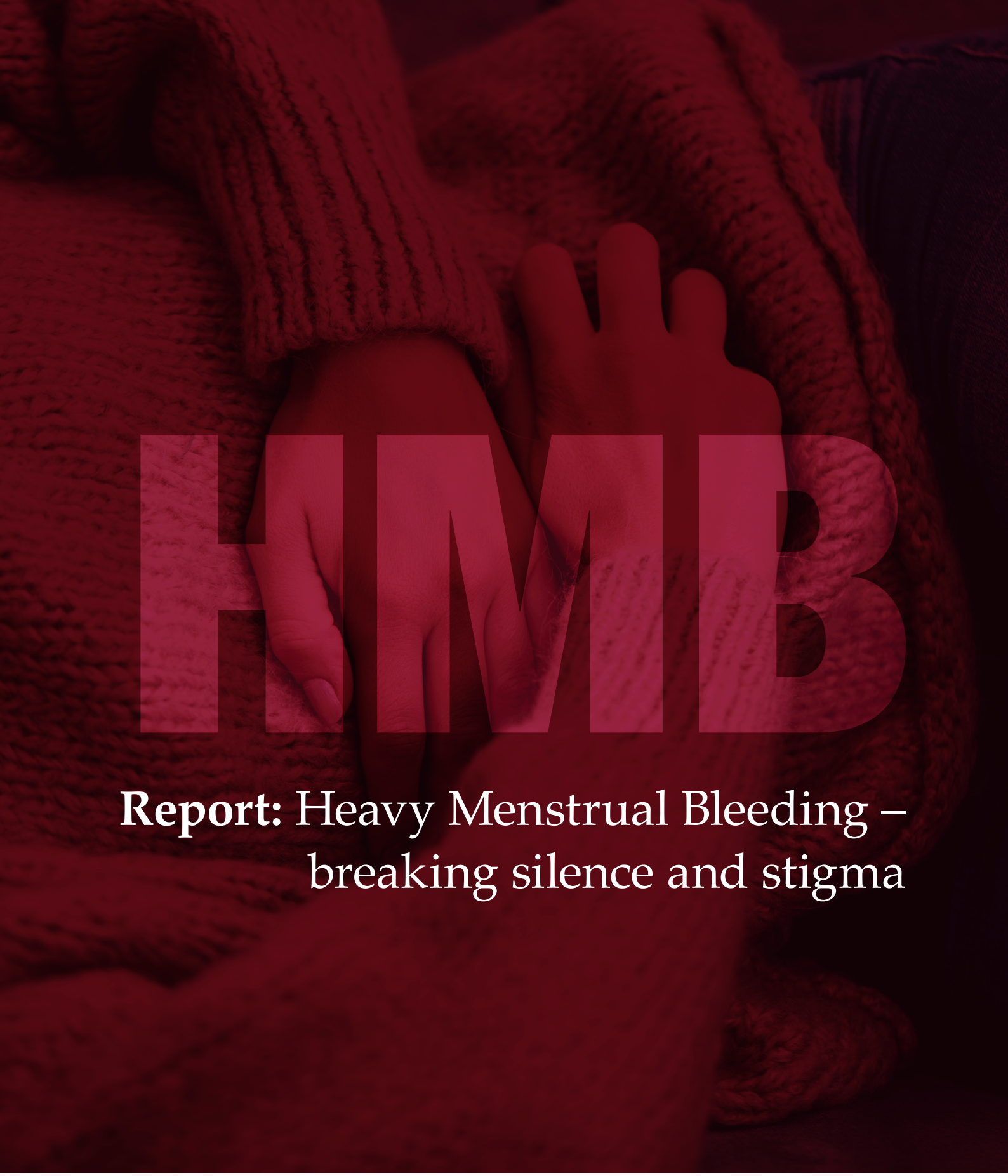

Report: Heavy Menstrual Bleeding – breaking silence and stigma

Menstrual Health Coalition

Acknowledgements and declarations

The Menstrual Health Coalition (MHC) is a coalition of parliamentarians, patient and advocate groups, life sciences industry, leading clinicians and individuals who have come together to discuss and make recommendations around menstrual health.

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Thank you to all those who sent contributions or spoke to the MHC regarding this report on Heavy Menstrual Bleeding.

PB Consulting, Secretariat to the MHC:

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Individuals:

Speakers at the oral evidence session - Anne Connolly, Lesley Regan, Wendy Telfer

Menstrual Health Coalition

Menstrual Health Coalition Aim

To raise the profile of menstrual health on the political and policy agenda, to reduce the stigma around talking about periods, and campaign for change to help women adversely affected by their menstrual health.

Coalition's Purpose

The Menstrual Health Coalition (MHC) is a coalition of parliamentarians, patient and advocate groups, life sciences industry, leading clinicians and individuals who have come together to discuss and make recommendations around menstrual health.

Executive Summary

The Menstrual Health Coalition conducted an inquiry, gathering data and input from a range of Royal Colleges, patients, patient groups and clinicians. It found that stigma around menstrual health is having a significant impact on access to care for women suffering with heavy menstrual bleeding (HMB).

Of those who responded to the MHC's inquiry the average rating for the prevalence of stigma around HMB was 8 out of 10 (10 being the highest level of stigma). This stigma is preventing women of all ages from learning about the symptoms of HMB and understanding what is normal for them during their menstruation, and therefore when to seek help. According to the findings, stigma also results in women being reluctant to talk about this condition with friends, colleagues or healthcare professionals. This, compounded with a lack of awareness, makes it more difficult for women to talk about health issues[1] and could lead to women being less cognisant of symptoms, which in turn delays access to appropriate diagnostic services and treatment. This is supported by the evidence which shows that 1 in 3 women who have heavy periods have never spoken to their doctor about it.[2]

The Coalition found that women are held back from accessing diagnosis and treatment for HMB for three key reasons:

1. Stigma, a lack of awareness of HMB and what is considered 'normal'
2. Lack of clinical awareness of HMB and the associated diagnostics and treatments
3. Commissioning barriers, service fragmentation and lack of access to services

1 in 5 women experience heavy periods, which as a result of the barriers encountered for accessing diagnosis and treatment for HMB means that they may not get the timely access to the treatment they need, impacting their quality of life.[3]

1 Plan International UK, Break the Barriers, 2018.
2 RCOG MHC oral evidence session
3 Centers for Disease Control and Prevention. Bleeding disorders in women: heavy menstrual bleeding. 2015 [Accessed June, 2018]

'Call to Action'

The Menstrual Health Coalition is calling on the Government, relevant NHS organisations (such as NHSE, NHS Digital and HEE) and stakeholders to ensure that women suffering with HMB get the right support, advice and appropriate treatment for their symptoms.

