**Inherited bleeding disorders must be recognised as a potential cause for heavy menstrual bleeding and outcomes optimised through joint haematological and gynaecological care.**

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Many women with an undiagnosed bleeding disorder will attend gynaecology services with heavy menstrual bleeding (HMB), often as the first manifestation of their bleeding condition. By way of example, one of the most common bleeding conditions, von Willebrand disease, is thought to account for up to one fifth of all patients presenting to gynaecology services with HMB [1]. NICE provides comprehensive guidance on the investigation and management of women with HMB [2]. However, a recent review and guideline published by the gynaecology working party of the United Kingdom Haemophilia Centres Doctors Organisation (UKHCDO), has highlighted the need for special attention around the diagnosis of inherited bleeding disorders (IBD) in patients with HMB [3]. This guideline covers the diagnosis and treatment of HMB with an emphasis on the association with IBDs. It also advises on the management of women with IBDs undergoing gynaecological surgical interventions for HMB. This commentary focuses on one aspect of this guidance, namely the recognition and management of IBD as a potential cause for HMB, because such diagnoses may be overlooked by gynaecologists in day-to-day clinical practice.

HMB affects up to 25% of all women and girls, whether or not they have an underlying bleeding condition. It prompts one million women a year in the UK to seek help for their symptoms, and accounts for many workdays lost in women of reproductive age [2]. Globally, annual direct and indirect treatment costs amount to $1 billion and $12 billion, respectively [4]. Despite national guidance [2] referral rates for HMB from primary to secondary care vary, as do management practices within secondary care, including surgical practices. This heterogeneity in practice is likely to be even more pronounced in women and girls with HMB initially seen within gynaecological or haematological services. Young women and girls with moderately severe and severe inherited bleeding conditions may be diagnosed with their IBD for reasons other than HMB, such as periprocedural bleeding or bleeding associated with minimal childhood trauma. However, the more common inherited bleeding conditions will often present with HMB. Von Willebrand disease (VWD) and mild platelet disorders are the most prevalent bleeding conditions, but they can be more difficult to diagnose than more severe IBDs. This is because both conditions frequently have normal laboratory results (e.g. normal routine coagulation and platelet numbers) and these patients will be less likely to offer a strong bleeding history outside of HMB, which is a common complaint in the general female population. A high index of clinical suspicion is therefore crucial when managing women and girls with HMB if the impact of IBDs is to not be overlooked.

Diagnosis of IBDs in women with HMB is not just limited by these clinical and testing challenges. Other, more nuanced reasons may make diagnosis harder. For example, it can be common for families with IBD to tend to ‘normalise’ the extent of bleeding within their family and patients may describe their HMB as no worse than other members of their family, so that seeking medical care can be delayed. Added to this, there may be reticence from some patients around discussing HMB within their family or indeed with a healthcare professional. Also, there has been a disparity of care between genders within haemophilia services, which is only now beginning to be addressed. The focus, until recently has been on men with severe haemophilia and maximising their clinical care, at the expense of the care of women with IBD [5]. Recognition of this problem has led to campaigns from patient groups such as the “Talking Red” campaign from the UK Haemophilia Society, which raised awareness of the problem of HMB in women with bleeding disorders [6]. There is a clear discrepancy between national and international guidance about how to approach diagnosis and management of HMB and IBD, as well as a paucity of high-quality evidence about how best to manage clinical situations [7]. Observational studies strongly support that as a group of clinicians we can do better: reports confirm that less than 1% of women and girls with HMB are investigated for an underlying IBD [8Jacobsen, 2018].

