

CODE RED

## HEAVY MENSTRUAL BLEEDING IN THE NETHERLANDS RESEARCH, CONTEXT & IMPLICATIONS

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#### Content

1. Introduction	3
2. Heavy menstrual bleeding (HMB)	3
3. Context: previous evidence on seeking and receiving help among people with HMB	4
4. Research methods	5
5. Research sample description	5
6. Research results	6
6.1. HMB and period poverty	6
6.2. Help and support seeking behaviors among participants with HMB	7
6.3. Summary of findings	9
7. Contextual analysis and implications	10
7.1 General awareness-building, accessibility of information	
& menstrual health education	11
7.2. Addressing menstrual stigma	13
7.3 Optimizing diagnostic procedures and physician engagement	14
8. Recommendations and conclusion	17
Priority 1: MENSTRUAL ACCESS & EQUITY	17
Priority 2: MENSTRUAL EDUCATION	18
Priority 3: MENSTRUAL RESEARCH	18
Appendix	20
I. NF Info Sheet on HMB	21
II. Pictorial Blood Assessment Chart	23
References	25

**'CODE RED: Heavy Menstrual Bleeding** 

#### Research, Context & Implications'

is a January 2025 Neighborhood Feminists advocacy and research report.

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Field research carried out by Opinium.

**Cover illustration by Marleen Geerts.** 

#### 1. Introduction

Although heavy menstrual bleeding (HMB) is a common condition affecting some 30% of menstruating people in Europe,<sup>1</sup> there is relatively little open conversation across the general population or within the medical community about its effects or how people with HMB engage in help-seeking behaviors. This report aims at providing more insights into the actual personal impact of heavy menstrual bleeding and help-seeking behavior among people with HMB in the Netherlands, by analyzing data from the **CODE RED** study carried out by Neighborhood Feminists and Opinium in the Netherlands in late 2024.<sup>2</sup>

#### 2. Heavy menstrual bleeding (HMB)

In clinical terms, HMB is defined as "blood loss of more than 80 mL per menstrual cycle or blood loss that interferes with the physical, emotional, social, or material quality of life".<sup>3</sup>

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HMB is most frequently studied among adolescents, where the results of prevalence studies indicate that it is the **second most common menstrual condition among menstruating adolescents (33.5%) aged 13-18.**<sup>4</sup> The amount of bleeding can be self-assessed and tracked with the help of a calendar (see pictorial blood assessment chart /pbac in appendix).

Although HMB can occur without an underlying medical cause, it can also occur as a symptom of a bleeding disorder.<sup>5</sup> **Evidence from the Netherlands indicates**  For purposes of selfassessment, the following list of symptoms is used:

- Flooding through clothes or on bedding
- Need for frequent changes of menstrual pads or tampons (every 2 hours or less, or using 12 products or more per 24 hours)
- Need for double period product protection
  - Passing blood clots larger than a 50 cent coin

that experiencing HMB puts people at higher risk of a delayed diagnosis for a bleeding disorder, such as a blood clotting disorder, endometriosis, uterine fibroids, adenomyosis, PCOS, endometrial or uterine cancer.<sup>6</sup> This means that, despite HMB being common among menstruating people with bleeding disorders, receiving a diagnosis for a bleeding disorder may take longer for people experiencing HMB.

<sup>&</sup>lt;sup>1</sup> Oderkerk et al., 2024.

<sup>&</sup>lt;sup>2</sup> Neighborhood Feminists, 2024.

<sup>&</sup>lt;sup>3</sup> Pouraliroudbaneh et al., 2014.

<sup>&</sup>lt;sup>4</sup> Nur Azurah et al., 2013.

<sup>&</sup>lt;sup>5</sup> Van 't Klooster et al., 2023.

<sup>&</sup>lt;sup>6</sup> Maas et al., 2023.



