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Shaping the future of London's haemophilia services and pathways

A Report on a London-wide Consultation Exercise by Haemnet

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Executive summary

Bleeding disorders are medical conditions in which the blood fails to clot properly. These conditions are rare in the general population, affecting around 24,000 people in the UK. Most are genetically inherited. They include haemophilia A and B (classified as mild, moderate or severe), Von Willebrand disease, and other rare bleeding and platelet disorders.

In recent decades, bleeding disorders have been treated with replacement therapy. Comprehensive care coordinated by specialist treatment centres has resulted in increasing life expectancy and quality of life. However, the range of treatment options is now evolving substantially, with implications for service delivery and the potential for greater individualised packages of care.

The national policy context is recognising that managing the pressure of delivering high quality care cannot be achieved solely by working harder. There is a focus towards greater patient choice and integrated care (both vertical and horizontal) as a means to improve quality in a context of continuing financial constraints.

Integrated approaches to care will clearly benefit older people with haemophilia and those with comorbidities. An often significant challenge for integration is the need for individual clinicians to be willing, if necessary, to give up some control of the reins to achieve more for the population they serve. In addition, the introduction of new haemophilia therapies will bring opportunities for greater individualised packages of care.

However, delivering personalised care and increased choice in a cost-constrained NHS poses many challenges for clinicians and commissioners, and raises the potential for increasing disparity in treatment goals and outcomes: a risk that will need to be addressed.

London haemophilia centres currently care for around one-third of people with haemophilia in England. To better understand the current shape of haemophilia services in London and the priorities for service providers in the coming years, Haemnet initiated a qualitative review with clinicians from across the multidisciplinary team (MDT). We also sought the views of patients and their families by means of an online survey.

Feedback from the clinicians interviewed and in responses to the online survey from patients, families and carers confirms that current services work well and impact positively on the lives of the people that access them. There is a willingness to work collaboratively in the provision of effective care and in developing integrated pathways that enable patients from one hospital to access specialists and services in others. The positive outcomes resulting from the 'treat intensively' approach, effective MDT working, patient numbers and the resulting levels, range of experience and access to clinical trials were also highlighted.

However, no service is universally perfect: some variations in practice between hospitals (particularly with local general hospitals), particularly with regard to physiotherapy and psychological support, and in the provision for people with mild and moderate bleeding disorders, could be addressed in order to make a real difference to the lives of patients, families and carers.

The likely changes in the treatment landscape and an ageing population bring both opportunities and challenges to London's comprehensive care centres. Our analysis suggests there are opportunities for the clinicians at the London centres:

- To further explore the potential for enabling patients to 'live well at home' through enhancing current services and developing new models of care, such as greater flexibility in appointment scheduling, more outreach services, and collaborative working with primary, community and local hospital services.

- To identify and develop integrated pathways that reduce inequities in access to care, such as specialist physiotherapy and psychosocial support, and minimise the risk of future inequities arising.
- To develop pathways that support older patients in the management of their condition and the complexities that accompany ageing. This will be facilitated by moving beyond general discussions around working with the ageing population towards a sharing of actions and 'real-world' experience.

In working collaboratively, there are also opportunities:

- To bring London's clinical expertise and experience to the debate about who will decide which products are available and what this may mean for individuals' care.
- To share experience in the use of new treatments, both within the clinical community and with patients, and to explore the impact of these treatments on both services and the relationship between centres and patients.

Practice-based research and knowledge sharing will be central to proactively addressing these changes, building on the foundations that are in already in place. However, any discussion of London's haemophilia service is best undertaken by commissioners in collaboration with clinicians and patients. Ideally, this would involve convening a forum in which a wider discussion can be held to consider what form of London-wide haemophilia services would best serve the needs of the people who use, offer and purchase them.

The London haemophilia centres and clinicians are well placed to respond positively to the growing complexity in the provision of haemophilia services and the evolving national policy context by building on existing formal and informal pathways and, together, delivering high quality care more equitably.

Seizing these opportunities will allow London's haemophilia services to stay at the forefront of the development of both practice and clinical research, *to improve choice and achieve more for the people with bleeding disorders that use them.*

Contents

The NHS Policy Context

In this section we cover aspects of the organisation of the National Health Service (NHS) and how it provides and organises services that are relevant to haemophilia care. We also outline some of the policy drivers that may change the context for delivery of NHS care in the coming years, and what this could mean for haemophilia care nationally.

How the National Health Service is Organised

Healthcare provided by the NHS is delivered by primary care providers (general practitioners, dentists, opticians, and pharmacists), secondary care providers (hospital and community) and tertiary care (highly specialised).

The NHS is funded by taxation supplemented by National Insurance contributions, with a fixed budget available to spend on services for the whole population. NHS organisations must spend that budget in a way that results in the best possible outcomes for individual patients and delivers value for money for the public. This planning and purchasing of NHS services is currently undertaken by organisations (or individuals) known as commissioners, who are responsible for assessing the needs of their populations and buying services that are affordable and of the highest quality. Clinical Commissioning Groups (CCGs), overseen by NHS England, now commission most of the hospital and community NHS services in their local areas.

However, services provided for people with rare and complex conditions are generally planned nationally and regionally by NHS England. This is because such services are:

- Used only by a relatively small number of patients
- Relatively high cost to provide
- Able to be provided only by specialist teams of doctors, nurses and other health professionals who have the necessary skills and experience (and so are not available in every local hospital).

The budget for specialised services – £16.6 billion in 2017/18 – has increased more rapidly than in other parts of the NHS. By 2020-21, this is expected to account for £18.8 billion, 16% of the total NHS budget [1].

But that budget is under pressure. Furthermore, the number of patients needing comprehensive specialised care is rising due to an ageing population and advances in medical technology.

The specialised services commissioned by NHS England have been grouped into six National Programmes of Care, each of which is run by a committee that coordinates and prioritises work across the services in that programme of care. Specialist input is provided by a Clinical Reference Group (CRG), a group of clinicians, commissioners, public health experts, patients and carers who use their specific knowledge and expertise to provide clinical advice and leadership on the specialised services and to advise NHS England on the best ways that the specialised service in question should be provided. CRGs develop service specifications that set out the core standards that all funded providers should be able to demonstrate.

The Clinical Reference Group

Services for people with haemophilia and other bleeding disorders are commissioned under these arrangements for specialised services. The Specialised Blood Disorders Clinical Reference Group (CRG) informs commissioning of haemophilia and other bleeding disorder services; medical conditions in which the blood fails to clot properly. These conditions are rare in the general population, affecting around 24,000 people in the UK.

Specialist services for haemophilia and other related bleeding disorders include all care provided by specialist haemophilia centres. This includes both inpatient care, where the cause of

admission is related to a bleeding disorder, and outreach delivered locally or at home as part of a provider network.

The Specialised Blood Disorders CRG has developed a service specification for haemophilia services [2]. The current specification (dated 2013/14) states that "The aim of the service is to enable patients with haemophilia and other bleeding disorders to live as normal a life as possible, ensuring optimum treatment with clotting factor to maintain a bleed free existence where possible, whilst maintaining good joint health and general health."

Haemophilia Care may, in future, be selected for formal service review by NHSE Specialised Services. It is reasonable to assume that any revision to the service specification will reflect the ambitions set out in recent policy guidance issued by the NHS.

National Policy Context

The context for delivery of care within the NHS over the next three to five years aims to deliver a very different patient experience from the current situation.

The Department of Health's Choice Framework, published in April 2016, sets out a goal of 'significantly improving patient choice by 2020 and in doing so, empowering patients to shape and manage their own health and care' [3]. This aim sits alongside that of NHS England's Five Year Forward plan for integration of care with a recognition that 'making progress ... cannot be done without genuine involvement of patients and communities' [4].

Integrated care is a national goal which recognises that continuing to achieve greater efficiency savings from the NHS is not the only answer. Following publication in 2014 of the Five Year Forward View by NHS England, every part of the country developed sustainability and transformation plans (STPs), which are described in the update published in 2017 [4] as 'pragmatic vehicles for enabling health and care organisations within an area to chart their own way to keeping people healthier for longer, improving care, reducing health inequalities and managing their money, working jointly on behalf of the people they serve'.

The Five Year Forward View update also states: 'Our aim is to use the next several years to make the biggest national move to integrated care of any major western country'. This aim is being taken forward through different forms of partnership arrangements that are emerging in different places with various labels being used for each type [4].

The update to the Five Year Forward View [4] continues: 'This will take the form of Sustainability and Transformation Partnerships covering every area of England, and for some geographies the creation of integrated (or 'accountable') health systems'. Work by the King's Fund describes observing three main forms of integrated care (see Box 1) [5].

Panel 1: Main forms of integrated care observed by the King's Fund

Integrated care systems (ICSs) have evolved from STPs and take the lead in planning and commissioning care for their populations and providing system leadership. They bring together NHS providers and commissioners and local authorities to work in partnership in improving health and care in their area.

Integrated care partnerships (ICPs) are alliances of NHS providers that work together to deliver care by agreeing to collaborate rather than compete. These providers include hospitals, community services, mental health services and GPs. Social care and independent and third sector providers may also be involved.

Accountable care organisations (ACOs) are established when commissioners award a long-term contract to a single organisation to provide a range of health and care services to a defined population following a competitive procurement. This organisation may subcontract with other providers to deliver the contract.

While much of the work is focused on integrating local primary care and hospital services, **it raises expectations of NHS organisations achieving more through working in partnership rather than competing**. As the King's Fund highlights, the effectiveness of integrated care systems and partnerships 'hinges on the willingness of local leaders to work in this way and if necessary to give up some of their own sovereignty for the greater good of the populations they serve.' Among the objectives for these bodies – those charged with 'joined up, better co-ordinated care' – are horizontal and vertical integration, with the challenges of:

- Demonstrating how provider organisations will operate on a horizontally integrated basis, for example, through clinical networks.
- Demonstrating how provider organisations will simultaneously operate as a vertically integrated care system, connecting hospitals with GP practices and local community services.

NHS England's offer includes: 'The ability for the local commissioners [...] to have delegated decision rights in respect of commissioning of primary care and specialised services' [4].

It is widely recognised that the development of these partnership working arrangements is at an early stage and much work needs to be done to realise the benefits for patients and the wider populations, for which they are responsible. The importance of clinicians being at the centre of integrated provision and recognition of the time it takes to build collaborative working relationships are among the challenges identified by the King's Fund:

- The importance of local leaders investing time and effort in building trust and collaborative relationships and overcoming competitive behaviours that in the past have created barriers to partnership working.
- The need for clinicians to be at the heart of integrated care developments, building on the work of the new care models and recognising the principal benefits of integrated care results from clinical integration rather than organisational integration.

'Engaging with communities and citizens in new ways, involving them directly in decisions about the future of health and care services' is an aim set out in the Five Year Forward plan that provides a platform for engaging people with haemophilia, their families and carers in the development of integrated provision.

This drive for integration is mirrored in the specialised services commissioning intentions, which outline the strategic intention to improve the way specialised services are commissioned and contracted, reviewed and transformed [6]. NHS England states that *'Achieving our ambition will require changes in how services are commissioned and provided, with specialised care as a fundamental part of more integrated care for patients'.*

Purchasing Factor Products

In the UK, most patients with haemophilia are treated with replacement factor concentrates produced by recombinant technologies. But this is an expensive condition to treat. The average adult with severe haemophilia A in the UK used 250,000 IU of factor VIII in 2011/2012, at an annual cost in excess of £100,000. The cost has led to a high level of scrutiny over treatment as well as pressure to procure clotting factor concentrates more efficiently and collectively [7].

The process by which these products are purchased for use within the NHS is centralised and initially involved a process of competitive tendering by which haemophilia clinicians work with the Department of Health's Commercial Medicines Unit to operate a 'reverse e-auction'. Essentially, over a period of time, factor manufacturers bid down against each other for differently sized portions of the NHS requirement for recombinant Factor VIII and IX products. At the end of this process the lowest price supplier meeting the specified quality criteria is awarded the largest volume contract, with higher priced suppliers being awarded lower sales volumes. This process is considered to have been successful in that it has driven down the degree of expenditure on factor concentrates. It is claimed that this system has cut costs by around a third in about 10 years without undermining access to medicines [7]. However, there is an inevitable downside to this success:

'Centres effectively shrank their budget in the short term and derived little or no direct benefit for their service in return. The money saved was retained by the commissioners. It would be easier to recruit support for such a scheme and to foster collaboration if haemophilia centres were allowed to plough some of the saving back into their service.'