For too long lack of awareness (by both clinicians and patients) and education, as well as limited access to information about treatment options and services, have contributed to a delay in diagnosis and treatment for those affected by the condition. This has an impact on the quality of life of patients and now it is the time to support these patients to access the right advice and treatment.

The Coalition has made a number of suggestions to address this inequity.

Recommendations:

1 Break down stigma and embarrassment through:
   - Public awareness campaign and messaging – Public Health England.
   - Effective and comprehensive RSE at schools – Department for Education.

2 Reliable, publicly available information for clinicians and patients:
   - Comprehensive information on NHS websites clearly signposted – NHS Digital / Health Education England.
   - Adequate training tools for clinicians and signposting to relevant resources e.g. RCGP Menstrual Health Toolkit and RCN's women's health education booklets – Royal College of General Practitioners and Royal College of Nursing.

3 Joined-up commissioning of services:
   - With additional accountability of local organisations to provide relevant services – local and national healthcare service providers.

4 Improve patient access to services:
   - Longer GP appointments available – Government policy / regional GP services (to allow for assessment of local population need).
   - GP practices working together pooling resources to provide specialist nurses and clinicians, offering a range of services – primary healthcare service providers.
   - Encourage the implementation of NICE guidance to improve access to outpatient clinics and ensure timely diagnosis and referral to treatment for women.

5 Ring-fence public health funding and increase grants given to secure long-term sustainable funding for services – Government / NHS England.

Findings from the inquiry have shown that women suffering from HMB would like to see that women's health issues are destigmatised through education, awareness, and better access to information so that they can spot the symptoms more easily and take an active and informed role in their treatment pathway.

Foreword from the members of the Menstrual Health Coalition's steering committee – Professor Dame Lesley Regan and Dr Anne Connolly

Menstrual health is an important part of a woman's life course but we continue to hear about the poor diagnosis and suboptimal treatment of common menstrual health problems. We hear from women who have experienced heavy menstrual bleeding (HMB), with the same themes arising again and again – delays in access and treatment, multiple referrals and sometimes a lack of empathy on the part of healthcare professionals.

Despite the fact that heavy menstrual bleeding affects one in three women, it is all too often hidden from sight. Which makes it all the more important that we listen to the testimony of girls and women, and together force this issue into the open to dispel the myths and taboos which continue to surround menstrual health.

The Menstrual Health Coalition (MHC) inquiry into HMB found that women considered the stigma surrounding HMB to be 8 out of 10, with 10 being the highest level of stigma on the scale. We heard how embarrassment and stigma often prevents women from talking about their period problems with friends, colleagues and healthcare professionals. When combined with a lack of awareness among some clinicians, women said they often felt ignored and ill-informed about effective treatments for what should be an easily resolved issue.

Findings also showed the impact that HMB can have on the overall wellbeing of women and their ability to lead a normal life. The condition often makes it difficult for women to manage their menstrual flow, resulting in them having to miss school and work because of it. This compounded with a feeling of embarrassment prevents women from openly talking about the condition and a lack of understanding from the general public can result in women missing out on opportunities that would have otherwise been accessible to them.

This report is crucial in helping to raise the profile of HMB and the impact it has on women's lives. By issuing a 'call to action' to the Government, relevant NHS organisations and other key partners, the Coalition hopes women suffering with HMB get the right support, advice, diagnosis and treatment.

The findings from the MHC's inquiry highlight the importance of continuing to advocate on behalf of women everywhere to ensure that 'women's problems' are no longer hidden, but instead receive the attention and funding they deserve at both a national and local level.

We remain committed to working with all parties, including parliamentarians, clinicians, Royal Colleges and others, to make sure that menstrual health receives the attention it deserves and that the voices of women suffering with HMB are not only heard, but listened to. Action is now required to raise the standard of care throughout the country.

Professor Dame Lesley Regan DBE

Dr Anne Connolly

Heavy Menstrual Bleeding report

Many women struggle to manage their menstrual health for various conditions including Heavy Menstrual Bleeding (HMB). HMB can often be a condition that is ignored, or it can be a sign of an underlying condition that women are uninformed about and for which women should be offered appropriate diagnosis and treatment.

The Menstrual Health Coalition's work has focused on pathway and best practice for HMB. Throughout engagement with stakeholders, clinicians, patient groups and patients, it became apparent that this was an area that required further scrutiny and discussion, to push menstrual health up the agenda and increase the profile of this condition with the public, parliamentarians and policy makers.

The MHC launched this inquiry in mid-2019, holding an oral evidence session in July 2019. This session aimed to gather further information first hand from key experts and patients, and to learn more about the experiences of women in accessing services and clinicians in providing treatment.

The MHC launched a written inquiry in September. Results can be divided into three overarching themes:

1 Stigma, education and awareness

2 Patient access and support

3 Treatment pathway and best practice

The MHC hopes that this report will help raise the profile of HMB, and reduce the stigma in discussing menstrual health, whilst calling for actions that will have a tangible impact for women experiencing HMB.

Chapter 1. Introduction

What is Heavy Menstrual Bleeding?

In clinical terms, the NHS defines HMB as the loss of 80ml or more in each period, having periods that last longer than 7 days, or both. This is significant given that on average women lose between 30-40ml of blood. However, this figure may vary depending on what is normal for each woman during their period and is difficult to measure given that what is normal is individual to each woman. This means that HMB is a subjective diagnosis.

The National Institute for Health and Care Excellence (NICE) define heavy menstrual bleeding as excessive menstrual blood loss which interferes with the woman's physical, emotional, social and material quality of life, and which can occur alone or in combination with other symptoms.[4] Any interventions should aim to improve quality of life.

Dr Vanessa MacKay, consultant gynaecologist and spokeswoman for the Royal College of Obstetricians and Gynaecologists:

"In about half of women with heavy menstrual bleeding, no underlying reason is found. But there are several conditions that can cause heavy menstrual bleeding. These include conditions like polyps, fibroids, endometriosis, pelvic inflammatory disease, womb cancer and polycystic ovary syndrome."[5]

Burden of the disease

HMB is one of the most common reasons for gynaecological consultations in both primary and secondary care.

