeding disorders but hopes her experiences and sharing her story can help others to be diagnosed earlier in life.

Pathways of care

A large cause of the challenges women and girls with bleeding disorders face is getting access to the pathways of care and staying in them. Short annual appointments can result in a lack of continuity of care and little access to the full comprehensive care team.

Most bleeding disorder care needs input from two or more disciplines. This could be an obstetrician and a haematologist or joint surgeon and a haematologist to fully understand the treatment and care required.

There are no linkages to other systems across the NHS so GPs can't see records held by hospitals, hospitals can't see other hospitals and A&Es don't have the full records of other hospitals.

Many participants in our focus groups wanted more contact with their centre. They would like to see visits to centres at least annually. Others however, want their bleeding disorder to be considered and understood only when relevant. This will depend on the stability of their treatment and care plan.

Good centres have dedicated nurses for triage with a 24-hour turn-around for all people with bleeding disorders. However, this requires that a care plan is in place. People can then always get a response and be treated in centre if required.

Some centres have been trialling patient-initiated follow-up. This could be a good model to ensure people have appointments and consideration of their bleeding disorder when they need it most without putting the additional strain on centres to review all patients if their bleeding disorder is well-managed. One challenge to this model will be ensuring less-engaged patients still have access to good care.

Recommendation 13

Annual appointments may not be sufficient to ensure continuity of care for women and girls with bleeding disorders and complex needs or bleeding that is not well managed. Trusts should provide sufficient resources to haemophilia centres to allow for more frequent appointments as required to effectively manage their patients.

Recommendation 14

Patient groups should develop further resources to assist women and girls with bleeding disorders or suspected bleeding disorders in understanding their rights in access to pathways for treatment and care.

Peta's experience

Peta was diagnosed with a bleeding disorder of unknown cause (BDUC) in her late teens after more than four years of investigation.

Although low factor levels were found following an operation to remove her tonsils at the age of 14, Peta's consultant told her that 'women don't get haemophilia' so her bleeding must be due to 'something else'.

Peta said: 'This was in 2014, so it wasn't long enough ago that it was an acceptable thing to say. That was a realisation moment for me that I was going to have an uphill battle to be believed and taken seriously.'

Peta's bleeding disorder care started as an adult and her experience has been mixed. Appointments with her consultant were unproductive until she was put into a joint gynaecology and haematology clinic which was 'lifechanging'. Peta said: 'I suddenly felt like the questions and concerns I had were listened to and addressed.'

She sees her consultant once a year, as her bleeding is largely under control, but is concerned that multiple requests for a family planning 'game plan' have been ignored. In addition to annual appointments, Peta would like to be able to communicate with her centre if problems arise.

'I've heard from men who have had ad hoc bleeding issues who have no difficulty getting help from their centres - however when I had concerns about a long and heavy period, I was told that there was nothing the centre could do.'

'I think the first objective in the shift to optimal care is an acknowledgment that while periods are regular occurrences for women with bleeding disorders, this doesn't mean that they're manageable or the same every month, and care is warranted and deserved for something not feeling quite right.'

Comprehensive Care

The care and treatment that people with bleeding disorders should receive at their haemophilia centre is determined in England by the NHS England service specification for haemophilia and related bleeding disorders (adults and children).[13]

The current service specification is more than 10 years old and is about to be replaced by a new version, currently under consultation. This puts greater emphasis on providing psychological support, access to physiotherapy and social care. It also includes far greater recognition of the needs of women and girls with bleeding disorders, particularly access to obstetricians and gynaecologists. It is vital that when the new service specification is implemented, pressure is put on trusts to provide appropriate resources to haemophilia centres to meet the service levels required.

The Department of Health and Social Care (DHSC) must hold trusts accountable for delivering these services in full. Although this applies to England, we expect the new service specification to be reviewed by commissioning organisations in the devolved nations.

In order to achieve the best outcomes, as well as access to effective treatment, people with bleeding disorders also need comprehensive care delivered by a full multidisciplinary team. The core members of that team, as laid out in the World Federation of Hemophilia guidelines for the management of haemophilia[14] include consultants, specialist nurses, musculoskeletal specialists, laboratory technicians and psycho-social professionals.