The tendering process has now moved on to a system whereby companies bid for volumes of the market every three years in sealed envelopes by a given closing date.

The London Haemophilia Service

According to the UKHCDO annual report 2106, around 35% of people with severe haemophilia A and B in England receive their haemophilia care at the seven London haemophilia centres (see Figure 1).

Before the introduction of specialist commissioning by NHS England, commissioning arrangements for haemophilia were local. As a result of one commissioning group having been hit hard by a number of very high cost inhibitor patients, the Pan-Thames Haemophilia Consortium (PTHC) was proposed and initiated by both commissioners and clinicians, essentially as a means of financial risk-sharing but also with the aim of developing best practice.

PTHC was to be the largest single purchaser of haemophilia services in the UK, covering a population of 15 million people across London and the South East of England. Within this geographical area, there were approximately 3,000 people with inherited clotting disorders. It was felt that the reconfiguration would leave the PTHC service as the largest haemophilia service in the UK, equalled in Europe only by Bonn for size. Furthermore, it would further improve services for patients and progress important research.

Initially, three London networks were proposed.

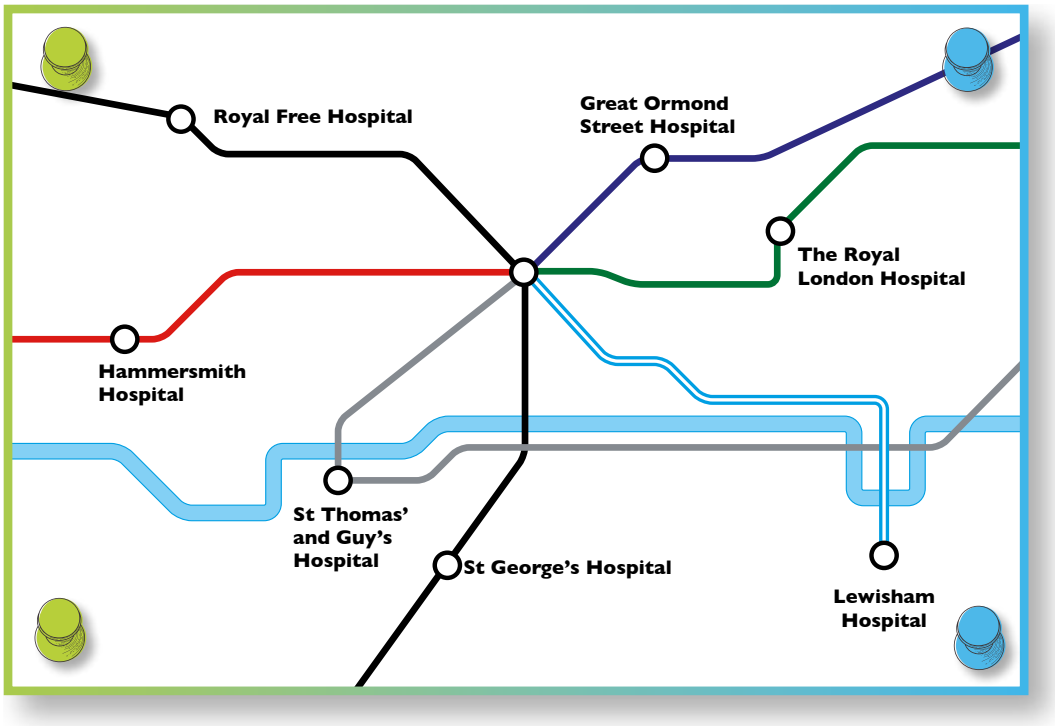

Figure 1: The seven haemophilia centres in London (2017)

- In north London, the Royal Free haemophilia centre became the hub of the North London Adult Haemophilia Network, with the Royal London and Hammersmith hospitals as spokes. The network began to function from October 2010, with financial implications from 2011. Essentially, this meant that all money from commissioners for north London's adult haemophilia care was funnelled through the Royal Free, which then allocated funding to the spoke services. There was to be a similar North London Paediatric Network centred on Great Ormond Street Hospital (the hub). Service specifications for both adult and paediatric care were developed.
- In south London, there was to be a single network with a hub located at Guy's and St Thomas', with spoke services being provided at St George's and Lewisham.

The two north London networks were characterised by a high degree of organisation among clinicians, who met regularly and developed service specifications for both adult and paediatric services. By contrast, the south London network appears to have been less well structured with respect to network meetings and more informal in its organisation.

Unfortunately, the PTHC proved unpopular from day one, largely due to the volume of data collection required by commissioners, which clinicians found onerous:

'There were a lot of repetitive requests for data, while the outcomes of data collection were not always clear. There was a lot of work and effort but the feedback loop wasn't necessarily in place.'

Furthermore, with hindsight it appears that much of the detail contained in the initial service specifications did not come into being.

'There was potential for a lot of cross-site working, but essentially today the three services all run in their own sweet way under their own management as they always did. There is a network board that meets and there is a little sharing of policy, but really and truly it exists on paper and as a financial arrangement only.'

Clinicians' and Service Users' Views on London's Haemophilia Service

An estimated 4,000-5,000 patients (35% of people with severe haemophilia A and B in England) receive their haemophilia care at the London haemophilia centres. In this section we capture the views of the clinicians who provide the service and of the service users, families and carers that access them.

These insights were gained from a qualitative review undertaken in summer 2017 with clinicians practising in London from across the multidisciplinary team, and from the views of patients and their families and carers who access London services. Full details of the methodology used are given in the Appendix. The key themes that emerged in the patient, family and carer research are summarised in the panel below.

What do you value about your haemophilia care in London?	**Patients:** appreciation of clinical team/MDT; responsiveness; quality of services; facilities; home delivery **Carer or family member:** support; kind and caring staff **Both:** specialist/team knowledge; relationship with team
What frustrates you about the services you use?	**Patients:** appointment flexibility; long-term vs acute care; data system/processes **Carer or family member:** trough level; confidentiality; dental care **Both:** lack of home/local specialist care/support; nights/weekend availability; distance/journey time; expenditure (e.g. parking)
What changes would make a real difference to your life?	**Patients:** communication; new treatment; flexible appointments/ scheduling; physio care **Carer or family member:** home visits; dedicated unit/centre; transition **Both:** improved local specialist care; mental health and wellbeing

World-Class Centres and Expertise

It is generally accepted that the wide-ranging needs of people with haemophilia and their families are best met through the coordinated delivery of comprehensive care provided by a multidisciplinary team of healthcare professionals [8]. The core multidisciplinary team (MDT) would usually consist of specialists trained in:

- Haematology
- Nursing
- Physiotherapy
- Psychosocial care
- Laboratory science.

The care provided by such teams, supplemented as needed by other specialists, is widely agreed to promote physical and psychosocial health and wellbeing while decreasing morbidity and mortality.

In 2017, the seven London centres comprised four comprehensive care centres (Great Ormond Street, the Royal Free, the Royal London and Guy's and St Thomas' Hospital (which includes the Evelina Children's Hospital)) and three treatment centres (Hammersmith Hospital, St George's Hospital and Lewisham Hospital).

We received comments from patients and carers attending all seven centres. Our analysis of the comments received indicates there is much that works well and impacts positively on the lives of people and families living with haemophilia. As a whole, London services are seen as 'centres of excellence' with a strong focus on research. Patients and their carers perceived the ability to attend centres involved in research as being beneficial.

The haemophilia care provided to patients is considered to be prevention focused, providing early and intensive prophylaxis with the aim of minimising the risk of the consequences associated with bleeds. They are also described as having world-class clinicians who have gained experience from working with significant numbers of patients, providing safe services as well as offering access to shared pathways of care.

Themes highlighted by clinical interviewees included:

- The positive outcomes resulting from the 'treat intensively at an early age' approach;
- Effective MDT working;
- Clinical expertise gained working with significant patient numbers;
- The established pathways for some specialisms, such as dental care;
- The quality of laboratories;
- Access to specialist paediatric support from Great Ormond Street (GOS), for example, with portacath insertion;
- Access to clinical trials;
- The shared aim of providing an all-round service.

This was mirrored in the responses from patients, families and carers, in which appreciation was expressed for:

- The relationships with members of the clinical teams, particularly nurses;
- The specialist knowledge available within clinical teams;
- The quality of services, including the centre facilities and home delivery;
- The support and responsive care that families and carers receive from 'kind and caring' staff;
- The access to/contact with other people and families living with haemophilia;
- The access to other London services, clinical trials and new treatments.

'World leading experts, supportive and personal care. The haemophilia clinicians really know their patients and listen to carers. I feel like we are in true partnership in the care of my son.'

'The nurses, consultants and physio are brilliant; they make you feel at ease and are always there to help however they can.'

'Second-to-none expertise, efficiency, professionalism, "can do" ethos, flexibility.'

In addition, for most patients there is also ease of access via public transport … if not necessarily ease of parking.

These centres are located in hospitals that are characterised by different and often unique areas of expertise, many of which offer specific benefits to people with haemophilia. However, no service is universally perfect: variations in practice between

centres were described along with opportunities for continued improvement.

People with haemophilia who responded to the survey described the lack of flexibility in the scheduling of appointments as frustrating, for example, when re-arranging clinics, as well as not having access to evening clinics after school or work.

'[It is difficult] getting a dental appointment on the same day as clinic appointments, even just once a year.'

They described greater flexibility with the scheduling of appointments as a change that would make a difference to their lives. This was mirrored by some of the clinicians, who highlighted the staffing challenges that centres face in providing greater flexibility, with a view that extended hours would be less of a financial challenge to introduce than weekends.

Other concerns and frustrations expressed by carers and family members touched upon:

- Whether or not a target trough level of 1% is acceptable;
- Concerns around confidentiality in open spaces and shared clinical areas;
- Access to local dental care.

This group also expressed lack of communication about changes in the membership of the team at their centre as a frustration, suggesting there are opportunities to improve communication channels between centres and patients.

For carers and family members, more home visits and greater support with transition were additional areas that would be welcome. Patients, families and carers described the lack of home and specialist care and support provided by local hospitals as being frustrating. While clinicians described examples of outreach support (e.g. school visits) being provided, they expressed frustration at now being able to provide less outreach. Where some had previously been able to provide 50:50 centre-based and outreach care, the complexity of the current caseload meant spending a greater proportion of time in the centre.

Patients, families and carers also identified improved local specialist care as something that would make a real difference for them. They expressed continuing frustration with the lack of access to home and local specialist care, especially at night and over the weekend. This is an ongoing challenge that clinical teams have aimed to address over the years, with examples of education provided to clinicians in local hospitals and on-call access to support for local clinicians being described by interviewees.

Access to specialist out-of-hours care/support (both directly to patients, and to generalists working in A&E and local district general hospitals) were described as having the potential to significantly improve haemophilia care, through a collaborative arrangement with centres. This could potentially mean fewer on-call shifts for doctors in London, but would require IT solutions and data sharing agreements to enable doctors in different hospitals to see patients' notes. The potential results of the national drive towards integrated care systems and partnerships may open the door for something of this kind to be established across London.

Local acute services are a particular challenge for users of London services in managing acute issues when living at a distance from their centre. Specialist advice and support for clinicians in local A&E services is available and could be extended to ensure that acute services are available for patients with bleeds.

Clinical respondents also noted that haemophilia treatment services were primarily geared towards those with severe haemophilia: interviewees felt that those with non-severe haemophilia and other bleeding disorders were missing out and so may not be doing as well as they would with more consistent physical and psychological care.

'It's wrong to assume that severe patients are more likely to need extra care than mild and moderate. Moderates can get a lot of problems too, and there is lack of awareness of the implications of von Willebrand's [VWD] in general practice. There can also be cultural issues for women with VWD.'