- Heavy menstrual bleeding is common; one in five women experience heavy periods with one in 20 women aged 30-49 presenting to primary care each year.[6] A recent patient survey of over 1000 women with heavy menstrual bleeding found that 74 percent had experienced anxiety and 67 percent suffered with depression.[7] This suggests that women might be at crisis point before presenting.
- 1 in 3 women who do have heavy periods have never spoken to their doctor about it.[8] HMB affects a woman's physical, psychological and social health and wellbeing.
- HMB is the fourth most common reason for secondary gynaecological referral, comprising 12% of all referrals to gynaecology services.[9]
- HMB may be caused by processes that interfere with normal endocrine, paracrine or haemostatic functions of the endometrium – the innermost lining layer of the uterus.[10] As such, conditions associated with HMB include uterine pathologies (polyps, fibroids, adenomyosis, and uterine cancer) and endometrial pathologies (endometriosis, endometrial cancer).
- An online survey on endometriosis or fibroids found that 40% of the women surveyed needed 10 GP appointments or more before being diagnosed.[11]
- Four in five women with HMB say it impacts their professional and personal lives.[12]
- Around three in ten women with HMB suffer for three or more years before seeking medical advice.[12]

4 NICE NG88: https://www.nice.org.uk/guidance/ng88/chapter/Context
5 https://www.thesun.co.uk/fabulous/10157383/heavy-periods-medical-condition-bleed-to-death/
6 https://www.rcgp.org.uk/menstrualwellbeingtoolkit
7 Wear White Again, The impact of heavy periods
8 RCOG MHC oral evidence session
9 Dharani K Hapangama and Judith N Bulmer, Pathophysiology of Heavy Menstrual Bleeding, January 2016; 12(1): 3-13; Ibid.
10 Ibid.
11 APPG on Women's Health, Informed Choice, Giving women control of their healthcare
12 Johannes Bitzer, Marco Serrani, Annalean Lahav, Women's attitudes towards heavy menstrual bleeding, and their impact on quality of life. Open Access Journal of Contraception. 23 April 2013.

- In the UK 20% of women have a hysterectomy before the age of 60, mainly to alleviate heavy bleeding.[13]
- According to the RCOG, two-thirds of hospitals do not have a dedicated menstrual health clinic, and almost half of hospitals do not have a written protocol in place for the management of HMB.[14]
- Over 10% of hospitals do not provide women with written information about HMB and the treatment options.[15]

The psychological impact of HMB is also currently underestimated. A recent survey of 1,000 women who have experienced HMB in the UK, undertaken by *Wear White Again*, found that:

- 62% did not realise heavy periods are a medical condition.
- 74% have experienced anxiety, 69% depression and 49% anaemia.
- 72% said it affected their sex life.
- 58% feel they are unable to carry out their usual daily routine.
- 50% have never been to see a GP about heavy periods.[16]

This data highlights the prevalence of HMB in England, and some of the wider interlinked issues that can arise with HMB. The MHC believes that the wider impact on women of HMB needs to be considered when this condition is discussed, such as the wider mental health and physical impacts beyond the primary symptoms of HMB.

Linked to this is the lack of clear data that would demonstrate the financial costs across the system of women with HMB. For example, improving care could help reduce unemployment as a result of menstrual problems and related issues, reduce sick leave, hospital appointments, surgery, and the general inequality that menstrual health concerns resulting from HMB produce. This would contribute towards developing the business case for improved access to quality services.

13 https://cks.nice.org.uk/menorrhagia#!backgroundSub:1
14 https://www.rcog.org.uk/globalassets/documents/guidelines/research--audit/advice-for-hmb-services-booklet.pdf
15 Ibid.
16 Wear White Again, The impact of heavy periods

Wendy Telfer – Patient Case Study

"Having endured heavy menstrual periods for a number of years and suffering in silence, I visited a GP who told me to take aspirin and carry on. Needless to say, they continued. It transpired I had a fibroid the size of a rugby ball and it was distorting the shape of my womb.

A myomectomy ensued and for a while the heavy bleeding and flooding disappeared. At the age of 44 they came back with a vengeance. I could cope with work because my school was 20 minutes away and I had fabulous colleagues and students who looked after me when I told them I wasn't well.

At 45 I changed jobs, it was over 30 miles away, the children were challenging, and I didn't enjoy the same relationships with either staff or pupils. I felt isolated. Ofsted was imminent, we were bluntly told that we could not leave our classrooms under any circumstances, to do so would result in the school being placed in special measures.

For five days a month there was a military style commando in operation, armed with the most absorbent Tampax, two night time towels, I prayed that this would be enough to see me through a two-hour session of teaching. I was anxious about the odours emanating, what would children say, would I be ridiculed, would I lose control of the classroom, would I lose their respect?

Those of us who suffer this will describe how when your body is purging what feels like pints of blood your brain focuses solely on what is going on within yourself. Your eyes glaze over, your thought processing either stops or goes into slow motion until the flood subsides – this could be seconds or minutes – then you panic about whether or not your protection has done its job or is there a dark patch of thick liquid oozing around you. You daren't sit down and you need to leave the situation immediately.

All of this impacted on my mental, physical and emotional health. The pressure to be a consistently outstanding teacher whilst dealing with physical and mental agony coupled with external family pressures was just too much. I left my job, my vocation, my profession, at the age of 45. I could not allow my physical issues to impact on the children I teach, nor could I allow my school to face special measures because of me.

As a result of talking to one of the mums on the schoolyard I went to see if I could have a coil fitted – the answer was no, another fibroid had caused my womb to become misshapen. I had laser treatment –this has not worked either. The alternative is hysterectomy – I don't want that.

I know I'm not the only one to suffer this. There are hundreds of thousands of women who have devoted so much time, effort and passion into their career only to be forced into cutting their working life short and not fulfil their potential because mother nature has decided to doubly curse them; police officers, nurses, doctors and other frontline workers to name a few.

It would appear that it is not the glass ceiling which stops some of us from achieving our potential, rather our own physical issues – if we don't talk about this how can others address them and make our working life more tolerable? Silence is not golden, it is mentally, physically, emotionally and professionally suicidal."