In our interviews and focus groups many women were clear that often the hardest part of living with a bleeding disorder was managing the psycho-social impact. In the last audit of haemophilia centres in the UK only three had a dedicated psychologist in the multidisciplinary team. Following the Infected Blood Inquiry, which investigated the contaminated blood scandal of the 1970s and 80s, more centres are providing psycho-social support. England, Wales, Northern Ireland and Scotland all offer dedicated bespoke psychological support for those infected and affected. This service, however, is not open to everyone with a bleeding disorder, except in Scotland.

People with bleeding disorders may suffer bleeding into joints and often develop joint damage over time. Specialist bleeding disorder physiotherapy supports rehabilitation following an injury or acute bleed. It also encourages participation in activities and sports which can in turn reduce the risk of injury, pain and joint damage.

Musculoskeletal health is important for women and girls with bleeding disorders who may have lower bone density and be at greater risk of fractures.

Recommendation 15

Trusts should provide funding for centres to offera psycho-social support to all women and girls with bleeding disorders.

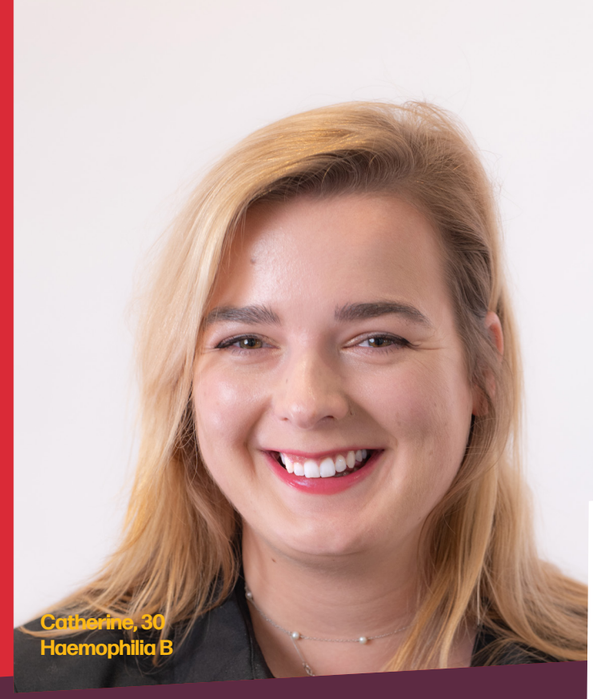
Recommendation 16

Many women and girls with bleeding disorders require physiotherapy to maintain joint health and take part in sport and other activities. This should be available as standard at all haemophilia centres.

Catherine's experience

Catherine Heylings estimates that she had more than 100 hospital visits before she was diagnosed with haemophilia B at the age of 12.

Despite a family history of the condition and experiencing frequent nosebleeds and bruising, she and her family struggled to get a diagnosis. A breakthrough came after her school reported her symptoms to a GP and she was referred to a paediatrician who suspected a bleeding disorder.



Catherine, 30
Haemophilia B

The slow diagnosis had a big impact on Catherine's education, which was frequently disrupted. Her care since diagnosis has been mixed. Now aged 30, she still experiences about three nosebleeds a week which have a big impact on her quality of life which, she believes, is not fully recognised by her medical team. She has permanent nasal damage from frequent cauterisation and would have liked a more holistic treatment and care plan. She also takes iron tablets for iron deficiency anaemia which results from her heavy menstrual bleeding.

Developing a satisfactory care plan as an adult has been difficult, with little sharing of information between centres. At her first UK adult centre she was initially rejected for care because she was 'just a carrier'. In fact, Catherine has mild/moderate haemophilia B, with her factor levels fluctuating between 3% and 20% since diagnosis. Catherine changed doctor multiple times until she found one she says was willing to listen and to support her quality-of-life aspirations.

When she moved to her current centre in the North West of England, she had to start completely afresh as no records were transferred from her previous centres. Here she was always referred to as a 'carrier' and says she was not offered much support, except in relation to pregnancy.

Her annual reviews consist of a five-minute phone call. Catherine says she was told this was because care was only offered to 'actual haemophiliacs'.

'It would nice to be taken seriously'

she said, noting that constantly being told that she was exaggerating her nose bleeds has a major an impact on her mental and physical health.

She now sees a private haemophilia doctor but needs to go through the NHS for treatment. She struggles to be treated as a person with a bleeding disorder.