'Mild patients often get neglected and lost to follow-up; then they may start needing treatment

and develop inhibitors or have another health problem (e.g. myocardial infarction), and they have problems getting the right care.'

The relationship with primary care was also highlighted, specifically a lack of awareness of the implications for patients with von Willebrand disease in general practice.

'Being able to have blood tests taken locally (at GPs possibly) would cut down on visits and travel to and from hospital.'

Primary care has a (potentially growing) role in providing integrated services for people with bleeding disorders, but the widely perceived and longstanding reticence to working with people with haemophilia and other bleeding disorders needs to be addressed. Also, there is a need for a more consistent approach to working with women who are carriers of haemophilia as well as those with rare bleeding disorders and platelet disorders. Interviewees suggested the goal should be testing when menstruation starts, with genetic counselling to understand what it means to be a carrier and reproductive choices.

Excellent but Variable Multidisciplinary Care

Physiotherapy

There is growing recognition of the benefits of specialised physiotherapy support:

'There's no substitute for specialist physiotherapy – just sending someone to a general physiotherapist doesn't work as they're too afraid to touch patients with haemophilia.'

The importance of the role of the physiotherapist in rehabilitation following a bleed and in monitoring and maintaining joint health was highlighted.

'As they age, today's younger patients will be in better shape than today's older patients, without such disabling joint problems. The view is that the likely exception will be ankle problems, and these require complex surgery for which research is needed into better prostheses. There is an assumption that young people won't need as much care, but they will still have health needs, including psychological needs.'

However, patients and families felt there were differences in the level of knowledge and expertise among physiotherapists and inequity in access to physiotherapy care: while some patients have no direct access to physiotherapy, others have access to excellent physiotherapy care. Furthermore, even where specialist physiotherapy is available, it was acknowledged by physiotherapists that this service is frequently geared towards those with severe haemophilia even though patients with non-severe haemophilia would also benefit.

'[There is a need for physiotherapists] to take time talking to mild patients because there's an assumption that they won't have any joint damage and, often, they sit on problems for long periods when they should be seeking help'.

For those with no access to a specialist physiotherapist in the haemophilia centre, it was recognised that development of an integrated pathway across London could address this gap. These patients could then potentially also be seen locally by more generalist physiotherapy services. The need for this was reinforced where patients, family members and carers identified greater access to specialised physiotherapy support as one change that would make a real difference to their lives.

Overall, it was felt that physiotherapists should continue to enhance the focus on building therapeutic relationship with patients (annual reviews and education), regular reviews of joints and perhaps have ultrasound/MRI to secure a baseline, so together joints can be better managed over time.

Physiotherapy support can reduce the impact of longer-term consequences on the lives of people with bleeding disorders, both physically and beyond, such as the impact of days lost from school and work – ideally, collecting the evidence for this should be included in future research around new treatments.

There was a recognition that the role of physiotherapists may gradually change following the introduction of the newer agents, to advising or pre-empting joint problems, educating people about why their joint is sore and what they need to do to prevent it. But it was highlighted that there

will be a continuing need for patients who already have some joint damage.

'The new drugs may stop further bleeds, but existing joint problems are likely to evolve into a disease more like chronic RA [rheumatoid arthritis].'

The need for physiotherapy is also likely to grow in the future and needs to be seen as a valuable component in medication management.

'If prophylaxis is costing £70,000 per year, physios need to do annual assessment to ensure it is working, already feeding into Haemtrack, where physios have contributed very useful information to identify subtle patterns. There'll be more requirement for physios to do 'extended scope' [e.g. ultrasound and joint injections] for older patients as they already do with RA patients, but this will only be possible if there are more specialist physios.'

Mental health and wellbeing

Living with a bleeding disorder can be tough and raises many issues. Patients and their carers can benefit immensely from the specialist skills provided by psychologists and social workers. There is growing understanding of the benefits of haemophilia-specific psychological support, with early intervention being important to prevent psychological issues becoming ingrained. Such support can keep people out of hospital. Wellbeing techniques around areas such as sleep, diet and social contact were highlighted as important features of support that can make a difference. Patients, family members and carers identified access to mental health and wellbeing support as a change that would make a real difference to their lives.

For young people, the positive changes being experienced – for example, relationships, sexual identity and ways of connecting that bring many advantages – were described, as was the need to recognise that a negative consequence, that of increasing anxiety and depression is also being observed. These changes are experienced equally by people with haemophilia alongside those within haemophilia; changes that bring uncertainties and unpredictability that would benefit from psychological support.

While the Royal Free has a proud history of offering patients access to specialist psychological and family therapy support, it is recognised that there is a general shortage of specialist psychologists and psychological expertise to support wellbeing and to enable individuals to address mental health problems. In many cases, other members of the clinical team, in particular nurses, provide wellbeing and emotional support to patients and their families and carers as they deal with issues that are a direct result of or related to their condition.

Clinicians working in paediatric centres frequently provide support to families and patients, from diagnosis and throughout development of the skills to treat and self-treat. Those working in paediatric and adult services frequently tackle the breadth of issues that are experienced by people living with bleeding disorders. In both cases, however, interviewees reported that onward referrals to specialist psychology services were usually available where needed. Ensuring easy access to solution-focused support was described as important across London services, as was the need to recognise that onward referral adds an extra step that can be a barrier for some people.

People power can bring about change

Following a campaign by patients, families and carers in Scotland, in January 2016 the Scottish Government funded a Psychological Support Service (PSS). This was a two-year pilot project based in the Edinburgh Haemophilia and Thrombosis Centre that, from January 2018, has been extended to work collaboratively with the other Scottish haemophilia centres, and is funded to April 2019 by the Scottish Government and NHS National Services Scotland. The aim is to ascertain the most successful and acceptable (for patients and staff) model for future psychological care across Scotland. The PSS comprises one full-time clinical psychologist and a session of liaison psychiatry. This is a lifespan service that provides direct clinical care for patients and families of all ages, as well as consultation and training for the wider MDT.

Research suggests that both adults and children living with chronic conditions are two to three times more likely to experience emotional and behavioural difficulties compared with those without. Within the haemophilia population, anxiety and depression occur in up to 32% to 37% of people respectively [9, 10], and it is estimated that around one third of adults with haemophilia will experience depression and/or anxiety at some point in their lives.

'People living with haemophilia can experience a reduced quality of life. Anxiety and/or depression can impact upon various areas of anyone's life, including socialising and activity levels, relationships with family and friends. For those living with a bleeding disease, there can be additional impacts on adherence with prescribed treatment (e.g. prophylaxis), missed clinic appointments or engaging in unhelpful coping strategies such as alcohol or drugs.'

Some things people may want to talk about include:

- Coping with and adapting to having a bleeding disorder;
- Feeling overwhelmed by being ill or in hospital;
- Feeling depressed, anxious or angry about their illness or treatment;
- Managing fear about treatment, such as fear of hospital or needles;
- Coping with pain;
- Relationships with family, significant others or friends;
- Preparing for college or moving on to adult services;
- Family planning concerns;
- Sleep problems;
- Challenges associated with having received infected blood products;
- Dealing with the loss of a loved one who may have received infected blood products.

A recent evaluation of the service demonstrated wide-reaching benefits for those who accessed the services through the promotion of communication between the health service and their patients. This has led to improved patient outcomes, including adherence to treatment, self-management, improved decision-making abilities and improved quality of life [11]. The evaluation also showed that the service is valued by healthcare professionals (HCPs), in particular for providing holistic care for patients and families and changing MDT practice. The introduction of the service has supported the team to work collaboratively, both as a team and with the patient, to target discussions to those issues that are most important for patients. Health professionals also report that the introduction of the service has resulted in increased knowledge and more confidence to better manage psychological issues, while integrating support with the MDT relieved some of the strain experienced by staff.

'It is suddenly such a huge relief; you just realise how much psychological need there is, and how much weight can be taken off me so I can concentrate on the clinical things.'

Having psychological practitioners with specialist knowledge embedded within the service has increased awareness among HCPs about the importance of screening for distress on an ongoing basis, as well as working proactively to increase people's emotional wellbeing and their skills to manage distress – an impact that could be described as 'emotional prophylaxis'.

'It has affected my practice; it has made me more aware, say, of identifying earlier that people might need some support.'

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Embedding the service within the MDT has also supported holistic decision-making around treatment and case management. Increased confidence and recognition of the value of the service by clinicians and patients who were uncertain at the outset are further positive outcomes. Education sessions and training in psychological models and techniques such as motivational interviewing has further helped support changes in practice for nurses and doctors. Psychologists also bring research and evaluation/ audit skills, both qualitative and quantitative, which can be utilised by others within the MDT.

Beyond the local centre, the service has impacted on transition practice by working collaboratively with nursing colleagues to host a focus group exploring people's experiences of transitioning to adult services in Scotland. The outputs from this event have been fed into the Scottish Inherited Bleeding Disorder Network (SIBDN) and will be shared through a poster presentation at the World Federation of Hemophilia (WFH) conference in Glasgow. The psychology service is an active member of various working groups within the SIBDN and a member of the expert group carrying out a clinical review of the impacts of hepatitis C.

The service has proven very popular with patients, as having access to psychological care from someone with specialist haemophilia knowledge is highly valued.

'Being able to talk through often difficult, personal topics with someone who has no emotional investment in my life but who has a professional commitment and understanding is very important to me.'

'It's refreshing to be able to let things out because I have said things to the psychologist I haven't said to other people, even my mum and dad.'

The hope for the service is for specialist psychological support to become 'a normal thing from as soon as a patient is diagnosed' across all Scottish haemophilia and thrombosis centres.

Opportunities for London 2020:

- To explore the potential for reducing inequity in physiotherapy and psychological care across London and providing greater health and wellbeing support.
- To explore the potential for enabling patients to 'live well at home' through new models of care delivery, greater flexibility in appointment scheduling, more outreach services, and collaborative working with primary,community and local hospital services.
- To better understanding the different service models and the cost-benefit equations both in-year and for the longer term
- To improve communication channels not only between centres but also with patients.

Future Challenges

In this section we outline two of the major challenges facing those who provide and access haemophilia services. These are:

- The Ageing Haemophilia Population
- The Evolving Haemophilia Treatment Landscape

We also begin to consider the opportunities for meeting these challenges – an area that is explored in greater depth in the next section.

The Ageing Haemophilia Population

In developed countries, advances in care and treatment have resulted in an increased life expectancy for those born with haemophilia. Even as recently as the early 1960s, most boys born with severe haemophilia died around the age of 10 years. Following the introduction of plasma-derived clotting factors in the 1960s, average life expectancy for those with severe haemophilia rapidly rose to over 50 years. Average life expectancy fell in the 1980s due to treatment-related infections but began to rise again following the introduction of clotting factors produced by recombinant technology in the mid-1990s.

As people with haemophilia live longer, the risks they face, whether from their haemophilia or from age-related comorbidities, change as shown in Figure 2 [12].

Many of these health risks can be difficult even for expert clinicians to manage. As one clinician noted: *'Ageing is medically complex and we are learning as we go along.'*

For older patients, a comprehensive care approach is needed that looks beyond their haemophilia-related comorbidities. But clinicians remain unclear as to what comprehensive care should look like for older people.

'We know the model for patients with haemophilia in the past (i.e. adult care has been modelled around hep C/HIV) but it now needs to consider all the specialists that older people with comorbidities need to see, including cardiology and so on, so there's a clear pathway.'