Policy Context

The Health and Social Care Act of 2012 divided responsibility for commissioning of women's health services in England between local government, Clinical Commissioning Groups (CCGs) and NHS England. It allowed for sexual health, reproductive health and HIV care to be commissioned by local government, gynaecology and abortion care by CCGs, and maternity and core contraception by NHS England. As other reports and comment pieces by the RCOG, RCGP, FSRH and AGC have highlighted, this split in commissioning has created issues around silo budgeting, service provision and ultimately patient access to diagnostics and treatments, in a timely manner. Furthermore, there has been no systematic action following the PHE survey on women's reproductive health in 2018.[17] When combined with the fact that the new sexual and reproductive health strategy for England has been delayed, this demonstrates the systematic inaction on women's health commissioning from the Department of Health and Social Care and Public Health England.[18]

The fact that it is expected that local authorities will remain in charge of commissioning of sexual and reproductive services[19] only adds to the problems experienced by this disjointed approach. Challenges will likely remain unless the Government takes national action to address this issue.

Accountability and responsibility need to be clearly laid out, as otherwise women's reproductive health will continue to lack systematic action, as progress to date shows.

However, there are opportunities on the horizon. Systems are changing and examples of joint commissioning are becoming more common. As of June 2019, more than a third of the country's population were covered by Integrated Care Systems and all GPs should now be part of a Primary Care Network as set out in the NHS Long Term Plan. It is hoped that such systems encourage improvements in patient pathways, in particular reducing the time between diagnosis and treatment, which could be a great relief if applied for women with HMB.

The NHS Long Term Plan has set out the future vision for the NHS, and the potential for collaboration within the community. Under future commissioning arrangements the community networks will be developed to deliver GP led or specialist outreach services and develop one stop diagnosis and wider services in the community as recommended by the NHS Long Term Plan. These multidisciplinary teams could be developed to include gynaecological specialists able to advise patients on conditions such as HMB.

17 https://www.gov.uk/government/publications/reproductive-health-what-women-say
18 Department of Health and Social Care, Government response to the Health and Social Care Committee report on Sexual Health, October 2019.
19 Department of Health and Social Care, Advancing our health: prevention in the 2020s – consultation document, 2019.

Chapter 2. Findings of a written call for evidence

The MHC launched a written call for evidence in September 2019, following an oral evidence session with experts and patient representatives in July. Results can be divided into three overarching themes:

1 Stigma, education and awareness

2 Patient access and support

3 Treatment pathway and best practice

2.1. Stigma, education and awareness

Overall respondents considered that there is a high prevalence of stigma associated with HMB, scoring 8 out of 10 on average. This is supported by many studies which have recognised that women at all ages suffer unnecessarily from the stigma surrounding menstrual health.[20]

There are a range of barriers that can result from stigma and a lack of education and awareness. If at entry level to the healthcare system women feel ashamed or embarrassed, they will be less willing to seek help, or they may brush off their symptoms and be reluctant to present at primary care. In addition, if women do not know what is 'normal' menstruation for them, and there is no awareness around when to seek help, results suggest that women would tolerate symptoms of HMB for too long.

Furthermore, if healthcare professionals, whether GPs or other clinicians, are not aware of the severity of HMB and the impact it can have on women's lives, they will not necessarily treat this condition with the understanding it requires. The majority of our respondents confirmed that awareness of guidelines and best practice around HMB is limited. This means that even once women present with their symptoms their concerns are sometimes undervalued, which can result in them being dismissed.

Stigma often prevents girls and women from discussing their symptoms, or learning about them, which means that they will be less aware of what is 'abnormal' menstruation, even for themselves, and when to seek medical advice. Even when seeking help, women may feel embarrassed or put off by the initial reaction of the clinician, which may be the result of a lack of awareness and education. This could in turn lead to a reluctance to continue down the treatment pathway.

Patient Case Study

A female police officer over the age of 40, experiencing HMB, approached her line manager to ask not to be put on duties that involved her being away from the office during her period, as she needed regular access to the toilets to change her sanitary wear and often clothing. This was refused. She had a traumatic week, leaking through her clothing, having to use public toilets and on one occasion asking a stranger during patrol if she could use their bathroom. She felt embarrassed, humiliated and that her colleagues did not understand what she was going through, especially her manager.[21]

"A lot of people shame them [girls] when they are open about it [periods]. I think we should be made to talk about them [periods] instead of hiding them away coz most lasses get them. So, I don't think it's something we should be ashamed of…At the end of the day we have to have it [periods], so why can't we talk about it?"[22]

20 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2947147/
21 FSRH MHC written evidence
22 https://plan-uk.org/file/plan-uk-break-the-barriers-report-032018pdf/download?token=Fs-HYP3v

Data

Wider data supports the finding of the MHC. A poll undertaken by Plan International UK of women aged 18-35 showed that the taboo surrounding women and their menstrual health hinders women from talking about menstruation at home, to friends and in the workplace:[23]

- Two thirds of women do not feel comfortable discussing their period with their father or male friends.
- More than one in 10 women do not feel comfortable talking about it with female friends.
- A quarter of women don't feel comfortable talking about it with their female peers at work.
- Only one third of women feel happy to speak about it with their female superiors at work.

In terms of education from an early age, approximately 70% of respondents highlighted the importance of tackling myths and breaking down barriers and taboos at a school age. This is supported by research conducted by Plan International UK, which is referenced in the RCOG's oral evidence session, that:

- Statistics show that 48% of women are embarrassed by their periods.
- Only 1 in 5 girls feel comfortable talking to their teacher about it.
- 49% of girls have missed at least one day of school because of their period. The vast majority of girls who miss a day of school because of their periods make up an alternative excuse.[24]

Inquiry results

Respondents largely expressed not feeling confident that women are aware of HMB, or what constitutes a normal or abnormal period. Lack of education at all levels, including school, university and work, means that there is an accompanying lack of awareness about what healthy menstruation entails for a woman, and about the treatments available when there are abnormalities.

The evidence also showed that there may be a lack of knowledge about menstruation in family settings. Respondents highlighted that there is the perception that heavy periods may be normal because they may run in the family, making those affected less inclined to seek professional help.

Generally, respondents believed that menstrual and reproductive health are considered to be 'women's problems' and that their condition may not be taken seriously by family, education settings or health care professionals.