Catherine feels that the focus should be on prevention rather than simply treating symptoms as they occur. She wishes she had a proactive care plan with comprehensive care. She needs access to physiotherapy, but this is not offered to her by her centre and once again and has to go private. She has also repeatedly asked for a referral to a specialist gynaecologist, but this is not available at her centre. It is clear that variation in care across the UK is vast. Different disciplines don't talk to each other and she has to return to her GP to get referred to a different specialism.

Importance of naming of centres and dedicated women's clinics

Currently most specialist centres that care and treat women and girls with bleeding disorders are known as haemophilia centres. This is seen as off-putting by many people with bleeding disorders if they have VWD, one of the rarer bleeding disorders or bleeding disorder of unknown cause.

The experiences of many women and girls with a bleeding disorder is that the naming of centres is reflected in their focus which prioritises their severe haemophilia patients to the detriment of other patients. We understand that in many centres as much as 90% of resources and staff time is spent on care and treatment of people with severe haemophilia leaving little capacity to provide services for people with other bleeding disorders who are disproportionately women and girls.

Centres can become the place where men and boys with severe haemophilia come for all their healthcare needs beyond simply their bleeding disorder. One participant in our focus groups told the example of male footballer with haemophilia visiting and being treated in their centre for a groin strain unrelated to their haemophilia.

Services are not set up to manage women and girls with bleeding disorders as the vast majority of severe bleeding disorders seen in clinic are men. But that doesn't represent the wider need for bleeding disorder care.

All centres should have dedicated women's clinics and should seek to name and promote themselves in way that ensures women and girls with bleeding disorders and all people with rarer bleeding disorders feel they are able to get the care and treatment they need.

Recommendation 17

There should be an evolution towards the renaming of haemophilia centres to bleeding disorder centres to reflect the wide range of bleeding disorders managed and treated there. Specialist haemophilia doctors and nurses should usually be called bleeding disorder doctors and nurses.

Emergency care

When someone with a bleeding disorder has an accident or emergency and ends up with an unplanned visit to hospital, the health system is designed to deal with the acute cause of their need for a hospital visit.

However, this is not always the most urgent thing for a person with a bleeding disorder.

In our focus groups and engagement with our members people often talk about problems in having their bleeding disorder recognised and acted on in emergency situations. This can lead to delays in accessing treatment in A&E which can lead to complications from poorly managed bleeding and the need for more frequent trips to A&E and longer and more frequent hospital admissions.

One participant in this project told of how at a local hospital they planned to start surgery on an abscess that her daughter had without consulting their bleeding disorder centre. Worried, the mother contacted their centre but she was confronted by the local hospital doctor who was angry that she gone behind his back which he felt undermined his medical opinion. Later her daughter needed to be transferred to the hospital where her centre was but no ambulance could be provided and they had to drive themselves.

Women and girls with bleeding disorders often must fight to have their conditions recognised by staff in A&E and for them to consult with their bleeding disorder centre in a timely manner to ensure the best care and treatment.

Best practice is to ensure that A&E have access to the full medical records of people with bleeding disorders, regardless of which hospital they present at in the UK. The input of a haematologist should always be sought in the management and treatment of person with a bleeding disorder.

Recommendation 18

All hospitals should be able to treat women and girls with bleeding disorders in acute situations, with appropriate support from haemophilia centres

Recommendation 19

Treatment and care records for people with bleeding disorders should be available to patients and to treating clinicians in all settings.

Working towards higher and consistent standards of care

A framework already exists for the standards and principles required for equitable treatment for women and girls with bleeding disorders called the European Principles of Care for Women and Girls with Bleeding Disorders.[15]

These principles were developed by a multidisciplinary working group composed of the Committee on Women and Bleeding Disorders of the European Association for Haemophilia and Allied Disorders (EAHAD) and members of the European Haemophilia Consortium's Women and Bleeding Disorders Committee. They offer a framework to guide haemophilia centres in providing equitable care for all women and girls with bleeding disorders, both in their own services and in other healthcare settings.

Implementation of these principles aims to improve the health, wellbeing and quality of life for women and girls with bleeding disorders, along with equitable access and quality of care for all individuals with bleeding disorders, irrespective of gender.

The 10 principles of care listed below serve as a benchmark for diagnosis and comprehensive multidisciplinary management of women and girls with bleeding disorders and improve awareness of their unique challenges.