First Age: Childhood
- Diagnosis
- Introductionof treatment
- Prophylaxis
- Inhibitors
- Adherence
- Schoolingand sport

Second Age: Adulthood
- Arthropathy
- HIV/HCVco-infection
- Prophylaxis
- Inhibitors

Third Age: Retirement
- Cardiovascular disease
- Renal disease
- Hypertension, obesity, diabetes
- HIV and HCV coinfection
- Tendency to fall
- Decreasing visual acuity
- Dementia
- Malignancy
- Mobility
- Arthropathy
- Bone health
- Loss of socialnetworks

Fourth Age: dependency
- As in third age but worse
- Seeking care/support outside the home or hospital

Figure 2: Some of the issues at the different ages of a person with haemophilia (adapted from Harrison C, et al, 2018 [12])

The European Haemophilia Consortium recently surveyed European countries about facilities for older patients with haemophilia and found there were no special standards. One centre director interviewed raised the need for *'a multidisciplinary group to determine what to do.*'

It seems likely that this should include the need for a relationship with primary care, with access to opportunities for regular screening of cardiovascular disease markers such as blood pressure and cholesterol, as well as the need to consider all the specialists that older people with comorbidities may need, for example, cardiology and outreach/community services.

'GPs are rather scared of patients with haemophilia, so we can't just leave it to them. They also need help with maintaining bone and muscle strength to reduce falls.'

We spoke to one elderly haemophilia patient at the Royal Free whose experience showed how care could be coordinated between his haemophilia centre and his local services. Like many older people, he was diagnosed by his GP as having atrial fibrillation. The subsequent risk of stroke is usually managed by treatment with vitamin K antagonists like warfarin, which prevent the blood from clotting. Knowing that the patient had severe haemophilia and was on low-dose prophylaxis, the GP contacted the patient's haemophilia team. A specialist cardiology referral was booked at the Royal Free, and the patient's heart arrhythmia is now jointly managed with the local district general hospital, with expert input from the haemophilia team.

Another clinician highlighted that *'Young patients may need social support, but older ones may need complication management (e.g. physio for musculoskeletal problems). And these 'older' patients won't even be that old – 35-40+'* – which raises the concern that older haemophilia patients will not qualify for social care support designed for people of retirement age and above.

'Patients with complications and poor venous access who are difficult to manage in the community ... hence the need for more outreach clinics. The idea of review clinics is attractive, but there is a need to question whether every patient needs access to the MDT. These patients (and patients with rarer bleeding disorders) will continue to need treatment at centres.'

'There's probably a case for physios to do home visits with community teams to help keep older patients in their homes – a safer option than bringing them to hospital.'

Haemophilia services are also starting to see patients with early signs of dementia who need additional support to ensure they take their intravenous factor infusions. The clinicians we interviewed described finding resistance among community nurses and local hospitals, who are unwilling to help as they do not feel sufficiently qualified, or who hide behind the suggestion that "there needs to be a risk assessment". Again, this raises the question of the need for more outreach support, although as one clinician raised: *'Outreach is a good idea but you need a critical mass to make it worthwhile.'*

Clearly, it would be ideal if local hospitals were to train staff in understanding and managing people with haemophilia, and outside of London there have been some recent success stories in this respect.

A further issue highlighted by interviewees is that of older patients becoming socially isolated. As with dementia, this was never an issue in the days when patients did not expect to live into old age and so may have not developed family and social networks, and possibly have little in the way of money or pensions. For some patients, there may also be treatment issues resulting from the poor health of their carers, so in many cases other options for treatment will be needed.

The discussions around ageing highlight that there is a significant role for the clinical expertise in haemophilia centres to support the development of knowledge among their generalist clinical colleagues. There is also a need to move beyond discussion of ageing as an issue, to develop models of practice based on work that is already happening, and to share experience of working with age-related issues with other haemophilia centres. As one clinician highlighted, *'There are also potential lessons that can be learned from ageing patient populations in other treatment areas, for example, rheumatology and the management of joints.'* Others suggested:

'The DGHs need to step up and train someone in haemophilia who can do this sort of thing. The subcutaneous therapies and long-acting agents will improve things because, if patients can't treat themselves, there may be nurses or others who can do [it for] them.'

Clearly, there needs to be greater effort invested and attention given to the development of clear pathways and the support needed to manage older patients and the complexities that accompany ageing. Ideally, this should be accompanied by a move away from the current general discussions around working with an ageing population to the 'real-time' sharing of clinical experience of working with these patients. In addition, thought needs to be given to novel service models such as outreach and integrated working with local community services, along with consideration of specific issues around what is already being offered, what could be enhanced and what support would be needed to do so; informed by learning from current practice.

The Evolving Treatment Landscape

For many years, haemophilia treatment has been characterised by intravenous infusions of clotting factor concentrates. In recent years, there has been a move towards longer-acting agents that offer more durable haemostatic control (Figure 3). Such agents have included longer-acting factor concentrates, bispecific antibodies, RNA inhibitors and gene therapy.

The use of such novel agents and approaches could result in more patient-specific approaches that may result in fewer patients developing joint complications. If introduced appropriately they offer the potential to transform clinical practice.

'Gene therapy, which is not that far away (phase III trials are underway), has the potential to cure haemophilia. In the meantime, new agents like emicizumab and potentially fitusiran, could change the paradigm.'

However, our clinician interviewees described the difficulties in predicting what would happen and uncertainties around what this would mean for clinical practice:

'New treatments will certainly make a difference with patients needing different care, so centres need to respond to the new needs and be more flexible and innovative, including telemedicine and phone calls.'

To date, some of the benefits of extended half-life (EHL) products that are being seen include improved dosing strategies and greater potential for personalised care.

'Drugs with extended half-lives are definitely starting to change practice, with severe patients getting bespoke regimens. However, in the longer term – for non-severe patients – the

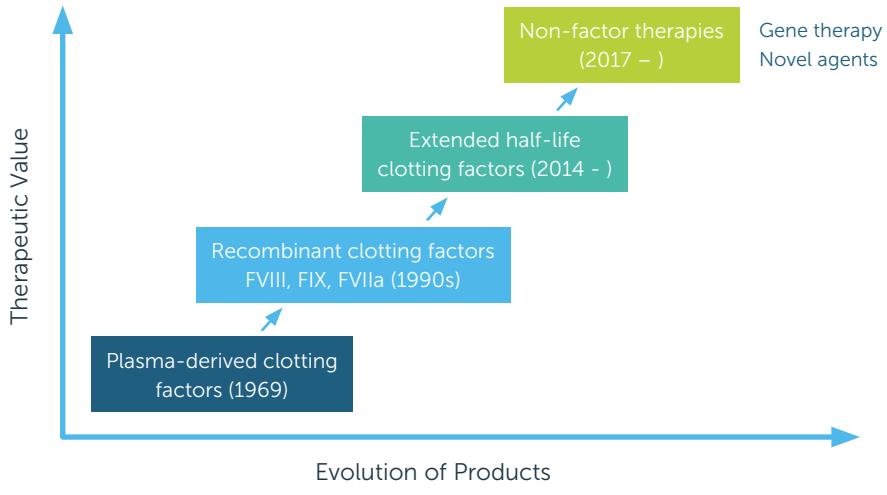

Figure 3: The evolving haemophilia treatment landscape

newer treatments may mean a less personalised approach because the bleed risk will be so low. Ultimately, the subcutaneous treatments can convert everyone to non-severe.'

While individualised care is an aspiration raised by many respondents, it is also recognised that time pressures may be one of the constraining factors in achieving this.

'But, with personalised care, there's a lot of information that isn't written down, so the challenge is ensuring that everyone in the MDT knows what it means. It can take a lot of time to get personalised care sorted out because it's not just ticking boxes but means talking at length to patients.'

Clinicians also described how new treatments required a rethink of treatment goals, with a shift away from bleed rates towards a greater focus on healthy joints and quality of life.

'For some patients on extended half-life products, haemophilia goes to the back of their mind and their focus is on their lives as the patient feels more protected.'

While clinicians aspire to consider the quality of life goals of individual patients, there is also a realisation that financial pressure may pose a limitation: the outcome of the recent tender negotiation is seen as having the potential to curtail some of these patient benefits through reduced flexibility in prescribing options. Whether cost remains an issue with new drugs remains to be seen. One clinician suggested that drugs like emicizumab and fitusiran are not expensive to produce so, *'hopefully, the pharma companies will decide to try to sell a lot at a low price rather than a small amount at a high price.'*

Concerns were raised that the wider range of treatment options would be offered principally to those with severe haemophilia, leading to the possibility that these patients might receive therapies that lead to achieving trough levels of 30% and above, while non-severe patients might continue to be managed at 1% trough levels.

'Factor VIII is too rationed. It would be much better to sustain a higher trough level to be on the safe side. A planned trough level of 1% means there is not much room for error.'

In addition, the potential for variations in trough levels and treatment outcomes between patients of the same level of genetic severity was raised. One clinician noted that: *'not all treatments will have same effect for each patient.'*

This underlines the fact that **the new treatments bring greater levels of uncertainty for clinicians, patients and their families and carers.** The community as a whole will only learn about each of the new products as they become more widely used in practice.

For centres: interviewees identified that although it is assumed that, in the medium term, the new treatments will reduce the number of patients requiring care provided at haemophilia centres, expertise will continue to be needed in developing bespoke regimens for severe patients and for establishing and educating patients and their families and carers about the new approaches.

'There will be a considerable role for nurses in transitioning patients on to them, and the change could be interesting and enjoyable for nurses – explaining to patients about the new drugs and ensuring they get the most from them.'

Some interviewees felt that the likely cost of new treatments might limit the immediacy of their impact on services, while others suggested that the usage of factor would decrease, offering the potential for cost savings, but that variations in healthcare needs would continue.

In exploring this further, some interviewees envisaged that the introduction of subcutaneous treatments would prove labour-intensive in terms of nursing time to advise patients and parents, as has been the case with intravenous therapy, particularly in paediatric services. It was also suggested that patients on subcutaneous therapy who develop inhibitors might need to transition to intravenous therapy, which would require considerable physical and psychological support for both patients and families.

A further complication might arise for those children and young people who go through many years with no need for intravenous therapy and so have little experience of recognising and/or treating a bleed. Patients could *'see themselves as "invincible", taking up high risk sports, until*

they end up at the haemophilia centre with a significant bleed.'

While there is great excitement in the clinical community around the likely availability of agents delivered by subcutaneous administration, there is also uncertainty about the impact on services. Assuming the results of clinical trials come through in clinical practice, and patients can be maintained on once-monthly subcutaneous injections, this would clearly suggest a need for 'closer to home' and outreach services. While this is certainly in line with the desires of patients, questions could begin to be asked about the need to maintain high-cost staff in haemophilia centres.

However, even if subcutaneous therapy were to become the "norm" for treatment, the need will remain to support patients who have been previously treated with factor concentrates. As has been the case with EHL concentrates, practice is still evolving as experience accumulates. Sharing these experiences between clinicians and centres is recognised as being of great benefit, but to do this effectively takes time. Ongoing learning has also been demonstrated with prophylaxis and has delivered significant improvements since it was introduced, even if, *'some patients on prophylaxis are still showing signs of joint damage due to micro-bleeds.'* Research into the medium to longer term benefits and consequences of the new treatments will be needed. In doing so, there are opportunities to explore the broader benefits beyond costs and annual bleeding rates.

The introduction of new drugs will alter but not reduce the need for physiotherapy services.

'With the introduction of the newer drugs, the role of the physio may gradually change to advising or pre-empting joint problems, educating people about why their joint is sore and what they need to do to prevent it. But there'll be a continuing need for patients who already have some joint damage. The new drugs may stop further bleeds, but they'll evolve into a disease more like chronic RA.'

For patients, their families and carers: clinicians interviewed described how the wider range of available therapies will bring new choices and, for some, dilemmas.

'Would you rather just give yourself an injection under the skin every day and you know you're normal [i.e. clotting is normal], as opposed to giving yourself an injection IV twice a week? Or would you rather just do something once every three weeks and know that you'll be okay, it's relatively safe, but you've still got haemophilia. It's a question for mild and moderate as well as severe patients. Mild and moderates may not have been having any treatment but they will probably be able to "normalise" with an injection once a month, so why not?'

Patients who responded to our online survey clearly wished to know more about the new treatments and the professionals we spoke to identified a need to work with and manage patients' expectations about the new treatments.

'There is great excitement about subcutaneous therapy within the haemophilia community, but also some nervousness about change. Patients who have been in trials of longer-acting drugs report huge impact on daily lives, but there are concerns about costs and whether all patients will get the new treatments.'

