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Improving patient pathways for heavy menstrual bleeding

Sarah Smith
Surgical Communications Manager, Hologic UK and Ireland

Foreword by Sarah Smith

Every day, across the country, women and girls struggle to manage menstrual health conditions that impact their ability to study, work, manage family life and enjoy leisure activities. And yet, many of these conditions remain hidden; taboo subjects rarely discussed, with women expected to 'just get on with it'.

Heavy menstrual bleeding (known as menorrhagia) is no exception. It is time we take action to create change.

At Hologic, we see it as our mission to champion women's health – not just access to technology and treatments, but also to drive awareness and understanding of health conditions. In 2021 we launched the Hologic Global Women's Health Index (HGWHI), a globally comparative study in partnership with Gallup, to measure and monitor the behaviours and attitudes that influence women's access to quality healthcare. It provides us with a unique insight into the experiences of women across the globe, including the UK.

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We know that we need to work collaboratively to change the status quo. This attitude is reflected in our every day - I spend a lot of my time speaking to clinicians and patients to better understand the challenges they face and the solutions that we can collectively create. It was in this spirit that we convened a roundtable of experts from across the continuum of menstrual health care to discuss how we can improve patient pathways for heavy menstrual bleeding. We were honoured to also be joined by Dame Lesley Regan, the first Women's Health Ambassador for England.

We examined three areas during our discussions:

- patient and clinician understanding of the symptoms of heavy menstrual bleeding.
- how to ensure that women can easily access help for the condition and that when they do their voices and experiences are heard and, critically, listened to when decisions are taken over treatment options, desired outcomes and treatment settings.

- how to make the best use of technology and novel processes to improve treatment pathways and help tackle the backlog for gynaecological conditions such as heavy menstrual bleeding.

The discussion was fascinating and inspiring, and brought together a diverse group of organisations who, along with Dame Lesley, were passionate about coming together and identifying the ways to improve patient pathways.

This report reflects the views, ideas and insights shared. The recommendations we have outlined are as specific and practical as possible. These are designed to complement the, necessarily, broader ambitions and ideas communicated in the recent Women's Health Strategy, which marks an important moment in the UK's public discourse around women's health.

I hope that this report makes a meaningful contribution to that debate and inspires long overdue action.

Sarah Smith,
Surgical Communications Manager,
Hologic UK and Ireland

September 2022

Our recommendations

Our roundtable and this report are the first steps in a conversation about the best approaches to improving treatment pathways for heavy menstrual bleeding. To help shape that journey, we have developed the following recommendations. These are based on the roundtable discussion and results of a survey of British women.

Recommendation One: The Office for Health Improvement and Disparities (OHID) should develop a specific communication campaign targeted at primary care networks, highlighting key symptoms of heavy menstrual bleeding and the various routes for treatment. This could take a number of forms, including an online continual professional development training module, or a dedicated NHS website as a 'one stop shop' on heavy menstrual bleeding.

Recommendation Two: Likewise, the OHID should develop a public information campaign aimed at women to destigmatise heavy menstrual bleeding and menstrual health. This delivery should reflect the broad demographics and use existing channels (such as NHS websites) and social media (like TikTok and YouTube).

Recommendation Three: The Department for Education (DfE) should include a module on healthy menstruation, including an understanding of what could signify abnormal periods, heavy bleeding and related conditions, as a core part of the relationship and sex education curriculum.

Recommendation Four: The Department of Health and Social Care (DHSC) should set an aspirational target for the time taken for the average referral for heavy menstrual bleeding in order to drive a more responsive approach by GPs.

Recommendation Five: The NHS should establish more women's health hubs in areas that, for cultural or religious reasons, have low levels of engagement around menstrual health and heavy menstrual bleeding. This would provide a more convenient, culturally sensitive and female-focused setting for appointments about menstrual health.

Recommendation Six: The NHS should explore the potential for including a 'screening' process for heavy menstrual bleeding in the routine set of checks and questions when a woman attends a primary care surgery for any gynaecological procedure or consultation, such as cervical cancer screening.