HMB can have a negative impact on daily life, affecting physical activities, productivity and attendance at school and work, sleep, productivity at home, ability to travel, sexual life, social life and relationships.<sup>7</sup> Experiencing HMB is associated with economic consequences, such as lower likelihood of employment in comparison to women with lighter or average menstruation.<sup>8</sup> Moreover, HMB is one of the most common causes of iron deficiency and iron deficiency anemia in girls and women, which can have further negative effects on activities, productivity, academic results and quality of life.<sup>9</sup>

# 3. Context: previous evidence on seeking and receiving help among people with HMB

A 2012 survey carried out in five different European countries (Netherlands, France, Germany, Spain and Switzerland) found that 1,225 of 4,506 surveyed menstruating people (27.2%) reported that they experienced at least two of the symptoms of HMB in the preceding 12 months. Of the 1,001 surveyed people in the Netherlands, 222 (22.2%) reported at least two HMB symptoms in the preceding 12 months. Only 14% of those reporting HMB in the Netherlands felt that they had their symptoms totally under control.<sup>10</sup>

In comparison to other countries in Europe, there is both a lower rate of help-seeking behaviors, as well as a lower rate of receiving help from physicians:

- Of the 222 people with HMB in the Netherlands, only 39.2% reported having ever spoken to a doctor about their heavy bleeding. This makes the Netherlands the country with the lowest percentage of consultations in the survey.
- Of those who consulted with a doctor about their HMB, only 31.6% reported that they were offered a prescription for their symptoms, making the Netherlands the country with the lowest percentage of prescriptions for HMB symptoms in the survey.

In response to the low overall rate of medical consultation when experiencing menstrual symptoms, the authors of a 2017 Radboud study of 42,879 women aged 15–45 years in the Netherlands sought to evaluate the scale and range of menstrual symptoms, and their impact on everyday activities. Among those surveyed, 38% were unable to perform all their regular daily activities during their period due to the severity of symptoms, predominantly

<sup>&</sup>lt;sup>7</sup> Fraser et al., 2015.

<sup>&</sup>lt;sup>8</sup> Côté et al., 2002.

<sup>&</sup>lt;sup>9</sup> Munro, 2023.

<sup>&</sup>lt;sup>10</sup> Fraser et al., 2015.



severe cramping and tiredness. Heavy menstrual bleeding, together with back pain and headache were reported by 1 out of 2 women in the Radboud study."

#### 4. Research methods

This report analyzes data collected during the **CODE RED** study conducted by Neighborhood Feminists and Opinium in 2024. Collecting survey data from 3,547 people in English and Dutch, the **CODE RED** study sought to provide insights on period poverty across the Netherlands, with additional focus on Amsterdam. Neighborhood Feminists also assessed HMB in the study, asking participants whether they had experienced menstrual flow that soaks through one or more pads or tampons every hour for several hours in a row, or menstrual flow with blood clots the size of a 50 cent coin or larger, for example.

More information on the **CODE RED** study data collection and the sample demographics can be found in the final report.<sup>12</sup>

#### 5. Research sample description

Of the 3,547 people that took part in the **CODE RED** Study, 2,519 participants were willing to answer questions about their menstrual flow. Of those, 865 people (34.35%) indicated that they had experienced HMB based on these above described criteria (99.42% female, 0.58% non-binary). The largest age group among the participants with HMB was 25-34 years (36.99%), followed by the age group 35-44 years (21.16%).

Many of the participants reporting they experienced HMB also reported having other symptoms during their period:

- 72% reported being tired, feeling a lack of energy or shortness of breath.
- 71% experienced constant pain in the lower stomach during their period (dysmenorrhea).
- 33% reported experiencing diarrhea.

<sup>&</sup>lt;sup>11</sup> Schoep et al., 2019.

<sup>&</sup>lt;sup>12</sup> <u>Neighborhood Feminists, 2024.</u>

#### 6. Research results

#### 6.1. HMB and period poverty

The assessed data also allows for insights into the experience of period poverty among participants with HMB. Over a third of the participants with HMB (35%,  $\mathcal{N}$  = 302) stated that they struggled to or couldn't access period products. People with and without HMB differed in their reports of period poverty at a statistically significant rate:<sup>13</sup> People who live with HMB are significantly more likely to experience period poverty.