Supporting patients to become more empowered and aware of their treatment options was raised by interviewees.

'What will it take for a patient to be able to advocate for themselves, for example, when they arrive at A&E and securing rapid access to treatment, and when they need to pick up the phone and make contact for advice? How do we support those less able and/or willing to advocate for themselves?'

Supporting patients around the changed clotting factor levels they may experience was also raised by interviewees.

'Changed clotting factor levels bring psychological change and need support. Individuals don't know how they will feel and what the psychological impact will be, it will be different for each patient.'

In the short term, it was felt that many patients will continue to want to tailor treatment to their own lives and needs, according to how worried they are about their joints, adjusting their levels to their social lives and sports activities. However,

not all patients are ready to proactively manage their condition with their clinical team, and some patients will continue to need support from centres where they have an established relationship that means solutions can be more readily found. Closer working with patient associations and advocates to ensure a focus on this for the broader population with bleeding disorders will also be needed.

'If patients are switched to newer treatments, good communication will be needed to explain these new treatments. Some patients do not currently share the same excitement about the new drugs as clinicians – it's not as well known or as clear-cut as some people think.'

In summary, clinicians expressed concern around which products will be available for them to prescribe and how they work with patients to manage expectations, and over the potential for greater disparity of treatment outcomes in the future. Overall, we heard that although the impact of new treatments has yet to be seen, and with them comes uncertainty for all, comprehensive care will continue to be needed to support the differing needs of people with haemophilia and other bleeding disorders. London has a population of 12 million people and people travel from beyond the greater London boundaries to access services. Complex cases will need specialist MDT input and, increasingly, access to specialised laboratories and coagulation services. Alongside this, the 'time to treat' *('It only takes two or three severe patients with urgent issues and the day can be gone')* was highlighted as something that needs to be recognised in the workload of centres, as is ongoing research and the need for more feedback from patients themselves.

If the potential of new treatments is to be achieved more equitably, there needs to more sharing of experience in their use, both within the clinical community and with the patient community. For clinical teams, thought needs to be given to novel modes and means of communicating the benefits and risks of new treatments to patients, whether through network-based websites and information channels or through the patient associations. In addition, further consideration should be given to the impact of new treatments on the relationships between patients and centres.

Access to investigational treatments in clinical trials

One of the elements that patients value from the London centres is access to clinical trials of new investigational treatments.

The novel bispecific antibody emicizumab has now been licensed for the management of people with haemophilia complicated by an inhibitor, but trials are now underway in people without inhibitors. We spoke to one patient who has been receiving emicizumab at the Royal Free since November 2016, who says his world has changed: 'It's chalk and cheese – it's like I don't have haemophilia anymore. No bleeds.'

For many years, prophylaxis caused him panic attacks and anxiety, but he got to a point where he was able to manage it by getting up early and getting himself into a good state of mind in order to avoid bleeds. But even so, with an active job and two young children, he would frequently have to make an extra journey into the Royal Free when he needed an additional treatment. When offered the chance to join a trial of monthly dosing with emicizumab, he jumped.

Of course, clinical trials usually last only a finite time. How he will feel at the end of the trial when access to the treatment may be withdrawn remains to be seen.

We spoke to another Royal Free patient who experienced the introduction not only of home therapy with cryoprecipitate in the early 1980s but also the launch of the first recombinant products back in the mid-1990s. Recombinant products, of course, were introduced following a period of great nervousness for the haemophilia community, and he described how being able to access a clinical trial of these new, safer products made him feel very much more comfortable and confident about his treatment.

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Unfortunately, at the end of the trial he was told he would have to resume treatment with his original plasma-derived product due to lack of funding. He recalls being devastated at the news, especially as his local health authority agreed he should remain on a recombinant product. Unfortunately, the contracting process proved inflexible and he lost his recombinant treatment as well as the good relationship he had built up with his treaters.

Today, he once again has an excellent relationship with the haemophilia centre and is being maintained on low-dose prophylaxis. He is also undergoing gene therapy as part of the ongoing programme at the Royal Free, which he hopes will convert his severe haemophilia to a mild form. The ability to travel without the "excess baggage" that most severe patients need will, he believes, be life changing. So, he is preparing for six months of intensive monitoring following his treatment. Trials are not without risk to individuals, but as he says 'if somebody didn't do it, then nobody would benefit.'

Opportunities for London 2020:

- To invest greater effort and attention into the development of clear pathways and support needed to manage older patients and the complexities that accompany ageing.
- To move beyond general discussions around working with an ageing population to sharing actions and real-world experiences of working with these patients.
- To bring London's clinical expertise and experiences to the debate about who will decide which products are available and what this may mean for individuals' care and the potential for disparity of treatment outcomes.
- To share experience in the use of new treatments, both within the clinical community and with patients, and explore the impact of new treatments on the relationships between patients and centres.

Enhancing London's Haemophilia Care

The NHS has a reputation for high quality haemophilia services and pathways for patients. London represents a high proportion of the UK bleeding disorders population and is perhaps the largest coordinated provider of haemophilia care in Europe. But, like elsewhere, the London service must deal with the challenges posed by the ageing of the haemophilia population, and also from the growing range of haemophilia treatment options.

All in all, given the likely impact of the most recent policy drivers within the NHS, it seems reasonable to assume that patients can expect to be offered greater choice in healthcare.

Similarly, the move towards more integrated care should mean that local NHS systems have the potential to impact positively on meeting the needs of people with haemophilia, especially for older people and those with comorbidities.

However, this is likely to be shaped by the challenges resulting from national commissioning constraints.

In this section, we consider the opportunities for transforming London's haemophilia care at a time when there are expectations of greater engagement of patients in the self-management of their condition, against a backdrop of the continuing goal of clinicians to improve clinical practice while the NHS is tasked with delivering efficiency savings.

Collaborative Clinical Leadership

It is clear from the views expressed to us that the combined expertise across London is extensive. One challenge for clinicians and commissioners is how to maximise the benefit for patients from this collective experience. Good working relationships are key to achieving this and where they exist, even just knowing the name of members of the clinical team was described as making a difference.

'There's a lot of enthusiasm for collaboration but we need to get together and show we could gain from working together [...] commissioners could provide the external leadership that's needed to bring all the expertise together.'

In some cases, there history can be a barrier to effective collaborative working, and this is where the need for 'honest and frank' conversations was highlighted by more than one interviewee if real benefits for patient are to be secured.

A willingness to work collaboratively in the provision of effective haemophilia care was described by interviewees from all centres. A primary goal is that of reducing inequalities: 'no longer operating as individual centres would provide easier access to services that cannot be delivered to the same quality in one's own hospital/trust.' Examples of good foundations in the provision of integrated services included:

- The multidisciplinary approach to provision with HCPs taking a prominent role, such as nurse-led telephone clinics and follow-ups, and senior nurses liaising with other clinical teams in preparing a surgical plan which are overseen and signed off by the patients' consultant.
- Consultants who work across sites to facilitate joint working, such as in the transition from children and adolescents to adult services.

The excellent care provided through established formal pathways enables patients from one hospital to access specialists and services in others, most notably with respect to dental care. There are also informal pathways being developed that harness the expertise of the hospitals within which the centres sit to further reinforce the quality of care provided across London, such as radiosynovectomy.

Shared care was also described as working well when patients move to other parts of the country

or while they are students and are not willing to change centres. This may be a temporary arrangement during a transition phase.

'Working with patients that when they move home they don't want to change centre, there are established relationships that result in reticence to transfer.'

'For challenging patients, there's no alternative to centre care, and a centre that really knows a patient's issues can achieve much more than passing him around between centres.'

As described earlier, integrated care is also a national goal based on the recognition that continuing to achieve greater efficiency savings from the NHS is not the only answer. While NHS England is more focused on the interface between primary, secondary and social care, as the King's Fund has highlighted: *'The promise of integrated care will only be delivered if doctors, nurses, allied health professionals, pharmacists and many others in clinical roles work much more with each other and with staff working in social care and the third sector around the patients and populations they serve'* [5].

Delivering higher quality provision has already been demonstrated by clinicians working together to develop the current and emerging integrated pathways (networked services) in haemophilia across London. Many of the people interviewed identified that more could be achieved through the extension of these ways of working. As discussed in the section on ageing, it is also increasingly important for specialised services like haemophilia care to integrate with local services so that patients have access to other services, such as health checks and dental care. Some patients do not wish to travel and, with the right local education for dentists, their care can be good.

'All patients should be able to get access to a properly trained dentist, via their haemophilia centre.'

Integrated pathways also offer opportunities to address inequities of access to specialised physiotherapy and psychology across London. Access to orthopaedic surgery was suggested as another area that would benefit from a networked service, where access to recognised experts in specific joints, such as hips, knees, ankles, could be achieved with physiotherapy and rehabilitation delivered locally.

The drive towards integration of care raises expectations of NHS organisations achieving more through working in partnership rather than competing. Much of what is achieved in the field of clinical research is the result of "healthy" competition that sees breakthroughs in the development of new treatments taking place. However, when it comes to the delivery of services, this competition can get in the way of working in partnership to provide integrated services for patients and their families and carers.

Towards Fully Functioning Clinical Networks

Clinical interviewees confirmed that the north London network functioned more effectively than the south London network, although it functioned better in some areas than in others.

'Setting up the networks wasn't easy, but it happened and agreement was reached; the managers and commissioners were good people and it worked well.'

One of the challenges for achieving more networked and integrated provision is the time needed to engage in in-depth conversations to explore the barriers to beneficial joint working.

'It is important to look into why a network doesn't work and why one person thinks it's great and another doesn't.'

However, of equal and potentially greater benefit is understanding the strengths that have led to effective networked approaches, as these would provide a basis on which to develop further integrated pathways. Different perspectives on the functionality of networked services were described, with some saying that previously there has been a lot of enthusiasm for networking and collaboration but this has diminished. Pan-London meetings on specific subjects helped build relationships but these appear to either no longer be happening or are accessed by some people and not others. Concern was expressed that *'Networking and collaboration can work but often don't where one side feels like the poor relation.'*

For networks to work well, there is a need for joint ownership with some joint clinical services; for

example, members of staff that work between the centres, such as is already happening between Guy's and St Thomas' and St George's, and Great Ormond Street and the Royal Free. However, these are not universal and it was highlighted that *'there's better cooperation within paediatric services but cooperation is less well established between many adult centres.'* Some identified previous resistance to doing so: *'People fought against it.'*

Interviewees expressed the view that. in their experience, even where networks work well, if a hospital is not in the same network there are practical problems referring across pathways. For example, sharing information and referring patients across Guy's and St Thomas' and King's works well, with staff readily being able to see test results and so on. Questions were asked as to why this does not appear to work as well with St Thomas's and St George's despite the hub-and-spoke model.

Looking beyond integrated pathways around specialties, it was suggested that *'if networks could be made to work, then patients could be registered to a network, not to a hospital.'* Integrated care partnerships, as described earlier, could offer a model for achieving this. The problem is that, within any network, one hospital is likely to be bigger than another and each can feel threatened by the other. As one clinician identified, 'a way needs to be found in which both feel they are equal partners'.

Networking any services is a dynamic process with relationships and interdependencies that ebb and flow over time: issues not unique to London and bleeding disorders. This perspective is reinforced in the body of work that describes collaborative leadership in different sectors. At the heart of the effective networking of services is mutuality, in which a degree of collaboration is needed but not total loyalty to the combined activity; between the extremes of symbiotic and transactional as shown in Figure 4.

Archer and Cameron talk about effective partnerships depending on partners working in a more independent manner for much of their day-to-day activity [13]. Integrated pathways are examples of this type of partnership, where there may be times when a close degree of collaboration is needed to resolve a particular problem, but more time is spent separately, with each partner getting on with delivering their contribution to the whole pathway and their independent services.