23 Plan International UK, Campaign for a period emoji gathers pace as 20,000 people cast their vote (2017)
24 https://plan-uk.org/file/plan-uk-break-the-barriers-report-032018pdf/download?token=Fs-HYP3v

Other findings include:

- Stigma due to lack of awareness and knowledge of what is a healthy and normal period. There is a need for improvement of early education, as well as training for primary care practitioners.
- Culture cannot be underestimated. For example, culture within certain religious or ethnic groups could affect outcomes as this may mean women are more reluctant to discuss their symptoms, let alone seek help.
- Education campaigns are needed and should be based on reliable evidence.
- There is currently a lack of reliable information through publicly available resources. NHS websites should be well signposted and include comprehensive advice supported by evidence from experts and patients. This would allow for access to up-to-date and appropriate information that could dispel myths propagated by social media about the different types of treatments.

Whilst there is information available online in a variety of places e.g. Royal Colleges, NHS websites, NICE – women are not regularly signposted and may not know where to seek help. It is vital that women are able to easily find accurate, evidence-based information online in one place.

Plan International set out in this report why teaching about menstrual health is vital at an early age, whilst at school:

'What has been shown is that girls and other menstruators are missing out on aspects of education that are vital in ensuring they are able to understand and manager their periods. As highlighted in *Break the Barriers* this will be overcome through earlier, more frequent education about biology and social and emotional aspects. This education should not be limited to girls and other menstruators but should also be widened to boys and communicated with parents to ensure the burden of information is not on young people but on their support networks inside and outside of the education setting.'

In order to help break down stigma and raise awareness respondents largely agreed that awareness of HMB can be improved by:

- Conducting public health and educational campaigns (with the general public and at school through RSE) that are evidence-based and contain reliable information. Raising the level of education would have a positive impact on perception of women's health. This could help tackle stigma around HMB and menstrual health in general.
- The point around early education was particularly stressed in the evidence received by the MHC, and the need for this is strongly reinforced by the reports from Plan UK, '*Because I am a girl*' and '*Break the Barriers*'.
- HMB should be considered in public health commissioned services, including in consultations around menstrual and reproductive health, during sexual health screenings (both at medical practice and women's clinics).
- Awareness campaigns featuring social media and GP waiting rooms (e.g. leaflets).

The inquiry concluded that there is a need for improving access to reliable information and education for both the public, from an early age (starting at school), and HCPs. It also highlighted the need for awareness campaigns for the public and health care professionals to empower women to seek advice and gain the right treatment at the right time.

Professor Helen Stokes-Lampard, former Chair of the Royal College of GPs:

"Even though in the modern day we don't expect there to be social stigmas around women's health matters, unfortunately… stigma does still exist and it is concerning that many women do not seek help for conditions which can often be very serious."[25]

2.2. Patient access and support

Throughout discussions and in submissions to the inquiry, the MHC has identified several key barriers in the HMB pathway around patient access and support.

There is an issue with presentation at primary care, which slows down any initial treatments and help that women can receive. The initial response women receive at presentation can also have a significant impact on their accurate diagnosis and treatment. The majority of respondents to the inquiry commented on the lack of empathy and understanding that healthcare professionals often display when speaking with women, some of whom are extremely nervous, and the detrimental effect it can have on women seeking further help.

Capacity issues at secondary care will also cause blockages in the pathway and restrict the number of women who are able to receive diagnostic tests and treatments. There is a need to improve access to diagnostics, as appropriate, including ultrasound scanning or direct access to diagnostic and operative hysteroscopy in an outpatient setting, as recommended in NICE guidelines.

All of this builds a picture in which patients struggle to access the help and treatment that they need.

Overall respondents believe that patients are not presenting at primary care because:

- Women delay diagnosis or do not pursue treatment because they are not aware that their menstruation is 'abnormal' and often delay due to negative experiences at medical practices. Fear of pain and the unknown can also play a strong role here.
- Access to routine appointments is often cited as being lengthy and working hours between patients and GPs can conflict. Pressures on primary care, combined with long waiting times and the perception that the issue will go away results in patients feeling unsupported and GPs lacking resource for adequate diagnosis and treatment.
- Women may feel embarrassed when contacting their GP via telephone and when examined. The latter was particularly associated with women citing religious or cultural reservations, or those who have experienced sexual abuse. Suggestions for improvement included the ability to make appointments via the internet, to avoid embarrassment, and greater access to women GPs.

25 https://www.rcgp.org.uk/about-us/news/2018/june/stigma-around-womens-health-must-be-addressed-says-rcgp.aspx

Respondents also largely agreed that patients are not widely receiving timely treatment due to a perceived lack of education on women's health and menstruation in primary health care, and the belief that due to this, their symptoms may not be treated with the compassion that they require. This suggests that there is a relation between education and symptom identification, which is currently lacking in primary care, and which impacts on timely diagnosis and treatment of women suffering with HMB.

Other findings include:

- Primary care services not being adequately commissioned. There are issues with prioritisation of women's health and training associated for GPs. Whilst every GP has to complete general training, including management of menstrual problems, the focus of QOF and other priorities such as long-term condition management of diabetes, CVD and reducing hospital admissions means women's health is not prioritised.
- There is a wide range of commissioning practice for treatments across CCGs and regionally. The silo commissioning effect of the 2012 Health and Social Care Act means that different bodies have different responsibilities for commissioning diagnostics and treatments, for different conditions, resulting in different procedures and investigations being commissioned in different ways across the country. This has led to reduced training for IUS insertions and a lack of access because of a lack of funding.
- Many respondents felt that referrals are not happening in a timely manner because women's health is not a priority issue for NHS commissioning, with one respondent saying referrals were 'gate-keeped' by commissioners.
- GPs are widely perceived to lack understanding and empathy for women suffering with heavy periods. Respondents believed that their concerns were not taken seriously.
- Lack of knowledge about the condition and NICE guidance on how to diagnose and treat HMB among primary care health care professionals. This links back to the need for more education and reflects the pressures on GP services, which leave primary care practitioners with little funding for training and make it difficult to keep up with continuing professional development. The demands of training include statutory training however this includes keeping up with all the demands of the wide variety of work associated with GP care.
- Lack of capacity for diagnostics, secondary care and tertiary care resulting in long waiting times and GPs being encouraged not to refer.
- Improving communication between primary, secondary and tertiary care, as well as with the patient. One suggested method to try to combat this was through Health and Care Partnerships, which could help improve communication and working between primary and secondary services. Make sure of IT systems to remind people of what to do and when to improve consistency of care.