If these principles were fully realised across the NHS it would lead to big improvements in experiences of care and treatment as well as outcomes for women and girls with bleeding disorders.

Principles of care

- Equitable access and quality of care for all individuals with bleeding disorders, irrespective of gender
- Timely and accurate diagnosis of bleeding disorders in women and girls
- Awareness of the additional challenges faced by WGBD throughout life
- Comprehensive care of bleeding disorders requires a family-centred approach which includes WGBD
- Inclusion of a dedicated obstetrician and gynaecologist in the multidisciplinary team
- Education of WGBD and their families regarding the menstrual cycle and management
- Early recognition and optimal management of heavy menstrual bleeding
- Provision of preconception counselling and access to prenatal diagnostics
- Provision of a patient-centred comprehensive management plan throughout pregnancy and the post partum period
- Involvement of WGBD in registries, clinical research and innovation

Recommendations

General

1. People with bleeding disorders should have equitable access to good quality bleeding disorder care irrespective of sex and gender and regardless of where they live in the UK.
2. Funding should be provided to centres and the National Haemophilia Database to collect more patient relevant outcome data to better measure quality of life in women and girls with bleeding disorders and support more research on the lived experience of women and girls with a bleeding disorder.
3. Women and girls with bleeding disorders should be offered frequent monitoring for anaemia and ferritin levels with treatment and referral as required.

Testing and diagnosis

4. Girls with a familial history of bleeding disorders or an increased bleeding tendency should have access to testing for factor levels, platelet aggregation and clotting screens from birth with tests repeated throughout childhood.
5. Where relevant for diagnosis or treatment, genetic testing should be offered to girls with bleeding disorders and girls with a familial history of bleeding disorders as part of routine practice.
6. Improved referrals from primary care would be supported by development of a specific bleeding assessment tool for women and girls. Bleeding disorder clinicians and patient groups should work to develop guidelines for primary care in relation to use of BATs and appropriate referrals to specialist services.

Obstetrics and gynaecology

7. Hospital trusts should fund more gynaecologists and facilitate improved links between haemophilia centres and gynaecology services. All regional bleeding disorder networks should include gynaecologists in the multidisciplinary team and haemophilia centres should run joint bleeding disorders/gynaecology clinics for patients that need them.
8. Haemophilia centres, working with patient groups should ensure girls with bleeding disorders have better access to information on what is normal menstrual bleeding and what their treatment options are. Haemophilia centres should ensure menstrual bleeding management plans are in place before a girl with a bleeding disorder has her first period.
9. Women and girls with bleeding disorders should receive better information on access to and use of tranexamic acid, and this should be included by centres in care plans as standard. When clinically indicated, women and girls should have equitable access to factor products and non-factor therapies, including as prophylaxis.
10. Funding should be sought for studies on the benefits of prophylaxis with factor products and other agents such as desmopressin in women and girls, particularly in management of heavy menstrual bleeding.

11. Haemophilia centres should provide women with bleeding disorders with pre-conception genetic counselling and consultation to create a comprehensive management plan for pregnancy with all treatment and care options during pregnancy, childbirth and post-partum.
12. Haemophilia centres should improve the pathway for care for women with bleeding disorders during menopause through specialised clinics and improved internal referrals.

Treatment and care plans

13. Annual appointments may not be sufficient to ensure continuity of care for women and girls with bleeding disorders and complex needs or bleeding that is not well managed. Trusts should provide sufficient resources to haemophilia centres to allow for more frequent appointments as required to effectively manage their patients.
14. Trusts should provide funding for centres to offer psycho-social support to all women and girls with bleeding disorders.
15. Many women and girls with bleeding disorders require physiotherapy to maintain joint health and take part in sport and other activities. This should be available as standard at all haemophilia centres.
16. Patient groups should develop further resources to assist women and girls with bleeding disorders or suspected bleeding disorders in understanding their rights in access to pathways for treatment and care.
17. There should be an evolution towards the renaming of haemophilia centres to bleeding disorder centres to reflect the wide range of bleeding disorders managed and treated there. Specialist haemophilia doctors and nurses should usually be called bleeding disorder doctors and nurses.
18. All hospitals should be able to treat women and girls with bleeding disorders in acute situations, with appropriate support from haemophilia centres.
19. Treatment and care records for people with bleeding disorders should be available to patients and to treating clinicians in all settings.