Recommendation Seven: When a patient presents with heavy menstrual bleeding, it should become mandatory for the GP to record the impact that the condition has on the patient's quality of life in their medical history – too often, this tool varies between GPs, so the NHS should develop and roll out a standardised questionnaire that fulfils this function (NHS Digital could then capture data on this and recognise the severity of the issue and ways to streamline).

Recommendation Eight: Once a woman receives a diagnosis of heavy menstrual bleeding, all potential treatment options and pathways should be discussed as set out in the NICE Quality standards for heavy menstrual bleeding (QS47), alongside the benefits and potential drawbacks. This information should also be provided in written form.[1]

Recommendation Nine: Every hospital in the UK should have facilities to offer an outpatient 'see and treat' hysteroscopy service[2] including endometrial ablation as a treatment for heavy menstrual bleeding – not only would this provide a less invasive treatment pathway for many patients, but it would also free up theatre time and help tackle the current elective care backlog.[3]

Recommendation Ten: Readdress the categorisation for heavy menstrual bleeding to be referred as a 'chronic disabling' condition rather than benign.

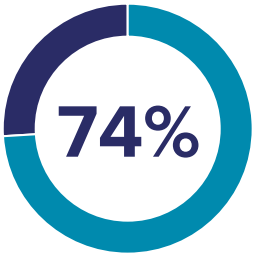
Introduction

Heavy menstrual bleeding, or menorrhagia, can significantly impact a woman's quality of life. According to the National Institute for Health and Care Excellence (NICE), around one in 20 women aged between 30 and 49 see their GP each year for help with heavy periods or menstrual problems.[4] It is the fourth most common reason for secondary gynaecological referral, making up 12% of all referrals to gynaecology services.[5] Of those suffering from heavy menstrual bleeding, 74% experienced anxiety and 69% suffered from depression.[6] Menstrual health was also the fourth most selected topic by respondents to the Women's Health Strategy, with 47% suggesting it should be included in the Strategy.[7]

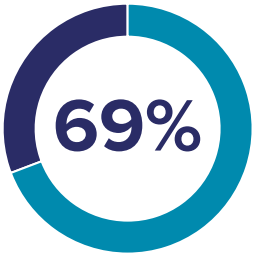
the symptoms of heavy menstrual bleeding or dismissive of the condition's impact.

The result is that many women may either be unaware that heavy menstrual bleeding is a medical condition for which they can and should seek help; or when they do seek help, they have to fight for a diagnosis. Many suffer unnecessarily for years in silence. Their quality of life, whether at home, in education or at work, is dramatically affected.

That struggle does not necessarily end when a diagnosis is made. Too often a woman may remain in the dark about her range of treatment options, with invasive and potentially debilitating



of those suffering from heavy menstrual bleeding experienced anxiety



of those suffering from heavy menstrual bleeding suffered from depression

Yet research found that only 53% of secondary school teachers reported that menstrual health education lessons were taught in their schools.[8] With teaching so inconsistent, and women often reluctant to discuss period health with their peers, it is unsurprising that there is a lack of awareness and understanding around conditions such as heavy menstrual bleeding.

This is not just confined to wider public understanding. Even if women seek help, they may struggle to receive a diagnosis from clinicians who might not be experienced in recognising

procedures such as a hysterectomy often almost a reflex response, despite a range of innovative, less invasive alternatives. Women deserve to know their options, and have their preferences placed at the heart of their treatment plan.

Of course, this is all happening against a backdrop of an unprecedented elective care backlog, a longstanding trend significantly exacerbated by the disruption caused by COVID-19. More than half a million women in the UK are on waiting lists for gynaecological appointments for diagnosis and treatment.[9]

Yet while the pandemic did make the situation worse, it also pushed new and innovative approaches to care to the fore, which could be deployed to provide the menstrual health support women deserve. Treatment within outpatient settings, new and less invasive technologies, and a 'see and treat' approach are all options that may provide some of the solution to tackling the gynaecological care backlog.

While these challenges are widely acknowledged, the solutions can often feel elusive. This report offers practical and tangible steps that can be taken by policymakers and health officials to drive improvement in understanding, diagnosing and treating heavy menstrual bleeding.