They go on to identify debate and discussion as key to developing partnerships. Some important

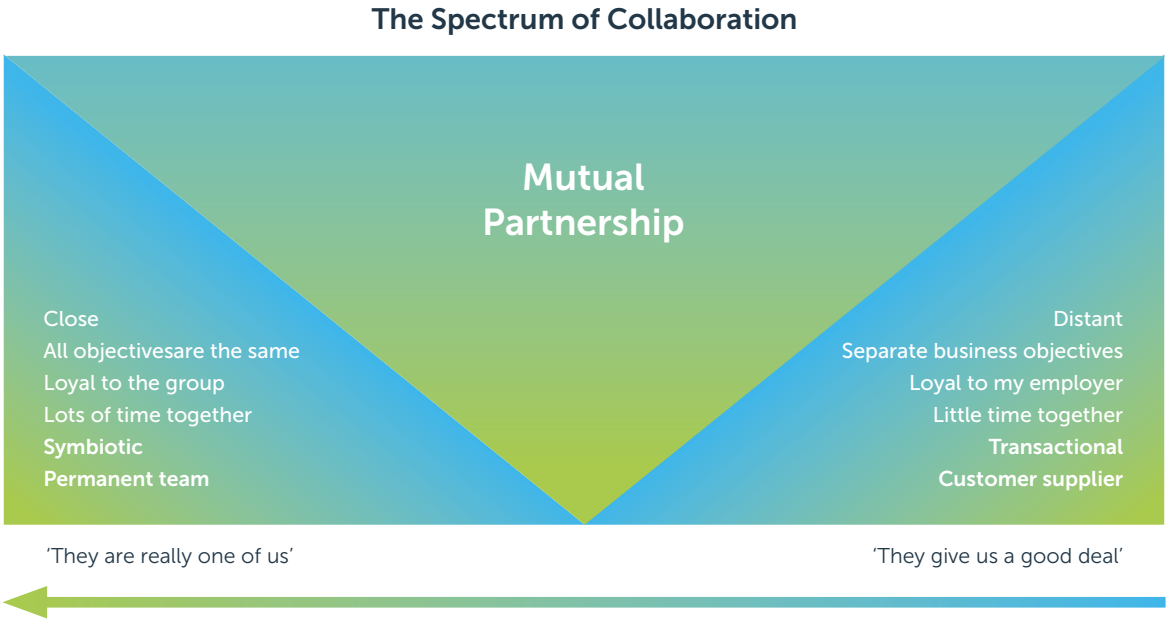


Figure 4: The Spectrum of Collaboration (based on Archer and Cameron, 2008 [13]).

questions adapted from their work that it would be useful for each partner within a network of haemophilia services to reflect on are:

- How much does each of you within the network/integrated pathway want to collaborate?
- Do you want to operate as independently as possible or interact closely?
- Where do you agree about the ways of working?
- Where do you disagree and what underlies your differences?
- Are there potential areas of conflict between you that are easy to predict?

One particularly useful aspect of working collaboratively is that of sharing learning and exchanging experiences as well as benchmarking. These are areas presented as having previously worked well and continue to be possible; for example, collaborations like the PTHC audits were described as beneficial.

Working collaboratively and having the opportunity to share learning across centres was an aspect raised by interviewees. A theme that we found in this respect was around new treatments as they move beyond trials and into wider practice. There are uncertainties about what clinicians have yet to learn: *'With EHL [products] there has been a real learning curve.'* It is clear from the respondents that there is much yet to know about how these changes in treatments will impact on centres and the services/clinics provided. Education days already take place and informal sharing/networking opportunities are used by all London centres to improve practice. Clinical teams are learning together within centres, and it was suggested that more could be done to share this learning across London: the challenge is finding timely ways to do this.

'There's a lot of enthusiasm for collaboration but we need to get together and show we could gain from working together [...] commissioners could provide the external leadership that's needed to bring all the expertise together.'

There is also a need for commissioners to work collaboratively. Respondents highlighted the need for more of a 'big picture' vision to be developed with patients, their families/carers and clinicians to ensure that the highest quality can be delivered for patients that use London services.

'There's a need for a "big picture" external commissioner and a "big picture" external clinician to really understand what's needed, and then get people round a table to work out the way forward.'

One aspect of this is the acknowledgement of the savings that are being made by those centres that actively engage in commercial clinical trials when looking for the financial envelope for treatment to be maintained.

Opportunities are arising from the national drive for integrated systems and partnerships. These would not only benefit people accessing haemophilia care, where it may be possible to address outreach challenges through expert support to local services, but also facilitate working together to deliver a coordinated pan-London response to the evolution in treatment and the changing patient populations.

'A shared "out-of-hours" service would require fewer on-call doctors but would require IT solutions to enable doctors in different hospitals to see patients' notes.'

London's haemophilia services could take advantage of the current policy environment by coming together and defining what is meant by working together, what we can agree on, and what our shared treatment goals (outcomes) are and where we differ, and whether those differences are insurmountable. They could build on the strengths that have resulted in the development of current integrated pathways and networked services, and collectively identify areas for developing further integrated pathways across London, for example:

- Reducing inequities in access to specialist physiotherapy, including radiosynovectomy;
- Access to specialised psychological support;
- Access to joint specific orthopaedic specialists.

In addition, the four comprehensive care centres could explore the potential for collaboration with local services in the development of outreach clinics. This should include members of MDTs supporting clinics in centres where they are less well resourced.

Living Well at Home

As discussed earlier, patients, families and carers want more care closer to home, wherever possible. Haemophilia care has traditionally been provided in a clinic-based (hospital) setting, and some clinicians described how the increasing complexity of their caseload without increasing staffing levels is keeping clinicians in the centres, leaving less time for outreach work.

But it does not have to be this way. Indeed, new care models are being trialled as part of the NHS England Five-Year Forward View, with Vanguard sites to support the improvement and integration of services [14]. The clinicians we spoke to identified ways in which haemophilia services could evolve and, in so doing, support the provision of care closer to home. These included:

Nurse-Led Clinics: Haemophilia specialist nurses already coordinate care and assess individual patients' needs, so the potential for nurse-led clinics is substantial. Some doctors estimate that, for around 70% of patients, the outcomes of care would be the same as clinics led by doctors. For example, at the Royal Free, most of the mild and moderate haemophilia patients are cared for by the nursing team, while the medical team looks after the severe patients. But having clear boundaries of responsibilities is important.

Community Haemophilia Nurses: Good chronic haemophilia nursing support in the community is significant in helping people to maintain their independence. Haemophilia nurses with a community aspect to their role can step in and advise patients, providing literature to care team managers about haemophilia if, for example, a patient breaks a leg and needs home support. Ideally, all complex patients should have at least one home visit annually for assessment. However, such services have been reduced in recent years due to lack of funding. Some of London's haemophilia nurses mentioned that they used to spend as much as half of their time in the community, but that their role now is one of firefighting and completing tasks. Of course, if more patients are to be treated in the community, community nurses will need specific training in managing people with haemophilia. Providing support for people living in care homes is variable and needs to be addressed: some clinicians describe this as *'nice to have'* and others as *'a necessity'* going forward. For specialist haemophilia nurses it was recognised that *'there may be problems of justifying community-based services as opposed to hospital clinics because outcomes will be based on the effect on quality of life.'*

Out-of-Hours Clinics: Clinical interviewees raised the possibility of monthly out-of-hours clinics at the centre. These would be convenient for younger patients and those who are working. Similar approaches were described as having worked for patients with other conditions, for example, sickle cell disease. It was highlighted that it may be easier to provide these clinics through extended hours rather than weekend services within the timeframe.

Mobile Clinics: In the future, as fewer patients need hospital-based care, clinicians felt that mobile clinics may offer a good option for ensuring that acute services are still available for patients with bleeds. Depending on GP interest, they could be held in local surgeries or primary care hubs, with options for home care and treatment when necessary. Useful working models already exist in the clinics offered by the Royal Free in several Camden practices and in the community anticoagulation service at the Royal London. Even doing just one outreach clinic once a year has potential, as is shown by the Royal Free clinics at Northwick Park, Luton and Dunstable, and Watford General, and by the Royal London in Basildon and Southend and Romford.

Greater Engagement with Primary Care Services: Historically, many have had access to care through their haemophilia centre. Going forward, centres will continue to play a role in facilitating patient engagement with their GP for access to primary care services such as screening, including cardiovascular risk assessment, access to IAPT and wellbeing services, and access to community services. *'This raises the challenge that if more patients are to be treated in the community then community nurses will need haemophilia training.'*

Similarly, when an occupational therapist is assessing someone's needs at home, it was identified that this needs to be a professional with some knowledge of haemophilia, not someone with less experience (as has been the case previously). An important aspect that was identified was *'the need to understand younger men with older bodies and their falls risks'.*

Provision in the community could be delivered by members of the specialist physiotherapy team and through education of community physiotherapists: *'There's probably a case for physiotherapists to do home visits with community teams to help keep older patients in their homes – a safer option than bringing them to hospital.'*

Bringing New Technologies into the Clinic:
Today, every haemophilia conference contains presentations on telemedicine and new approaches to the traditional clinic. While there is no substitute for hands-on patient assessment, in recognition of patient preference, the Royal London is undertaking a trial of a Skype clinic for mild haemophilia patients, primarily children. This is proving popular with patients, who find it more convenient than visiting the centre, resulting in fewer days lost from school. A further study has seen patients capture their own ultrasound scans of possible joint bleeds by means of a small hand-held device connected to a tablet.

Is That an Elephant Over There?

In undertaking this work, we set out to explore and highlight ways of working to enhance haemophilia care in London rather than to propose structural changes. However, during the interviews, clinicians frequently mused on the long-standing question as to whether or not the capital needs seven haemophilia centres. One clinician noted that Madrid and Berlin each have only one centre, although both are likely to be seeing fewer patients.

'We may need to start focusing services at major centres, and release money for more community services, gene therapy and trials [... but] if you start talking about closing places, people get very anxious. So we need to communicate well with patients, perhaps including options such as outreach clinics. If we could develop a model that really worked, it could be used by the NHS for other rare diseases, such as muscular dystrophy.'

Although not all clinicians echoed this viewpoint, one noted that:

'We could probably lose two centres in London and use the savings to improve services at the others and make care more fluid, so patients can be treated wherever is most convenient.'

In delving further into this question, it became clear that, although views differed, there was agreement that any focus on arrangements would need collaborative conversations between all centres, with oversight by commissioners in the context of a "Big Picture" vision for London. Previous discussions and reviews about how services should develop have raised concerns that centres will close, with negative implications for patient care and employment of clinical staff.

'Our concern is that, if somewhere like [centre] were to close, we'd just be given all their patients but without any additional money. However, we'd need more nurses, physios, data managers and admin staff.'

It was clear from interviewees that any reduction in the number of centres should not simply be a cost-saving exercise but should be accompanied by an improvement in the overall service within the capital. Any resulting transition of patients should be accompanied by running/revenue costs to permit further investment in nurses, physiotherapists, data managers and administrative staff at centres that take on additional patients. This could therefore provide more flexible services at those centres (for example, community-based services) and additional research capacity.

However, any such reconfiguration should clearly involve a wider discussion on what form of London-wide haemophilia service would best serve the needs of the people who offer and use the services.

Two, Four, Six, Eight, How Should We Communicate?

Almost every NHS Trust nowadays includes a commitment to better communication between healthcare professionals and patients as part of its "mission" statement. Clearly, effective information and communication are vital components of patient-centred care.

The NHS England Accessible Information and Communication Policy [15] states that:

'Providing accessible information will help to improve access to services, promote social inclusion and enables people to make more informed choices about their care. For staff, the provision of accessible information will aid

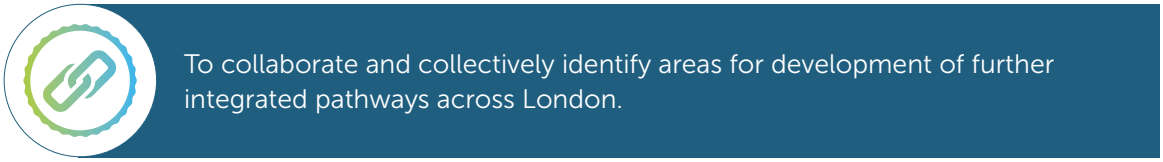
communication with service users, support effective engagement activity, and support choice, personalisation and empowerment. It will also promote the effective and efficient use of resources. The provision of accessible information can reduce inequalities and barriers to good health.'