Statement on territorial extent and devolution of healthcare

The Haemophilia Society is a UK-wide charity with members across all parts of the UK. The recommendations are written as far as possible to apply equally to all people with bleeding disorders no matter where they live in the UK.

When we say "the NHS" in this report we mean collectively the four health systems, the NHS in England, the NHS in Scotland, the NHS in Wales and Health and Social Care Northern Ireland. When we mean one of them specifically, we will say so. Similarly, when we are talking about guidelines, standards, and commissioning these will often be the responsibility of NICE and NHS England (NHSE) in England, the Scottish Medicines Consortium (SMC) and NHS Scotland in Scotland, the Welsh Health Specialised Services Committee (now part of the NHS Wales Joint Commissioning Committee) and NHS Wales in Wales and the Health and Social Care (HSC) Board in Northern Ireland. In practice most new treatments and care standards for people with bleeding disorders are introduced across the UK but there are often differences in timings and rate of adoption.

Statement on sex and gender

Throughout this report we use the phrase Women and Girls with Bleeding Disorders (WGBDs) to describe people who are the focus of the report. As this report talks about genetics and genetic testing, we mean this phrase to mean people assigned female at birth, who live and identify as a woman or a girl and who will usually have XX chromosomes.

Transmen with bleeding disorders and other people who menstruate or have the potential to menstruate but do not identify as a woman or a girl will also benefit from many of the recommendations of this report.

Some of the recommendations and experiences shared will also be relevant to transwomen and non-binary people with bleeding disorders and their experiences of engaging with the health systems in the UK.

Statement on women and girls with the haemophilia gene

Haemophilia has historically been seen as a male disease with women described as "carriers". When they have low factor levels clinically relevant bleeding symptoms they have been referred to as "symptomatic carriers" It has become accepted practice to categorise women and girls with low factor VIII or IX levels in the same way as men and boys, so that women with levels below 40 will have mild haemophilia. Similarly, women with levels below 5 now have moderate or severe haemophilia. Collectively they are described as women and girls with haemophilia.

There is no clear convention on how to describe women with levels above 40 who carry the haemophilia gene. In publications and practice they are often called "haemophilia carriers". In this report we use the term women and girls who have the haemophilia gene to describe all these women and girls whether or not they have bleeding symptoms and will use women/girls with (mild/moderate/severe) haemophilia or women and girls with bleeding symptoms/increased bleeding tendency as appropriate when we mean a subset of them.

Acknowledgements and methods

This report could not have been produced without the involvement of our members, women and girls living with bleeding disorders and their families as well as the wider bleeding disorder community involving clinicians, researchers and expert patients.

We would like to thank all the individuals who shared their stories, many of which were challenging and difficult.

We worked hard to understand the lived experience of all women and girls with bleeding disorders, including ethnic minorities, people in rural versus urban parts of the UK. The stories and findings in this report cover a range of educational and socio-economic backgrounds. We looked at people with a history of bleeding disorders in their family and people where bleeding disorders were new to their family.

We hope it will start conversations between women with bleeding disorders and in every haemophilia centre in the UK, resulting in profound and enduring improvements to treatment and care. It is also important to us that this work helps us reach and advocate for more people from diverse backgrounds and experiences, particularly those less able to advocate or involve themselves in their care and access the full range of treatment options.

We would like to thank the clinician groups in the UK including the Haemophilia Nurses Association (HNA), the UK Haemophilia Centres Doctors Organisation (UKHCDO) and groups and individuals representing other parts of the multidisciplinary team (MDT) including obstetricians, gynaecologists, psychologists and physiotherapists.

The Haemophilia Society regularly speaks to our members by phone and email and in person at our events. We also ran smaller and larger focus groups at our Talking Red and Big Get-Together conferences to produce the themes and stories discussed in this report.

The report and its recommendations were reviewed and discussed by our Women's Working Group and Rare and Bleeding Disorders of Unknown Cause (BDUC) Working Group. We appreciate all those who give up their time to contribute to the Haemophilia Society's work and keep us focused on the needs of the communities we represent.