It is informed by the insights shared by experts from across the continuum of menstrual health care at a roundtable held in Parliament, as well as data gathered through a survey of women from across the country on their understand and experiences of heavy menstrual bleeding.

With the Women's Health Strategy published in July 2022, there has never been a better or more important time to identify and promote new approaches to educating, diagnosing, treating and destigmatising heavy menstrual bleeding.[7]

Roundtable Attendees

Professor Justin Clark
Consultant Gynaecologist and Honorary Professor, Birmingham Women's Hospital, and the University of Birmingham

Professor Hilary Critchley
Head, Deanery of Clinical Sciences, Edinburgh Medical School

Dr Christine Ekechi
Co-Chair, Race Equality Taskforce, Royal College of Obstetricians and Gynaecology

Gail Fortes Mayer
Commissioner at Place and System, NHS England

Terri Harris
Menstrual Sexual & Reproductive Health Manager, Bloody Good Period

Debbi Holloway
Women's Health Forum, Royal College of Nursing

Mike Kane MP
Member of Parliament for Wythenshawe and Sale East

Janet Lindsay
Director, Wellbeing of Women

Dame Lesley Regan
Women's Health Ambassador for England and Professor of Obstetrics and Gynaecology, Imperial College London

Tim Simpson
General Manager, Hologic UK and Ireland

Sarah Smith
Surgical Communications Manager, Hologic UK and Ireland

Emily Stewart
Co-Founder, The Real Period Project

Dr Natalie Brown
Research Officer, Swansea University

1

Awareness and education among women and clinicians

1 Awareness and education among women and clinicians

It is a simple fact that unless a woman suffering from heavy menstrual bleeding is accurately diagnosed, she cannot be effectively treated. The process of diagnosis begins with a woman feeling confident, informed and able to voice her concerns to a clinician.

However, currently many women do not understand that their heavy periods are not something that has to be endured. As noted in the introduction, the extent of menstrual education can be mixed, resulting in an inconsistent understanding among women and girls regarding what they should expect when it comes to menstruation.

In light of this, it is certainly a welcome aspect of the Women's Health Strategy that girls and boys will receive high-quality, evidence-based education on menstrual and gynaecological health from an early age.

This view was endorsed by the group, with it being noted that we simply need to talk more about periods - women have 12 periods a year for nearly 40 years, and yet people are reluctant to discuss the topic.

One place to begin talking about periods, and sharing information, is in schools. While there is a requirement to teach menstruation and wellbeing, crucially there is little guidance on what that constitutes.

Emily Stewart, co-founder of the Real Period Project noted that much of the education in schools still focuses on the science of menstruation, but not "the practicalities of how to manage a period, what's a normal period, what's not a normal period." She added that "the Department for Education teaching materials

> "It's really about helping young people understand what's normal, because there's a lot of misnomers and misconceptions."

This was a point raised by **Gail Fortes Mayer, commissioner at Place and System, NHS England**, during the roundtable, when she highlighted the role of imparting knowledge effectively from a young age. Gail noted that, "It's really about helping young people understand what's normal, because there's a lot of misnomers and misconceptions."

are quite good, but they talk about differentiating what a normal period is compared to a painful period, they don't yet mention anything about having heavy bleeding."

Another important source of information on periods is social networks such as TikTok and YouTube. While these communication channels may provide an excellent route to reach,

in particular, young women and girls, concern was expressed that the information shared is often inaccurate.

Dr Natalie Brown, a researcher at Swansea University, identified the trend as part of her study on menstrual cycle education. During the roundtable discussion, she talked about the conflicting value of social media for the women she studied: “In some ways, it was great, because they had some awareness, maybe more than potentially slightly older women and girls I’ve spoken to, but at the same [time], it’s also a concern because you have no idea if that information is correct or what you’re receiving.”

On this point, **Professor Justin Clark, Consultant Gynaecologist and Honorary Professor, Birmingham Women’s Hospital, and the University of Birmingham**, suggested that “NHS website should give pre-eminence to providing reliable information. We need reliable, NHS badged information to access through these social media platforms that young women actually use or at least advertise links using those platforms.”

Other potential avenues to educate women about healthy periods, and the symptoms of heavy menstrual bleeding, include through employers.