Failure to suspect, recognise and confirm IBDs presenting with HMB has a huge knock-on effect to the health of this patient group: the impact of poorly controlled HMB is legion. There is a large literature base that sets out in stark clarity that women who suffer with HMB are impacted across all aspects of their daily life: education; university attendance; clinical symptoms due to iron deficiency anaemia and iron depletion; sexual and emotional aspects; missed days from work and menstrual poverty. This is something that the haematology and gynaecology communities should be aiming to address, and we are suggesting that all women and girls, of any age, who present with HMB have the presence of IBD excluded. The UKHCDO guideline sets out how to approach the patient with HMB, and the most important part of the management strategy is the recognition that all women attending with HMB should be assessed with a thorough bleeding history covering all aspects of their health. For women with a history of HMB, and who are considered at risk for an IBD, the guideline recommends that routine bloods at presentation include as a minimum: full blood count, ferritin and/or iron studies. A full clotting screen (PT, APTT, TT and Clauss fibrinogen) can be requested in the gynaecology clinic but must not be used to exclude an IBD if the results are normal. If a coagulation screen is requested, it should be taken as a ‘first sample’ whilst awaiting haematology review rather than a test of exclusion of disease. In some hospitals, von Willebrand Factor (VWF) levels can be requested by non-haemophilia services and may be taken whilst awaiting haematology review. Early referral to haematology should be sought for any patient who raises a clinical suspicion of an underlying IBD.

Areas where gynaecologists and haematologists could improve care readily, is by ensuring strong links between services. This can be ensured by establishing joint speciality clinics, or where this is not possible, the development of a local standard care pathway for this patient group [9]. A recent survey of European haemophilia treatment centres (HTCs) identified that 42% of the HTCs lacked a strategy for the management HMB and 58% lacked a combined gynaecology / haematology clinic [10]. Also, we need to strengthen the means by which we share health responsibilities with our patients, for example, by providing them sufficient support to access our services when they need to rapid assessment (e.g. when there is an acute change in their HMB symptoms) and then offering patient initiated follow up with clear points of contact when symptomatology is well controlled. In the UK, patients with IBD are looked after by specialist haemophilia multidisciplinary teams. There are 27 Comprehensive Care Centres and 31 smaller haemophilia centres across the country, and all HCs and CCCs provide specialist haemostasis care. All women with an IBD should be registered for specialist IBD care at one of these centres. This innovation will provide representative data collection across the UK and allow evaluation of care, highlighting any variation in access to secondary care and diversity in management.

At present, national data are collected for men with haemophilia but we are lacking in collecting patient reported outcomes for women with IBDs, and we collect no data at all on HMB and UK practices for the care of women. To successfully implement the UKHCDO guidelines and improve the care of women with known or unknown IBDs associated with HMB, there is an urgent need to collect standardised national data including patient reported outcome measures (PROMs). The National Haemophilia Database [11] could potentially be used to collect the national demographics and baseline characteristics of women with IBDs and with appropriate resourcing. Identifying the population in this way can allow the development of a high quality prospectively collected standardised database [12]. Not only is baseline data collection poor for this patient group, but the evidence available in the medical literature to inform clinical practice is scarce. There are very few clinical trials in this area, even though women with IBD far outnumber the numbers of men with haemophilia. For example, the most recent National Haemophilia Database figures confirm that 55% of all patients registered in the UK with a IBD are women [U11]. By collecting high quality data describing clinical practice, compliance with UKHCDO guidance and PROMs, we can begin to understand how contemporary care is accessed and delivered for this group of women across the UK. Furthermore, clinical outcomes as regards alleviation of HMB and other gynaecological conditions in women with IBDs following medical and surgical interventions can start to be evaluated. It is important that the gynaecology and haematology communities work closely with patient societies such as the Haemophilia Society to help improve the care directly of this group. Importantly, such engagement can inform future research to improve clinical outcomes.

As a UKHCDO working party group, we welcome working together with gynaecologists across the UK to look to establish a national registry of women with IBD and gynaecological conditions to understand the burden of disease more fully with a focus on outcomes following surgery and interventions for HMB, as well as patient reported outcomes. In addition, the establishment of a joint national research network between haematology and gynaecology which could include trainee research groups would help to bring in junior researchers into this field and jump start our ability to address the unmet needs in this patient group.

# Declaration of Interests

All authors are members of the Gynaecology Working Party of the UKHCDO and co-wrote the ‘Gynaecological Management of Women with Inherited Bleeding Disorders. A UKHCDO Guideline’. The authors declare no other relevant conflicts of interest to the publication of this manuscript. **References.**

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