All photographs in this report are of women and girls with a bleeding disorder or women and girls who are related to someone with a bleeding disorder. They were taken at events, such as Talking Red Live, our event for women and girls with a bleeding disorder, our Big Get-Together annual conference and Youth Camp. We are grateful to Imaan, Safiya, Nicola, Tegan, Catherine, Hannah and Val, who all live with bleeding disorders, for attending a special photo shoot to help publicise this report.

Report working group

This work was led by The SACRed Project Steering group:

Catherine Heylings

A Senior Consultant in Healthcare and Life Sciences at IBM, Catherine works on digital transformation projects for NHS and pharma clients, specialising in AI, data, and workflow optimisation. She was diagnosed with mild/moderate haemophilia B at 12, after years of misdiagnosis. She now advocates for holistic, proactive care and greater awareness of women with bleeding disorders.

Jo Traunter

Jo is a Doctor of Education and Early Childhood, working as a lecturer and researcher at the University of Hull in East Yorkshire, where she is employed as Programmes Lead for Education, Childhood and Youth Studies. After struggling with the symptoms of a bleeding disorder all her life, Jo was diagnosed with Type 2 Von Willebrand Disease (VWD) 20 years ago. Jo has three children, two of whom also have the condition. She is a trustee of the Haemophilia Society.

Peta Dixon

Peta is a business development professional for a large global defence firm. She has a mild unclassified bleeding disorder that was diagnosed at 18. Peta is a Young Ambassador and trustee of the Haemophilia Society and is passionate about raising awareness about bleeding disorders. She has taken part in a number of tough physical challenges while volunteering at the Haemophilia Society to raise awareness about the importance of participating in sport.

Sonia O'Hara

Sonia, a former trustee of the Haemophilia Society, is a senior real-world evidence manager specialising in genetic conditions. With lived experience- her husband has haemophilia and her daughter has inherited the condition – she has observed the many outcomes of what it is to live with a bleeding disorder and navigate its management. Sonia has actively campaigned for improved treatments and equitable access to care for all affected, advocating for fairness regardless of location, age, or sex.

Natalie Lawson

Natalie is a Bleeding Disorder Specialist Nurse at Birmingham Children's Hospital and a trustee of the Haemophilia Society. She qualified as a paediatric nurse in 1992, training at Great Ormond Street Hospital, and has worked at Birmingham since 1997. After many years working in surgery, she moved to haematology in 2000, and specifically to haemophilia and bleeding disorders 10 years ago.

Jess McLean (Page)

Jess worked as a primary school teacher and was an advocate for women and girls with a bleeding disorder. Diagnosed with haemophilia A and von Willebrand disorder, Jess became a Young Ambassador for the Haemophilia Society in 2018. She was a mentor for girls with a bleeding disorder and addressed international conferences about the importance of being empowered to advocate for the right care. During the writing of this report Jess was diagnosed with acute myeloid leukaemia and died aged 29 in 2024.

About this report

We believe outcomes and standards of care could and should be better which is why in 2023 we began work on this report to improve access to treatment and care for women and girls with bleeding disorders across the UK.

Initially christened the SACRed Project (created using amalgamation of standards and care and Talking Red), this work represents a step towards achieving that aim.

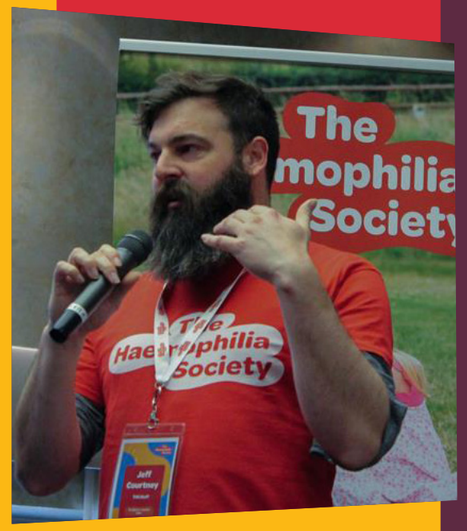
The SACRed project was a two-year study that used existing research, submitted evidence, focus groups, surveys and centre visits to map the current care landscape for women and girls and set out ways in which it can be improved. We ran a call for evidence to collect data, stories and studies we needed to inform this work. We are took evidence from women and girls with bleeding disorders, their families, healthcare professionals, NHS and government organisations and any other interested stakeholders to help inform this work.