Debbie Holloway is a nurse consultant in gynaecology and part of the Women’s Health Forum at the Royal College of Nursing. She shared an anecdote about her work delivering women’s health education at Guys and St Thomas’ NHS Foundation Trust and how amazed she has been that in a predominantly female workforce, “how many people don’t know anything about periods… a lot of people are walking around the Trust in a health environment without any access to knowledge, or if they do have any questions, they don’t know where to take them.”

Janet Lindsay, CEO of Wellbeing for Women, agreed, pointing to one potential solution - “employers having women’s health networks and, for example, menopause cafes” to provide opportunities for employees to access information.

Education is also essential in ensuring that when a woman does seek help, she is met by a sympathetic and engaged GP.

While participants at the roundtable were quick to acknowledge that we cannot expect our general practitioners to be experts in every area, there was broad agreement that more could be done to ensure that women received care and attention more quickly when presenting with menstrual health concerns such as heavy menstrual bleeding. This is a point echoed by the Women's Health Strategy, which has the ambition of healthcare professionals in primary care being well informed and trained in menstrual and gynaecological health.

There is much work to do in this area. **Professor Justin Clark**, reflected that he often hears "stories from patients saying that they've had to go two or more times to be seen before being offered treatment or getting a referral."

This challenge of a woman's voice not being heard and, critically, listened to was echoed by **Dr Christine Ekechi, co-chair of the Race Equality Taskforce at the Royal College of Obstetricians and Gynaecology**. She commented that "when you then go to a healthcare professional and say you have heavy menstrual bleeding, it's often then determined by that professional as to whether it is heavy or not...[but] it really is about empowering the individual and saying, if an individual presents and says that they have heavy menstrual bleeding, they have heavy menstrual bleeding."

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Of course, women in particular minority or more vulnerable groups may find it even harder to make their voices heard. As noted by **Terri Harris, Menstrual Sexual & Reproductive Health Manager, Bloody Good Period**, "refugees and asylum seekers in the UK have faced huge barriers assessing any type of care, because general practitioners don't know their rights within the UK health system."

But how can we help GPs offer improved support for women presenting with heavy menstrual bleeding?

Professor Hilary Critchley, Professor of Reproductive Medicine, University of Edinburgh, highlighted that "Education about heavy menstrual bleeding needs to be revisited in our medical school curriculums, with trainees having enough time to focus on gynaecology."

She also noted that we need to change the mindset of GPs, so that they ask patients about their periods as a measure of health more widely: "Heavy menstrual bleeding is probably the commonest cause of anaemia and iron deficiency. We need to educate other areas of medical care that you need to ask about periods if you're being referred for investigation of anaemia, this is currently not happening."

As **Professor Critchley** put it, "It's not difficult to say, how are your periods?"

Importantly **Dr Ekechi** made the point that even if a GP is quick to identify heavy menstrual bleeding, and wants to refer a patient, they may struggle to do so. On the time taken to refer a woman for secondary or tertiary care for heavy menstrual bleeding, she noted that "there are difficulties in referring women on to secondary and tertiary care - there's a very strict criteria that has to be reached before we can accept her from the GP. GPs are not the barrier".