Example of variation in commissioning of treatments: IUS as a treatment for HMB

IUS can be used as a contraceptive and as a treatment for HMB. If IUS is used as a contraceptive the treatment is paid for out of public health money, but if it is used for HMB it is commissioned via primary care from a different pot of money in England. This fragmented service often means GPs are not commissioned and funded to provide the treatment for HMB. This can be for a variety of reasons, including payments not covering costs, numbers being too low to keep up clinical skills in fitting and time pressures in primary care which mean this is not seen as a priority.

Linked to some of these concerns around access to treatment is the wider funding of sexual and reproductive health. Evidence highlights that there will have been a £700m real-terms reduction in the public health grant between 2014/15 and 2019/2020.[26] Furthermore, The King's Fund estimates that between 2014/15 and 2018/19 there was an 18 per cent real-terms reduction in spending on sexual health services.[27] This is supported by the data showing that out of 86% of GPs in England who provide LARC (such as IUS) in their practice, 39% said they have experienced cuts to the funding for this service.[28]

The findings around patient access and support suggest that patients do not, on the whole, feel supported and that healthcare professionals feel under pressure, lacking resources to provide adequate diagnosis and treatment.

Respondents generally agreed that best practice should be based on NICE guidelines, as a minimum standard. This should be reflected throughout the whole pathway – from GP practice, access to first line treatments, appropriate referral, access to diagnostics and hysteroscopy services, access to specialist centres and appropriate treatment.

Louise Haigh, Member of Parliament for Sheffield Heeley:

"We need to normalise discussion about women's health and about periods so that women can seek treatment and support for their condition."[29]

2.3. Treatment pathway and best practice

Improving awareness of current guidelines

Whilst a number of guidelines exist, and best practice guidance from Royal Colleges aims to signpost to clinicians' best practice, results showcase that the level of care by primary and secondary care practitioners could be improved. The main concern remains around health care professionals' awareness and implementation of the national guidance that is currently available.

Respondents to the MHC inquiry agreed that NICE guidelines on HMB are not always being followed. There needs to be a heightened emphasis placed on adherence to the guidelines, a first step to which is spreading awareness of their existence.

The findings also showed that there is a lack of specialists in women's health, which has an impact on timely diagnosis of HMB. An All Party Parliamentary Group (APPG) on Women's Health report found that there is a 'chronic lack of awareness among healthcare professionals' of two of the most common causes of menstrual problems, fibroids and endometriosis. The APPG surveyed 2,600 women and found that more than 40% of women surveyed needed 10 or more GP appointments before being referred to a specialist, and 12% of women with fibroids took between 1 and 2 years from diagnosis to receiving treatment.[30] This is an unacceptably high figure for visits, wasting valuable GP time and incurring avoidable cost associated with these appointments, as well as causing women distress as they are kept waiting substantially long periods for diagnosis and treatment.

26 https://www.health.org.uk/news-and-comment/news/additional-%C2%A332bn-a-year-needed-to-reverse-impact-of-government-cuts-to-public-helath
27 Multiple medical bodies,2019, Holistic Integrated Commissioning of Sexual & Reproductive Healthcare - AoMRC, RCOG, FSRH, RCGP, RCPath and RCPCH Position. Accessible here: https://www.fsrh.org/documents/fsrh-rcog-rcgp-position-holistic-integrated-srh-commissioning/
28 Multiple medical bodies,2019, Holistic Integrated Commissioning of Sexual & Reproductive Healthcare - AoMRC, RCOG, FSRH, RCGP, RCPath and RCPCH Position. Accessible here: https://www.fsrh.org/documents/fsrh-rcog-rcgp-position-holistic-integrated-srh-commissioning/
29 https://www.independent.co.uk/life-style/health-and-families/louise-haigh-endometriosis-polycystic-ovary-syndrome-labour-mp-twitter-westminster-a9176491.html
30 APPG on Women's Health, Informed Choice, Giving women control of their healthcare

The inquiry highlighted that due to time pressures on primary care settings, where women's health issues are often diagnosed, and the continuous update of guidelines, these issues have contributed to poor diagnosis of women suffering with HMB. There is little time and resource to provide training in a more traditional manner, and as such it would be better to educate healthcare professionals in a clear and efficient way that involves fewer tests and provides clinical pathways to follow. For example, this could be provided through Continuing Professional Development (CPD) training where relevant guidelines and advice could be updated. Primary Care Networks could also provide an opportunity for primary care practitioners with a specialist interest in women's health to develop. Other tools are also available, and awareness needs to be built to signpost clinicians to use these tools. The Coalition particularly welcome the recent publication of the RCGP Menstrual Wellbeing Toolkit and the work of the RCN on women's health guidelines.

Furthermore, to make it easier for time-constrained primary care practitioners to have access to important information about HMB and the treatment pathway, resources should be made easily and readily available. Respondents suggested that this information could be collected on an NHS website, supported by evidence from Royal Colleges, patient groups and charities, to facilitate access to appropriate and comprehensive information. These resources should also be made available for patients to allow them to make informed choices and take an active role in their care.

HMB guidelines

As outlined above respondents generally agreed that best practice should be based on NICE guidelines as a minimum standard. The draft updated NICE Guideline NG88 is outlined below.

NICE guideline NG88 (Heavy menstrual bleeding: Assessment and management) sets out the following for healthcare practitioners. The link to the NICE guideline is https://www.nice.org.uk/guidance/ng88.

- Recognise that heavy menstrual bleeding (HMB) has a major impact on a woman's quality of life and ensure that any intervention aims to improve this rather than focusing on blood loss.
- Take a history from the woman.
- If the woman has a history of HMB with other related symptoms, offer a physical examination
- Carry out a physical examination before all investigations or LNG-IUS fittings.
- Carry out a full blood count test for all women with HMB, in parallel with any HMB treatment offered.
- Before starting investigations for the cause of HMB, consider starting pharmacological treatment for HMB without investigating the cause if the woman's history and/or examination suggests a low risk of fibroids, uterine cavity abnormality, histological abnormality or adenomyosis.
- Take into account the woman's history and examination when deciding whether to offer hysteroscopy or ultrasound as the first-line investigation.
- Provide women with information about HMB and its management.
- Provide information about all possible treatment options for HMB and discuss these with the woman.