About the authors

Jeff Courtney, Project Lead, Policy and Public Affairs Manager

Jeff is responsible for leading the charity's campaigning and influencing activity. He developed and delivers a policy and public affairs strategy by engaging with MPs, civil servants and the NHS to further the organisation's political agenda and influence government decisions.

An expert advocate, Jeff represents the Haemophilia Society on health bodies associated with bleeding disorder care and new treatments. He sits on the Specialised Healthcare Alliance (SHCA), a coalition of patient groups, charities and corporate supporters who campaign on behalf of people with rare and complex conditions and acts as a patient advocate representative for NICE consultations on new treatments. Jeff also advocates on behalf of people infected and affected by contaminated blood and provides the administrative support for the All Party Parliamentary Group on Haemophilia and Contaminated Blood.



Debra Morgan, Project Coordinator, Head of Policy and Public Affairs

This report is Debra's brainchild who identified that more research was needed to guide our future campaigning on behalf of women and girls with a bleeding disorder. Debra coordinates the Haemophilia Society's Women's Working Group, sits on a number of influential health bodies and is involved in the tender processes for treatments and the delivery of services.

She acts as the Patient Public Voice representative on the specialised blood disorders Lead and Inform Clinical Reference Group (CRG) which covers haemophilia and other bleeding disorder services. Debra has been involved in the development of the peer review standards - the way in which the UK's haemophilia centres are audited by patients and clinicians – and in the new service specification of bleeding disorder services within NHS England. Debra also leads the Haemophilia Society's infected blood advocacy and member support.

Abbreviations

A&E – Accident and Emergency hospital department

BDUC – Bleeding disorder of unknown cause

DDAVP – Also known as desmopressin, a manufactured hormone

DHSC – Department of Health and Social Care

EAHAD – European Association for Haemophilia and Allied Disorders

EHC - European Haemophilia Consortium

FFP – Fresh frozen plasma

GI – Gastrointestinal

GP – General Practitioner (doctor)