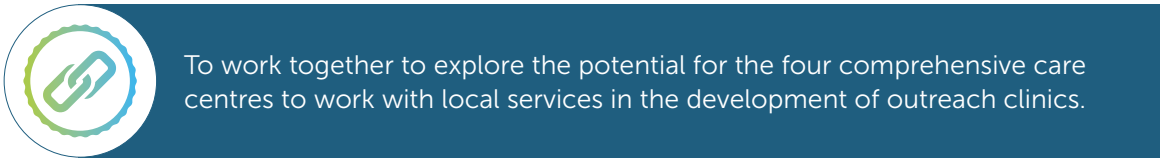
Given the close connection that develops between haemophilia professionals and patients, families and carers, communication is probably a great deal healthier than is the case in many other specialties.

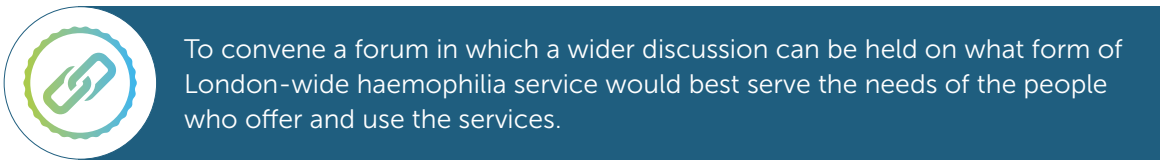
'Patients will often ring and speak to us if they have a problem. We try to keep a note of these calls, and e-notes has made that easier, but it can be difficult to get everyone to do this and we don't capture everything.'

Nevertheless, our survey revealed that patients, family members and carers often felt frustrated at poor communication with centres, particularly around changes in the membership of the care team. But the need was also expressed for more information on treatments, especially novel treatments. One such initiative currently in development at the Royal Free is the patient-focused website for the North London Adult Haemophilia Network.

Opportunities for London 2020:







2020 and Beyond: Next Steps

During the interviews a range of suggestions were made as to how services could and/or will need to respond to the changing landscape within which care for people with haemophilia and other bleeding disorders will be delivered. As one clinician responded, *'How and where we deliver will change.'*

Some of the suggestions that were described as important and/or achievable by 2020 with regard to enhancing services are:

- Extended hours to increase appointment flexibility;
- The use of technology to improve appointment flexibility;
- Providing updates on changes in staffing at centres.

New models of care will be needed and a number of areas of practice were suggested that are either already in development or need to be trialled to move beyond discussion into action. Whether it is sharing learning about new treatments or collaborating around integrated pathways of care, it will be important to research and share experiences in developing and delivering them. The panel below summarises further suggestions that were identified as being important to be well underway by 2020.

Variability in services

- Collaborate in identifying pathways that reduce inequities in access to care, such as specialist MSK expertise, orthopaedic surgery, psychosocial support
- Greater networking and collaboration between centres
- Further development of shared care and outreach clinics with local primary, community and hospital care
- Share case experiences and knowledge in 'real time'

Novel treatments

- More flexible services, such as nurse-led clinics, outreach clinics, community-based services
- Explore changing roles, for example, for physiotherapists
- Enhance educational opportunities for community nurses and patients
- Better understanding of patient priorities for 'normality' and how options and implications can be discussed with patients

Ageing population

- Develop pathways to support symptoms of ageing among patients
- Explore outreach and community-based services (including support for care homes)
- More support for ageing carers
- Share experiences of actions to support older people

Financial constraints

- Wider discussion on meeting the needs of people who use, offer and purchase services - consequences of changes and the evolving national context
- Explore centralised commissioning with services commissioned from centres across London based on areas of expertise
- Savings from budgetary cuts ringfenced for reinvestment within services

Foundations for research and knowledge sharing around clinical practice are already in place for London. The time to build on these foundations is now, and much could be achieved by 2020 that benefits patients, families, carers and clinicians alike.

Research: The evolving patient profile and treatment landscape brings with it changes in clinical practice and service delivery. Further research to understand the service changes that will make the most of the new treatments within the financial constraints was identified as being needed. This includes building the evidence base for the roles of different members of the MDT and better understanding the health outcomes. While research that focuses on understanding practice (including service evaluations) already happens, access to further support is needed, especially for non-medical members of the MDT, in terms of the provision of dedicated time for research, clarifying research questions and undertaking statistical analyses, for example.

Knowledge sharing: The importance of continuing to share experience within and between professions was highlighted; for example, physiotherapy and nuclear medicine, pain assessment and management, wellbeing and physical activity, and managing patients being treated with EHL products.

Final Thoughts

London haemophilia centres currently care for around one third of people with haemophilia in England. The feedback received from the clinicians interviewed and responses to the online survey from patients, families and carers confirms that current services work well, despite some variations in practice that need to be addressed. The envisaged changes in the treatment landscape and an ageing population bring both opportunities and challenges. These will need to be addressed if London is to remain at the forefront of the development of practice as well as clinical research, in order to improve the quality of services for the people that use them, and to achieve this within the NHS's financial constraints.

Looking to the future, the need to share experience of new treatments in practice with a wider population was a recurring theme; be it dosing strategies and the role of laboratories or developing knowledge and understanding among clinicians, patients, families and carers. There is growing recognition that the introduction of new haemophilia therapies in the context of the national policy drive towards greater patient choice will bring opportunities for greater individualised packages of care and resulting health benefits. Delivering personalised care and increased choice in a cost-constrained NHS will bring many challenges for clinicians and commissioners, including the potential for increasing disparity in treatment goals and outcomes.

The importance of personalised care, continuing to address variations in services between hospitals (particularly local general hospitals), provision for people with mild and moderate bleeding disorders (much of which could be nurse-led), MDT involvement, the potential for greater and different nurse roles, and the need for more physiotherapy and psychosocial support were all raised. Questions were asked about who will decide which products are available and what this may means for individuals' care, in addition to what the balance of outreach provision closer to home will be alongside evolving hospital provision to meet different needs. Working together across London and building on the existing formal and informal pathways will be key to continuing to deliver high quality care.

If the above are to be achieved and, in so doing, deliver real benefits for people using London haemophilia services, there needs to be frank and open conversation between clinical teams that acknowledge the inherent competition. While competition increases the potential for new discoveries in treatment, it can mitigate against providing the most comprehensive services.

As highlighted at the outset, managing the pressures of delivering high quality care for people with bleeding disorders in the NHS cannot be achieved by just working harder. There is a need to develop new models of care to meet the requirements for care in the community as well as in hospitals.

Our analysis simply brings together much of what is being discussed across London, the UK and beyond. The people working in London services can continue as they are, in the main providing

excellent preventative and management services. Individual centres can continue to respond to the evolving treatment options and the needs of patients as they arise by introducing changes to services within their own available resources; or they could grasp the opportunity arising from the changes in the national context, where the language of integrated care has come into focus.

The drive for integrated care will not deliver results quickly and needs a longer term commitment to providing and funding care going forward. It offers an opportunity for haemophilia services across London to build on their strengths and the effective pathways that already exist and, through collaboration, improve choice and achieve more for people with bleeding disorders.

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Appendix

1. The London 2020 Methodology

The aim of the London 2020 project was to better understand current services, identify examples of effective practice and explore what could be delivered differently in order to make the most of the opportunities arising from the changing treatment landscape, the drive to integrate provision and addressing some of the challenges that will be faced.

Patients and their families/carers were invited to complete a simple Google Forms questionnaire hosted on a dedicated website (see image).

The survey was promoted using social media, through posters in each of the London centres, and through short video interviews with clinicians and patients/carers hosted on the Haemnet YouTube channel. People completing the survey were entered into a prize draw for an iPad. The campaign to engage responses ran for eight weeks and was endorsed by the Haemophilia Society. Three simple questions were asked, with open text boxes used for responses:

What do you like about your haemophilia care in London?

What frustrates you about the services you use?

What changes would make a real difference to you?

In all, 51 people responded to the survey, 49% of whom were people with a bleeding disorder and 51% a carer or family member. All centres had at least one person responding to the survey, and 21 of the 25 patients were between the ages of 20 and 39 years. Most respondents were from Greater London (43%) and the South East (39%) with the further 18% covering the North West, South West, Yorkshire & Humber, East Midlands and East of England. The responses to the three key questions are shown in Appendix 2.

In parallel, we developed a questionnaire with a lead clinician in London (RL) before undertaking a series of structured face-to-face interviews with eight doctors (all centre directors as well as consultants), four senior haemophilia nurses, two physiotherapists and a data manager from the seven London haemophilia centres. We also interviewed representatives of the Haemophilia Society.

The questions focused on:

- Current haemophilia services in London (what works well and what could be done differently);
- The potential impact of new treatments for patients and models of care;
- The potential impact of the ageing population of people with haemophilia;
- Exploration of the opportunities for greater collaborative working;
- Priorities for a future London service.

The approach was overseen by a steering group with patient, family and clinical team membership.

2. Participant Survey Responses

The following table contains the detailed responses to three key questions in our survey of patients and carers. They are included verbatim.

What do you like about your haemophilia care in London?	What frustrates you about the services you use?	What changes would make a real difference for you?
St George's		
The nurse specialist team are easy to contact.	Cancelled appointments / rescheduled appointments for far in the future.	GP/other clinicians understanding more about my bleeding disorder.
Everything! Our nurse Julia Sexton is just the best. She cannot do enough for my son and my family. She goes above and beyond what we could ever hope to expect from a nurse and is always there for us. She never forgets anything. She always does what she says she will do. She is always very busy but never too busy for us. This must be hard to maintain but we really appreciate her for it. Our consultant is also great although we see her less often. We have had some very difficult times with treatment over the last year, but they have always been totally supportive, clear and honest, open and frank with us about our situation. They take the time we need for them to explain everything to us. It has been a very hard time, but they have really helped us through it all. We have email contact as well as phone and mobile, so know we are never alone. The registrars are always great and have worked hard to ensure any urgent trips to A&E are as easy and straightforward as possible. We would be totally lost without the support of our centre. It would be devastating and dangerous for our family if we didn't have their expert advice available to us.	Not much really. Lack of flexibility over clinic times, which we understand is very difficult, but it would be great if there was more choice over times so that we could have after-school appointments. The clinic do all they can to accommodate us, but it's just not possible or probably realistic. But it would be ideal for us if this could happen.	Most of these are a real wish list and not really expected, but you did ask! Most are to do with overnight stays rather than actual care given, but they do have an impact on the hospital experience. After-school appointments for outpatients. To have a more dedicated unit on which to stay, so we might meet other boys with the same condition when we have to stay in hospital rather than all general kids' things. Or even of a similar age so maybe the patients are able to chat or play something together. We are usually with much younger babies so it's hard to pass the time together. Age appropriate toys / activities / books for older than 10 years – the playroom is for the very young which used to be fine but now we really have to go prepared. A quiet room / space away from the bed where the patient can go to read or do homework and get out of bed when not immobilised, just to give a change of scene and somewhere quieter to get away from the general noise. Somewhere more comfortable for parents when they stay overnight – this is really hard to provide and not a priority, but it would make a real difference, e.g. more comfortable bed, parents' shower. A ban on people having their curtains around them all day, as it totally blocks out light and air and any sense of community on the wards. A ban on watching TV or using noisy toys without headphones.