Recommendations

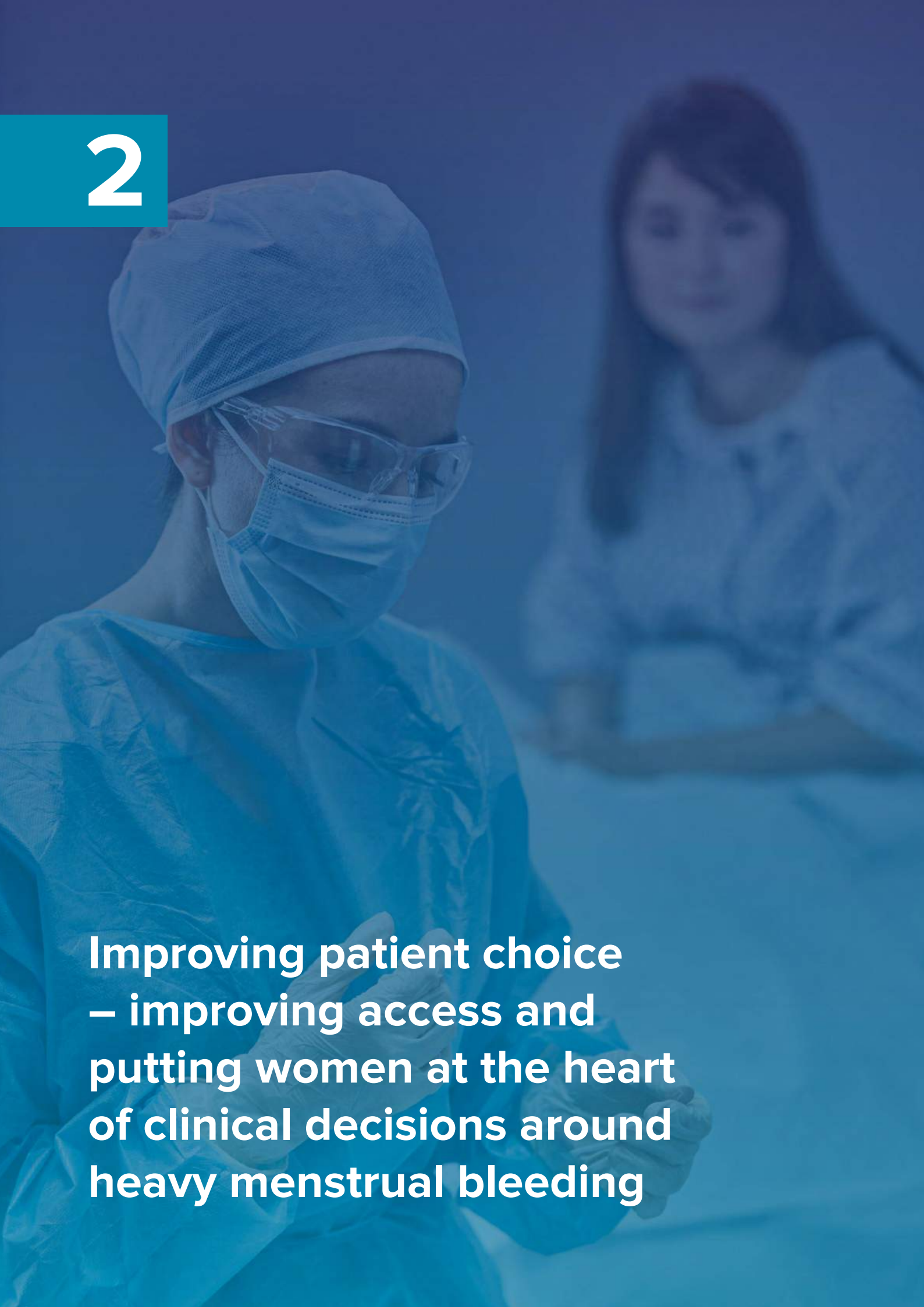
Based on the insights and expertise shared at the roundtable, we recommend the following actions to improve understanding of, and education about, heavy menstrual bleeding among the public and primary care practitioners.

Recommendation One: The Office for Health Improvement and Disparities (OHID) should develop a specific communication campaign targeted at primary care networks, highlighting key symptoms of heavy menstrual bleeding and the various routes for treatment – this could be in the form of a continual professional development training module rolled out digitally, and a dedicated NHS website as a 'one stop shop' on heavy menstrual bleeding.

Recommendation Two: The OHID should develop a public information campaign aimed at women and girls to more widely destigmatise heavy menstrual bleeding and menstrual health. This delivery should reflect the broad demographics involved, including religious and cultural sensitivities, and utilise existing channels (such as NHS websites) and social media (e.g. TikTok and YouTube).

Recommendation Three: We welcome the Women's Health Strategy's commitment to "Improve education and information provision on menstrual health and gynaecological conditions through the introduction of RSHE in schools". The Department for Education could deliver on this by mandating the inclusion of a module on healthy menstruation, as a core part of the relationship and sex education curriculum. Focusing on ensuring there is an understanding of what could signify abnormal periods, heavy bleeding and related conditions they would be ensuring they specifically tackle the issue of heavy menstrual bleeding.