HBDCA – Haemophilia and Bleeding Disorders Counselling Association

HLA – Human Leucocyte Antigen

HMB – Heavy menstrual bleeding

IDA – Iron deficiency anaemia

MDT – Multidisciplinary team

NHS – National Health Service

TXA – Tranexamic acid

UKHCDO – United Kingdom Haemophilia Centre Doctors' Organisation

VKCFD – Hereditary combined deficiency of vitamin K-dependent clotting factors

VWD – von Willebrand disorder

VWF – von Willebrand factor

WGBD - Women and girls with a bleeding disorder

WFH – World Federation of Hemophilia

References

[1]Khair K, Pollard D, Steadman L, Jenner K, Chaplin S. The views of women with bleeding disorders: Results from the Cinderella study. Haemophilia. 2022; 28: 316–325. https://onlinelibrary.wiley.com/doi/10.1111/hae.14514
[2]Paroskie A, Gailani D, DeBaun MR, Sidonio RF Jr. A cross-sectional study of bleeding phenotype in haemophilia A carriers. Br J Haematol. 2015 Jul;170(2):223-8. doi: 10.1111/ bjh.13423. Epub 2015 Apr 1. PMID: 25832012; PMCID: PMC4490107. https://pmc.ncbi.nlm.nih.gov/articles/PMC4490107
[3]Iris Plug, Eveline P. Mauser-Bunschoten, Annette H. J. T. Bröcker-Vriends, Hans Kristian Ploos van Amstel, Johanna G. van der Bom, Joanna E. M. van Diemen-Homan, José Willemse, Frits R. Rosendaal; Bleeding in carriers of hemophilia. Blood 2006; 108 (1): 52–56. doi: https://ashpublications.org/blood/article/108/1/52/133542/Bleeding-in-carriers-of-hemophilia
[4]Morgan, G., Traunter, J., Morgan, D., Yarnell, H., & Bristow, S. (2025, February). Introduction to the UK PIVOT-vWD Study: A direct to community, cross-sectional study to capture and quantify the impact, voice and outcomes of VWD (PO369). EAHAD 2025. https://doi.org/10.1111/hae.15148
[5]UKHCDO Girls and Women with Bleeding Disorders Working Party NHD Data request, December 2024
[6]World Federation of Hemophilia: Women and Girls with Hemophilia https://www1.wfh.org/publications/files/pdf-2342.pdf
[7]Recommendations for the clinical interpretation of genetic variants and presentation of results to patients with inherited bleeding disorders. A UK Haemophilia Centre Doctors' Organisation Good Practice Paper: https://www.ukhcdo.org/wp-content/uploads/2019/05/Recommendations-for-the-clinical-interpretation-of-genetic.pdf
[8]Raso S, Lambert C, Boban A, Napolitano M, Siragusa S, Hermans C. Can we compare haemophilia carriers with clotting factor deficiency to male patients with mild haemophilia? Haemophilia. 2020; 26: 117–121. https://doi.org/10.1111/hae.13891
[9]Knox L, Swart-Rimmer I, Rahimi N, Harris C, Benson G,Carvalhosa A, Clarke T.J, Garside S, Raheja P, Warren C, Abdul-Kadir R, Lowe G, Curry N. Current gynaecological management of women and girls with bleeding disorders in the UK: a UKHCDO haemophilia treatment centres survey and evaluation of real-world clinical practices. (Draft, used with permission of the authors)
[10]Curry N, Bowles L, Clark TJ, et al. Gynaecological management of women with inherited bleeding disorders. A UK Haemophilia Centres Doctors' Organisation Guideline. Haemophilia. 2022; 28: 917–937. https://doi.org/10.1111/hae.14643
[11]Millions, Michelle & Shelton, Jaclyn & Sun, Haowei. (2023). Rates and Predictors of Prophylaxis in Women with Von Willebrand Disease and Heavy Menstrual Bleeding. Blood 142. https://www.researchgate.net/publication/376149900_Rates_and_Predictors_of_Prophylaxis_in_Women_with_Von_Willebrand_Disease_and_Heavy_Menstrual_Bleeding
[12]WFH guideline for genetic assessment: https://www1.wfh.org/publications/files/pdf-1868.pdf
[13]NHS Standard Contract for Haemophilia (All Ages): https://www.england.nhs.uk/wp-content/uploads/2013/06/b05-haemophilia.pdf
[14]WFH Guidelines for Management of Hemophilia 3rd Edition: https://www1.wfh.org/publications/files/pdf-1863.pdf
[15]van Galen K, Lavin M, Skouw-Rasmussen N, et al. European principles of care for women and girls with inherited bleeding disorders. Haemophilia. 2021; 27: 837–847. https://doi.org/10.1111/hae.14379

The Haemophilia Society (THS) is the only UK-wide charity and free membership organisation for everyone affected by a genetic or acquired bleeding disorder.

Formed in 1950, we support people affected by a bleeding disorder to get the most out of life. We provide support, including in-person events and access to online communities, as well as the latest news and treatment updates and publish a range of bleeding disorder care booklets. THS also advocates and campaigns for the best care, safe and effective treatment and equitable access for everyone affected by a bleeding disorder.

We have 5,500 members across the UK who have a range of bleeding disorders, including haemophilia, von Willebrand disorder, Glanzmann thrombasthenia and other rare disorders. Membership is also open to the families of people with a bleeding disorder.

Improving the treatment and care of women and girls with a bleeding disorder has been an important campaign and advocacy priority for the Haemophilia Society (THS) for at least 30 years.

At that time there was very little recognition of 'women who bleed' and it was a challenge for our campaigners to be heard and taken seriously. Ten years ago we stepped up the campaign and renamed it Talking Red. We wanted to get a meaningful conversation started about improving women and girls' treatment and care. This report has built on the solid foundations created by this campaign and we would like to pay tribute to the many women and clinicians who have supported it over the years.

Progress has been slow, but we are starting to see a genuine shift in attitudes, particularly among clinicians, many of whom are strong advocates of Talking Red. The new service specification for bleeding disorder care in England, which is in draft as this report is being finalised, contains far greater recognition of the needs of women and girls than we've ever seen before.

Data collection is changing too. The peer review – a UK-wide audit of haemophilia centres – is now collecting more data about services for women and girls, allowing us to identify accurately where gaps in provision lie.

The haemophilia doctors' organisation, the UKHCDO, has created a Girls and Women with Bleeding Disorders Working Party which will focus on improving the treatment and care of women and girls with a bleeding disorder across all centres.

As this report shows, significant change has already started to take place but there's so much more to do.

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