- Explain to women about the impact on fertility that any planned surgery or uterine artery embolisation may have, and if a potential treatment (hysterectomy or ablation) involves loss of fertility then opportunities for discussion should be made available.
- Have a full discussion with all women who are considering hysterectomy about the implications of surgery before a decision is made.
- When agreeing treatment options for HMB with women, take into account the woman's preferences, any comorbidities, the presence or absence of fibroids (including size, number and location), polyps, endometrial pathology or adenomyosis, other symptoms such as pressure and pain.
- Offer outpatient hysteroscopy to women with HMB if their history suggests submucosal fibroids, polyps or endometrial pathology because:
    - they have symptoms such as persistent intermenstrual bleeding or
    - they have risk factors for endometrial pathology
- Ensure that outpatient hysteroscopy services are organised and the procedure is performed according to best practice.
- Ensure that hysteroscopy services are organised to enable progression to 'see and-treat' hysteroscopy in a single setting if feasible.
- Explain to women with HMB who are offered outpatient hysteroscopy what the procedure involves and discuss the possible alternatives.

Upcoming guidelines: NICE draft quality standard

QS47 (updated March 2018)	Draft quality standard (2020)
QS1. Women presenting with symptoms of heavy menstrual bleeding have a detailed history and a full blood count taken.	QS1. People presenting with symptoms of heavy menstrual bleeding have a detailed history taken that includes the impact on their quality of life. [updated 2020]
QS2. Women with heavy menstrual bleeding who have a suspected uterine cavity abnormality, histological abnormality, adenomyosis or fibroids have a physical examination before referral for further investigations.	QS2. People with heavy menstrual bleeding and suspected submucosal fibroids, polyps or endometrial pathology have outpatient hysteroscopy. [new 2020]
QS3. Statement has been removed.	QS3. People with heavy menstrual bleeding have a discussion with their healthcare professional about all their treatment options. [2013, updated 2020]

The draft quality standard provides an update to quality statements 1 to 3 of the current Quality Standard QS47 used in the NICE HMB recommendations (NG88). This makes changes to the way in which patients are diagnosed and the advice they receive on treatment options.

Of particular note is the fact that when a patient is diagnosed, the draft QS now asks clinicians to consider 'the impact on their quality of life' when taking a detailed history of the patient. According to NICE, by considering quality of life the QS enables people to have access to appropriate diagnostic tests, further investigations for any underlying pathologies, and prompt and effective treatment. This also avoids unnecessary referrals to secondary care.

The draft QS introduces a new quality statement relating to outpatient hysteroscopy. The new guidance would recommend that people with HMB and suspected submucosal fibroids, polyps or endometrial pathology have outpatient hysteroscopy. This is preferred to pelvic ultrasound. The rationale behind this is that when hysteroscopy is performed in accordance to best practice guidelines it is an efficient and safe technique with a low risk of complications and distress for most people. However, draft recommendations say that before this is carried out, clinicians should discuss the procedure with the person and advise on the possible alternatives.

In the draft QS, quality statement 3 is reintroduced and relates to the discussion of treatment options. This statement recommends that people with HMB have a discussion with their healthcare professional about all their treatment options. The 2013 quality standard specifically recommended that people with HMB and suspected structural or histological abnormalities be offered pharmaceutical treatment after the initial consultation. Instead, the proposed quality statement seems to place an emphasis on discussing options rather than being prescriptive.

The MHC welcomes the renewed focus on ensuring that information about appropriate treatment is shared with patients, as we believe that choice for women should be at the centre of any treatment pathway. The Coalition also welcomes the fact that, if adopted, the Quality Standard would consider quality of life when HMB is initially diagnosed. Such changes would support a patient-centric approach, which has been highlighted as a necessary improvement in this report and would ensure that there is wider access to various diagnostics and treatment, taking into consideration what is right for each patient.

Improving treatment pathway and sharing best practice

For the treatment pathway to be improved, respondents believed there needs to be a joined-up approach to women's health between primary, secondary and tertiary care settings. This would make access to healthcare services easier, improve patient experience, reduce health inequalities, and cost-save for pressurised services.

Financial pressure was often cited as an issue preventing improvement of treatment pathways. Some respondents believed there needs to be integrated commissioning and sustainable funding, which would support best practice nationally, as well as to improve support for HCPs. Achieving these would require engagement with government, Public Health England and other stakeholders to prioritise women's health in the same way as other conditions. Whilst more funding was cited, respondents also largely agreed that there were innovative ways in which this issue could be addressed. For example, by medical practices pooling resources to share specialist nurses and GPs, practices could share the financial burden. This would mean that across an area, women could get specialist advice and support, but GP practices would not need to invest additional time and money individually.

In the recommendations in the NICE HMB Guideline there are also specific references to direct referral to hysteroscopy for patients with suspected uterine pathologies and the recommendation

on 'see and treat' services wherever possible, which may enable improved access to services for women.[31] Another example discussed by FTWW was to create 'women's health hubs' where expert patients, and primary, secondary and tertiary health care professionals can share their expertise and personnel locally, which would reduce the burden for cash-strapped practices. This idea of collaborative working came through strongly in the responses received by the MHC.

Moving forward it would also be useful to carry out further research into public health data to understand what cuts are taking place and where money is being spent, as discussed by the Health and Social Care Committee report on Sexual Health in 2019.[32] This would help discussions on future spending to ensure more joined-up commissioning, placing the patient at the heart of the service and ensuring that they could access the best services.

Example of best practice:

Oxfordshire County Council: working closely with GPs

Oxfordshire County Council has worked closely with local GPs to ensure women have access to LARC and the system is administered fairly in terms of whether it is the council or NHS that pays for the service. This case study forms part of our sexual health resource. (https://www.local.gov.uk/oxfordshire-county-council-working-closely-gps)

Example of best practice:

LGA: Sexual health commissioning in local government Collaborating for better sexual and reproductive health and wellbeing.

LGA: Integrated sexual health commissioning across Leicester, Leicestershire and Rutland

Joint commissioning of a specialist sexual health service, and use of Section 75 agreements to align IUS fitting for contraceptive and non-contraceptive purposes. A Section 75 agreement was used to enable each council to commission IUS fitting for non-contraceptive purposes, including for heavy menstrual bleeding, as per National Institute for Health and Care Excellence (NICE) guidance, on behalf of their local CCGs. This took the form of a new schedule added to existing Section 75 agreements. In this way, the same general practice and specialist sexual health providers are now able to fit IUSs for both contraceptive and non-contraceptive purposes, costs are allocated to the appropriate commissioner, and local women can access a seamless service.