Recommendation Four: The Department of Health and Social Care (DHSC) should set an aspirational target for the time taken for the average referral for heavy menstrual bleeding in order to drive a more responsive approach by GPs.



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Improving patient choice – improving access and putting women at the heart of clinical decisions around heavy menstrual bleeding

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The roundtable participants were unanimous in their belief that more needs to be done to improve education about heavy menstrual bleeding, to support more women to feel empowered to seek help. However, too often, even if she is empowered, a woman may still struggle to access care and her voice and needs are lost in the process of diagnosing and treating the condition.

So how can we put women and their needs at the heart of our approach to heavy menstrual bleeding?

One of the main challenges is giving people time to feel listened to, with short GP appointments making it hard to discuss often complex menstrual health issues.

There was general agreement across our experts that women's health hubs are one solution to giving women the space and time to be heard, and to access care in a way that better suits their lifestyle.

Or, as **Terri Harris** put it, going to women "in communities, in employment, wherever they are, that's how we should be talking to them... women have really been silenced and not listened to for so long, just being listened to once, then allows you to want to access that care again."

This was a sentiment echoed by **Janet Lindsay**, who noted that "women for so long have felt dismissed... going to see their GP six or seven times... So what a woman's health hub would do

> "Women have really been silenced and not listened to for so long, just being listened to once, then allows you to want to access that care again."

As **Professor Critchley** noted, "it's about having a longer vision where clinical care could be more efficient if only more time was devoted to addressing the [woman's] need... one of the first steps to putting the woman at the heart of our approach is that you give her the time she needs. And we look again at whether we could be more efficient about the number of times she has to attend or the number of potential interventions or discussions."

is have people who are genuinely enthusiastic and passionate about women's health. So, when somebody visits them, they know that they're going to be listened to."

Professor Clark agreed, saying "I've done years of promoting high street gynaecology – women's health hubs should be set up next to Starbucks on every high street and open all night!"

Emily Stewart from the Real Period Project noted that there is an opportunity to explore menstrual health with women when they attend settings for other procedures or tests – in many ways a form of informal screening. She said, "In general practice, I see a lot of women for smear tests or contraception, and it feels like when we give them a smear, we ask them about breast health. It's such a perfect opportunity to do some education around menstrual wellbeing at that time."

The idea of screening for menstrual health problems such as heavy menstrual bleeding, rather than relying on women presenting to a clinician, was widely supported. **Dr Ekechi** gave the example of a project she is involved with in Hammersmith and Fulham, in which community nurses who are trained to perform cervical screenings also provide breast health education.

On the theme of women's experiences and perspectives being at the heart of how they are diagnosed and treated, **Sarah Smith, Hologic's UK Surgical Communications Manager**, highlighted the fact that there is still no standardised approach to GPs taking a patient history when an individual presents with a menstrual health condition.

She said, "There aren't really standardised tools available for GPs. So, there's real disparity when it comes to inequalities, and that's where I think we're seeing the challenges where patients aren't being managed as effectively or triaged to recognise symptoms such as fibroids and endometriosis. I think that starts at the very beginning, that first consultation."

The need to improve the recording of a patient history is highlighted by the NICE quality standards for heavy menstrual bleeding.[10] The standards also emphasise the need to implement protocols and data collection tools to effectively recognise and diagnose the condition.[10]

There was broad agreement that cultural and religious sensitivities, and socio-economic differences, must also be considered - what works for one demographic may not be as successful for another.

Dr Ekechi highlighted the challenge that some black women face in receiving a diagnosis and treatment, and how not having their voice heard early in the process can lead to negative consequences down the treatment pathway: "One of the conditions that we know that women often present with when suffering from debilitating heavy menstrual bleeding, is fibroids. We understand that black women tend to find that they come across many barriers when it comes to presenting with heavy menstrual bleeding, leading to a delay in the diagnosis of fibroids for which they then need surgical intervention, which has morbidity attached to that."