What do you like about your haemophilia care in London?	What frustrates you about the services you use?	What changes would make a real difference for you?
Easy to get help and advice from people who know about my condition and the related problems. Appointment waiting times are short.	The distance to travel for appointments.	Being able to have blood tests taken locally (at GPs possibly) would cut down on visits and travel to and from hospital.
The friendly doctors and nurses that make the centre a welcoming place and not just a hospital clinic.	The only thing that frustrates me is this new way the NHS has been forced to work. I never use my GP – they don't understand and it was better when the centre could refer me to other departments if they felt it was the right thing.	If the government would stop trying to privatise the NHS and allow them to get on and do their job. Always felt it would be a good idea if we had some physio sessions each year as it is hard to keep being motivated to exercise on your own.
The nurses	Nothing	If mental health services were incorporated or offered with the care given.
Very helpful and kind staff. Always quick to reply and do the needful.	Nothing	I think they provide the best service.
Fantastic – care nurses are amazing	Parking at the hospital	Parking. I'm also not entitled to a disabled badge and thus [it] is tricky with leg issues.
Local	Lack of options to come and have a check-up	Expand on more than just one Wednesday afternoon each month
Continuity of care and direct contact with the medical team	The lack of funding to the department	The system works for me but [I would like] to be kept up to date with changes.
Quick diagnosis with genetic test. Seeing consultant at each appointment. Specialist nurses available on email. Multidisciplinary specialist clinic in the paeds [i.e. paediatric] wing and their quick response. Also like that [we] have on-call Reg [i.e. registrar] details in case [we] ever had [a] serious bleed.	Slightly conflicting messages on whether school needs meds (tranexamic acid) and when to carry Factor on you if travelling (for mild haemophilia). The school issue can have quite an impact in terms of hassle factor and stigma for [the] child as [they] have to collect meds from [the] school nurse every time they leave [the] site for games, swimming, etc., each week.	Addressing [my] child's anxiety a bit more. He has [a] bad association with clinic after about eight tubes of blood [were] taken for test at one appointment. [He] Needs a lot of reassurance. Also, I carried the factor overseas but don't really know how it is administered if needed in [a] foreign country – [it would] be helpful to see a YouTube video of this or something, just so I know, in case [I] ever needed [to do it] and to know [that] any overseas doctors know what they are doing (planned travel to South America). Being put in touch with others with mild haemophilia could be helpful.
They are always helpful and quick to respond to situations.	Nothing really	Nothing really
Very caring and helpful	Sometimes it can take a while	Having medication which could cover my clotting levels at a constant rate for a week plus, rather than taking injections every other day.

What do you like about your haemophilia care in London?	What frustrates you about the services you use?	What changes would make a real difference for you?
St Thomas' Hospital		
I like the access to the comprehensive and holistic health service that I receive in London, with a high focus on personalised care and self-management. In particular, the access to high-quality and full-time physiotherapy as a preventative service, as opposed to a reactive intervention, enhances my satisfaction with the service. The use of health promotion alongside regular screening through HJHS [Haemophilia Joint Health Score] and POCUS [point-of-care ultrasound] allows for greater engagement in treatment planning and greater empowerment in self-management of my condition. I also like the low labour turnover in core staff, which has allowed me to build a strong rapport with the clinical team over many years. This has enhanced my experience as a patient, as my clinical team fully understand me [and] the demands my condition puts on both my personal and professional life, as well as the best ways to engage me in any changes in my care plan. I also like that I haven't been offered a telephone clinic by my centre. I advocate the use of HJHS and POCUS at regular intervals, and telephone clinics would compromise the implementation of these screening tools.	I have no direct annoyances. I would like to see the out-of-hours service be examined to see how it can fit in with the life demands of the local working population (potentially looking towards a seven-day service), in line with reforms occurring widely in the NHS to increase access to services and further reduce impacts of the condition on professional lives. As I currently commute I have no issues with access to my centre; however this may be an issue to other service users within the South-East who either have busy professional lives or have reduced mobility. As far as I am aware there isn't provision for primary care services for adult patients (apologies if this is incorrect), which may benefit some service users. I can understand how the limited number of patients, mixed with the large catchment area, would make a dedicated primary care service unrealistic and not be cost-effective.	Currently I have no requirement for any changes in my care. In the future, the opportunity to access a comprehensive seven-day service may become important as my professional life progresses. Should my mobility be compromised, access to a dedicated primary care service would be ideal. In balance, however, a seven-day day service with continued emphasis on health promotion and screening would be beneficial.
They know what they're talking about	[The centre is] So far away from home. Docs take ages to get back to you.	Friendlier docs
Excellent care around the clock	Distance we have to travel	More updates on team members/ personnel changes within the department
That the medical team care	Long journey	Being nearer to centre
They have factor and can spell haemophilia without prompting, unlike my local hospital.	The recording systems are not strong enough - things get forgotten, lost or missed (referrals, bits of information, etc.).	If there was enough staff to do all the things the centre currently has to do. Like everyone else in the NHS they all need more time.

What do you like about your haemophilia care in London?	What frustrates you about the services you use?	What changes would make a real difference for you?
Decades of continuity. Great clinical team at Tommy's. Text message reminders.	[I] Worry about what treatment I would receive if admitted as an emergency to another centre without my records.	Remote or virtual reviews. Taking time off work for appointments is a pain. Auto-syncing of appointments with my Google calendar (i.e. email appointment reminders).
Easy to access, friendly and [they] really try to listen.	At times attention to privacy and dignity could be more present.	Sometimes to pause and think about who can overhear in public areas.
Most things	N/A	Stability – staff and location
Comprehensive care and reliable product	No out-of-hours or weekend service	An out-of-hours and a weekend service
Evelina		
Confident about [the] haemophilia team	[It's a] 35-minute train ride away. [I] Don't like going to [the] local hospital in an emergency as [I have] no confidence in them.	Local hospitals having more knowledge, or at least local A&E paediatrics having training on haemophilia.
The nurses are very friendly and efficient.	How far away it is, so the travel time.	The car park to be cheaper!
The staff. And the Evelina is a very lovely child-friendly place to be.	The size of the room the paediatric haemophilia nurses have	More space for the department
The haematologist consultant and her team are really good at what they do. And we get quite a lot of support from the team.	N/A	Can't think of any
Lewisham		
The doctors are friendly and are very welcoming and ease a difficult situation.	I just don't like hospitals in general.	If a separate clinic was made for bleeding disorders.
Great Ormond Street Hospital		
All the medical team seem to be on the ball about current and new treatment on offer. Friendly and caring and highly professional team.	Factor VIII is too rationed. It would be much better to sustain a higher trough level to be on the safe side. A planned trough level of 1[%] means there is not much room for error.	Having more home visits. We've only had one so far, and the rest have been cancelled due to staff shortages.
Amazing staff, the best treatment/ care, the ability to see the whole team in one place on the same day, feeling empowered to manage the condition, the way my son is welcomed and made to feel special, the flexibility shown by staff to our needs.	Nothing, I believe it's the best. It frustrates me when I hear the experiences of others in different centres where young boys are suffering bleeds and damage due to differing treatment regimes.	We are being encouraged to think about a move to adult services (we are in denial :o). I would love for our transition to adult services to be smooth and for the team to be as wonderful as those at GOSH – they are a hard act to follow.
Very thorough, friendly and approachable	None	None
Professional, caring	None	None

What do you like about your haemophilia care in London?	What frustrates you about the services you use?	What changes would make a real difference for you?
The nurses, consultants and physio are brilliant. They make you feel at ease and are always there to help however they can.	Nothing (maybe parking!)	Nothing. It is a fantastic centre with amazing staff.
Friendly staff – [I] am always kept well informed and I am listened to.	Can never get dental appointments	Getting a dental appointment on the same day as clinic appointments, even just once a year.
Brilliant	Nothing	More consultations
Everything excellent all round.	Nothing	None that I can really think of.
Second-to-none expertise, efficiency, professionalism, 'can do' ethos, flexibility.	Lack of home support/local support.	Home support for training, which is readily and regularly available at other centres. For us, in particular with IV training, where we were left to our own devices and actually denied local support that was available. As a result, we unfortunately failed.
Lovely team of consultants/nurses and physiotherapist that listen to you about any concerns and do their best to help. Great treatment.	Travelling time (but [it is] my choice to come to London)	I am happy with the treatment and care I receive now.
Fantastic staff who are so up-to-date with their knowledge and who care for the whole family.	Just the distance to travel and expense of travel	If Great Ormond Street had a branch nearer to where we live.
Helpful, patient, approachable and supportive. Always happy to for us to get in touch with concerns and questions and help us manage the condition.	We are happy with the care that we receive.	We are happy with the care that we receive from GOSH. Medical advances in the treatment of haemophilia would make a difference.
World leading experts, supportive and personal care. The haemophilia clinicians really know their patients and listen to carers. I feel like we are in a true partnership in the care of my son.	Ancillary care – the dentist service at GOSH is awful. Nine times out of 10 they cancel or move your appointment, which is frustrating if you're planning a multidiscipline visit to the hospital on one day. You can also never get through to them [on the phone] and it seems to be that only one person can book appointments - highly inefficient.	Improve the way the ancillary care supports the haemophilia centre/ their patients.
Royal Free Hospital		
Always on hand to help and give advice on bleeds.	Not being available nights and weekends.	Having an on-call haemophilia specialist.
Continuity of staff and treatment.	Nothing really. Having moved away from London they are harder to access.	Flexibility of appointments.

What do you like about your haemophilia care in London?	What frustrates you about the services you use?	What changes would make a real difference for you?
All of the staff are really knowledgeable and helpful.	Nothing at the moment	Nothing at the moment
Continuity of staff	Not much really! They are very good.	An on-site dentist
I have extremely good access to a physiotherapist who specialises in haemophilia. I have extremely good access to gym and hydrotherapy facilities for physiotherapy sessions. The physiotherapist is a core integrated member of the care team who I see regularly and is consulted during every joint bleed I experience. I am expected and it is scheduled that I see the physio after each joint bleed. The physiotherapy I receive during the rehabilitation period after a bleed is correctly deemed as important as the treatment I receive to stop the bleeding. My consultant expects me to see the physiotherapist as part of the treatment for a bleed as well as ongoing sessions to maintain my joint strength to reduce the number of bleeds I experience. When I experience an acute bleeding episode there is a dedicated haematology ward in the same building. I do not have to go to a general ward to receive treatment for an inpatient stay in hospital. I'm able to drop in to the centre knowing that I will be able to see a nurse I know about any problems I am experiencing. Seeing a therapist is part of the schedule of review appointments.	Review appointments are booked up months and months in advance. There is often little flexibility due to the sheer number of patients vs appointments available. It can be frustrating knowing there is no service over the weekend. Having to wait in A&E for doctors who do not know you to assess an acute bleed can take a long time and can mean treatment and painkillers take a long time to receive.	Even if a new drug is available and does not suit me, the patient, to take or be put onto a trial for, it would be really nice to be regularly updated on new haemophilia medications that are coming onto the market. As a patient, often your consultant is the first and only point to receive this information, I think it's easy to presume patients keep up with new medications or upcoming ones, which is often not the case. Having been based in two cities outside of London to study over the last five years, it is difficult to criticise the care I have received in London. It is head and shoulders above the care I have recently had access to. I only wish the standard of treatment available from the Royal Free was available everywhere in the country.
Royal London		
Doctors/nurses are happy to speak/see you without a formal NHS appointment.	Nothing particularly	For blood tests to be taken straight after the appointment in the same room. This would save time.
Experienced staff	Travel and expenses. Also, to be referred takes too long.	Local hospital service. To be referred more rapidly.
The support and friendly staff	N/A	N/A

What do you like about your haemophilia care in London?	What frustrates you about the services you use?	What changes would make a real difference for you?
Hammersmith Hospital		
Clean modern hospitals with excellent doctors and nurses, high standards, on the level	Most hospitals in the UK do not have such facilities so there can be a lot of travel during a bleed, but obviously excellence is improved by consolidation. Also, patients used to feel like "guinea pigs" and there was duplicity experienced by others, but those days are (I assume) long ago. Hospital-acquired infections are probably off the menu now, but it's hard to forget it happened to thousands, and people died.	More haemophilia centres of excellence outside major cities. Getting awareness out, to GPs in particular, that possible bleeds and undeniable bleeds are really serious and are something to worry about, needing fast action, not denial.
Home delivery	Communication	Not applicable
Home delivery	Communication	Not applicable
Friendly	Care for long-term joint damage is frustrating compared to short-term haemophilia care, which is good	Better long-term joint care services, better access to physios.

3. Acknowledgements

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