'Joining up commissioning does not have to be complicated, controversial or large-scale. For example, adding an extra schedule to existing Section 75 agreements, as in Leicester, Leicestershire and Rutland, is a relatively simple mechanism for delegating the commissioning of specific services, such as IUS fitting for non-contraceptive purposes, from CCGs to councils.'

It is important to share examples of best practice, specifically about integrated or delegated commissioning between CCGs and PHE, to ensure that women can access care in one place by skilled clinicians rather than being bounced around the system as a consequence of fragmented and siloed commissioning arrangements.

31 https://www.nice.org.uk/guidance/ng88/resources/heavy-menstrual-bleeding-assessment-and-management-pdf-1837701412549
32 https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/1419/1419.pdf

Chapter 3. Conclusions and recommendations

Recommendations

The Coalition has made a number of suggestions throughout this report regarding specific changes and attitudes that can be taken to help improve access to HMB diagnostics and treatment. These primarily focus on placing the patient at the heart of the system and ensuring that women can access the best possible resources and services to be able to make informed choices about their care. These recommendations are consolidated below:

1 Break down stigma and embarrassment through:

- Public awareness campaign and messaging – Public Health England.
- Effective and comprehensive RSE should be commonplace at schools – Department for Education.

2 Reliable, publicly available, information for clinicians and patients:

- NHS Digital should work with the Department of Health, NICE, Royal Colleges and patient groups to ensure that every condition is catered for on NHS websites resulting in a clearly signposted, effective website. Furthermore, NHS Digital should also work with diverse groups and charities specialising in women's health to ensure that the NHS UK website links to the other support networks and tools available for women and girls and is as accurate and up to date as possible – NHS Digital.
- Ensure adequate training tools for clinicians, for example through CPD courses, and signposting to relevant resources e.g. RCGP Menstrual Health Toolkit – RCGP and NHS Digital.
- Ensure availability in a local area of specialist GPs and nurses with an interest in women's health. Ability to signpost to other practices if no one is available in a GP practice or entry point who is able to provide expertise.

3 Joined-up commissioning of services:

- The MHC supports the call from the RCOG, RSRH, RCGP, RCPath and Academy of Royal Colleges for an approach of joined-up commissioning of sexual and reproductive health services. This would:
  - make access to healthcare services easier for women
  - improve patient experiences
  - reduce health inequalities
  - cost-save for pressurised NHS and locally commissioned services.
- Primary Care Networks and other community based interactions to improve access for women – organisations to work together to provide treatments e.g. IUS – ICS's and Primary Care Networks.
- Ensure accountability of local organisations to provide relevant services. NHS England should have oversight of commissioning arrangements so that together the CCG, Local Authority and NHS England are providing the women's health services that are needed – NHS England to provide oversight, CCGs ensure referral pathways are in place and patients can access services.

4 Improve patient access to services:

- Longer appointments - the RCGP has found that the standard 10-minute appointment is no longer fit for purpose and its research indicates that a third of GPs have been unable to provide appropriate care and information within that limited timeframe, let alone provide them with their correct treatment. It is also not cost-effective as women often require multiple appointments before accurate diagnosis and treatment can take place. It is for this reason that the RCGP has called for 15-minute appointments as a standard, with longer for those patients with complex health needs who require it.[33] Changing this timing would improve high-quality care for all women, including those who suffer with HMB.
- GP practices working together, potentially through Primary Care Networks, pooling resources to provide specialist nurses and clinicians, offering a range of services.
- Encourage access to outpatient clinics to provide diagnostic services more easily to women, including access to diagnostic and operative hysteroscopy in accordance with NICE guidelines.[34]

5 Ring-fence public health funding and increase grants given to secure long-term sustainable funding for services. Given the financial constraints NHS services face, the MHC recognises that this might entail a rethink of service provision to ensure that women can access the best services in a timely manner.

33 RCGP, Fit for the future: RCGP's vision for general practice (2019)
34 https://www.nice.org.uk/guidance/ng88

Conclusion

The Menstrual Health Coalition aims to shine a spotlight on heavy menstrual bleeding and contribute to breaking down the stigma and taboo of this condition. Responses to the inquiry conducted by the Coalition have shown that there is a complex picture restricting patient access to diagnosis and treatment for HMB. However, there is much that can be done to improve this and help those women affected.

Positive progress has been made and the MHC welcomes work that has gone on in this area, including the Women's Health Taskforce, the Menstrual Wellbeing Toolkit from the RCGP, the RCN Menstrual Wellbeing Booklet, as well as examples of collaborative working on the ground, such as those highlighted in this report.

Moving forward the MHC recommends the main priorities should be around:

1 Awareness and education to inform women about what is normal and abnormal menstruation and remove stigma. This would encourage more women to seek help and ensure that those who are approached are able and qualified to provide help;

1 Adequate, easily accessible and evidence-based information should be available for women and clinicians. The information should be comprehensive, including input from Royal Colleges and patient voices, as well as NHS and PHE resources.

3 Access to services should be prioritised and systems linked up to ensure that women can access the help that they need in a timely manner.

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RCGP Menstrual Wellbeing Toolkit - https://www.rcgp.org.uk/menstrualwellbeingtoolkit

RCGP's Women's Health Library[37]

Plan UK, *Because I am a girl*

Plan International UK, *Break the Barriers – Girls' Experiences of Menstruation In the UK*

Glossary of abbreviations

AGC: Advisory Group on Contraception

FSRH: The Faculty of Sexual and Reproductive Healthcare (FSRH)

FTWW: Fair Treatment for the Women of Wales

HMB: Heavy Menstrual Bleeding

LARC: Long-acting reversible contraception

MHC: Menstrual Health Coalition

NICE: The National Institute for Health and Care Excellence

RCGP: Royal College of General Practitioners

RCN: Royal College of Nursing

RCOG: Royal College of Obstetricians and Gynaecologists

35 For example, BSGE Guidelines and best practice information for clinicians
36 For example, RCOG Advice for Heavy Menstrual Bleeding (HMB) Services and Commissioners
37 The RCGP's Women's Health Library provides educational resources and guidelines on women's health that are relevant to GPs and other primary healthcare professionals. It brings together national guidance, resources produced and accredited by the RCGP, and resources from the RCOG and the FSRH

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