On that note, **Dr Ekechi** suggested one way to include the voices of more women on heavy menstrual bleeding, is by "making sure that we have diverse voices who are providing this education, which means that you pull every single woman along."

Recommendations

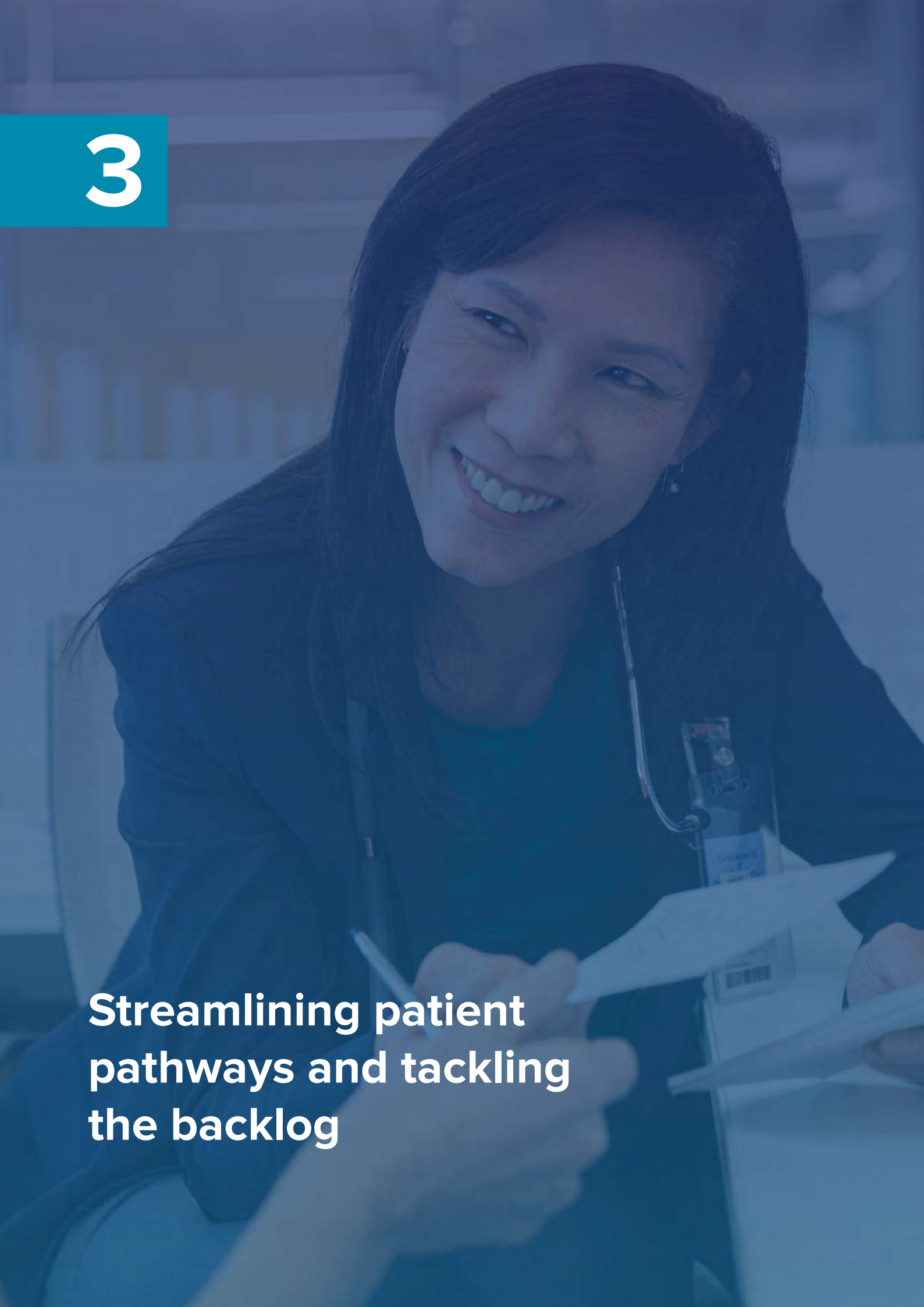
Based on the insights and expertise shared at the roundtable, we recommend the following actions to better ensure that women find it easier to access help and treatment for heavy menstrual bleeding, and that when they do, their needs are placed at the heart of the decision making process on treatment:

Recommendation Five: The NHS should set out a goal to establish more women's health hubs especially in areas that, for cultural or religious reasons, have low levels of engagement around menstrual health and heavy menstrual bleeding to provide a more convenient, culturally sensitive and female-focused setting for appointments about menstrual health.

Recommendation Six: The NHS should explore the potential for including a 'screening' process for heavy menstrual bleeding in the routine set of checks and questions when a woman attends a GP surgery for any gynaecological procedure or consultation, such as cervical cancer screening.

Recommendation Seven: When a patient presents with heavy menstrual bleeding, it should be mandatory for the GP to record the impact that the condition has on the patient's quality of life in their medical history. As this varies between GPs, the NHS should develop and roll out a standardised questionnaire that fulfils this function. Additionally, NHS Digital could then capture data on this and recognise the severity of the issue and identify ways to streamline the patient pathway.

Recommendation Eight: Once a woman receives a diagnosis of heavy menstrual bleeding, all potential treatment options and pathways should be discussed as set out in the NICE Quality standards for heavy menstrual bleeding (QS47), alongside the benefits and potential drawbacks. This information should also be provided in written form.[1]



3

Streamlining patient pathways and tackling the backlog

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The UK faces an elective care backlog crisis, and no more so than in gynaecology. More than half a million women in the UK are on waiting lists for gynaecological appointments.[9] With heavy menstrual bleeding making up 12% of secondary gynaecological referrals, the condition represents a significant contributor to the backlog.[5]

There was broad agreement among our experts that language and terminology has a key role to play here. In particular, the use of the word 'benign' to describe the pathway for women with heavy menstrual bleeding. This suggests a less serious impact on women's lives than those living with the reality of the condition report.

not a standardised approach. It It is a postcode lottery as far as being able to access those types of services in a variety of treatment settings, such as outpatients."

It was agreed that the language around heavy menstrual bleeding needs to change, and 'chronic disabling' is more appropriate, because it is a life altering issue.

Professor Critchley agreed, noting that we need to recognise that heavy menstrual bleeding is a symptom, because "if we're developing pathways, the first thing we have to do is understand the cause underlaying the symptom of heavy menstrual bleeding, because without the cause, we will not get precision of care."

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On this point of precision of care, **Professor Justin Clark** stressed the need for health care professionals in primary and secondary care to "adhere to NICE guidelines" around diagnosis, and make best use of testing and new technologies "to make correct diagnosis and affect the most effective treatment." He noted that "the technologies are there for non-invasive or less invasive treatment in out-patient settings."

However, as **Sarah Smith** stressed, while thereare recommendations and guidelines, "there is still

Dr Christine Ekechi provided one possible reason for this potential 'postcode lottery'. She described a 'rapid access clinic' that she runs, at which a woman can present with symptoms, "have their history taken, be examined, have a scan and then they have access to out-patient hysteroscopy clinics." But this sort of 'one stop shop' requires the local integrated care service "to have the personnel with the expertise to be able to provide that, which is not homogenous across the country."

The challenge of course is that services such as this become overburdened, "because the reality is that GPs are unable to perform some of these steps, so therefore, women come to us as the tertiary centres."

This 'See and Treat' approach was endorsed by the group, as it was agreed that such an approach would allow women to attend an appointment and return to their day-to-day life, rather than having to wait for an assessment and treatment for weeks.

Recommendations

Based on the insights and expertise shared at the roundtable, we recommend the following actions to streamline patient pathways for heavy menstrual bleeding, and help tackle the elective care backlog in gynaecology:

Recommendation Nine: Every hospital in the UK should have facilities to offer an outpatient 'see and treat' hysteroscopy service[15] including endometrial ablation as a treatment for heavy menstrual bleeding – not only would this provide a less invasive treatment pathway for many patients, but it would also free up theatre time and help tackle the current elective care backlog.[3]
Recommendation Ten: Rename the pathway for heavy menstrual bleeding to refer to conditions such as this as 'chronic disabling' rather than benign.

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