Participants experiencing HMB and period poverty were also **significantly more likely to report additional negative impacts as the result of their difficulty accessing menstrual products**:

- 33% see an impact on their mental health.<sup>14</sup>
- 32% have to change their daily routine.<sup>15</sup>
- 31% have to stay home for some of their period.<sup>16</sup>
- 28% see an impact on their physical health.<sup>17</sup>
- · 27% miss out on socializing.<sup>18</sup>
- **19% miss work.**<sup>19</sup>
- 16% miss school.<sup>20</sup>

- $^{15}$  X<sup>2</sup> (1,  $\mathcal{N} = 940$ ) = 27.2479, p < .001
- $^{16}$  X<sup>2</sup> (1,  $\mathcal{N} = 940$ ) = 50.3029, p < .001
- $^{17}$  X<sup>2</sup> (1,  $\mathcal{N} = 940$ ) = 36.8559, p < .001
- <sup>18</sup> X<sup>2</sup> (1,  $\mathcal{N} = 940$ ) = 25.6984, p < .001<sup>19</sup> X<sup>2</sup> (1,  $\mathcal{N} = 940$ ) = 18.7065, p < .001
- $^{20}$  X<sup>2</sup> (1,  $\mathcal{N} = 940$ ) = 27.2722, p < .001

<sup>&</sup>lt;sup>13</sup> X<sup>2</sup> (1,  $\mathcal{N} = 2519$ ) = 68.2365, p < .001

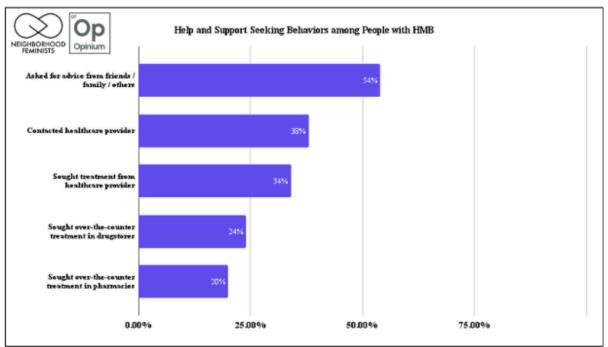
<sup>&</sup>lt;sup>14</sup>  $X^2$  (1,  $\mathcal{N} = 940$ ) = 38.8468, p < .001



#### 6.2. Help and support seeking behaviors among participants with HMB

Participants with HMB were asked if they engaged in different health and support seeking behaviors as a result of their bleeding. As seen in Figure 1, the most frequently reported help and support seeking behavior was to ask for advice from friends, family or close others, followed by seeking treatment from one's healthcare provider.

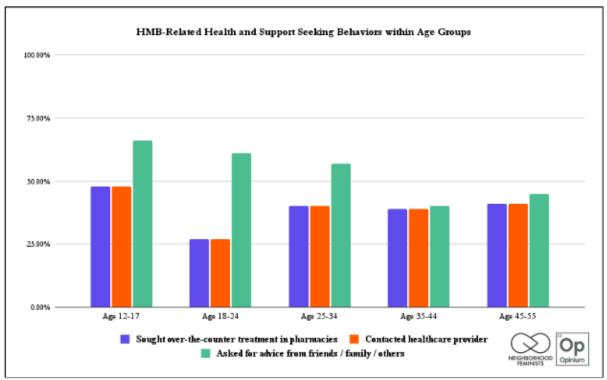






As seen in Figure 2, the ratios of participants with HMB differed significantly between age groups regarding the following help-seeking behaviors:<sup>21</sup> Asking for advice from friends, family, and others,<sup>22</sup> contacting one's healthcare provider,<sup>23</sup> and seeking over-the-counter treatment in pharmacies.<sup>24</sup>





The ratio of participants seeking advice from friends, family and others was higher among younger participants, with the highest percentage in the youngest age group 12–17 (66.29%), followed by age group 18–24 (61.59%), age group 24–34 (58.04%), and participants aged 45–55 (45.71%). Participants between 35 and 44 years reported the lowest ratio, with 40.78% reporting that they sought out help from friends, family and close others.

The ratio of people who had contacted a healthcare provider was lowest among participants between the age of 18-24 years (26.67%) and highest among underage participants (12-17 years, 48.31%). For the other groups the ratios varied between 39.78% (35-44 years) and 42.31% (45-55 years). Although there was no significant difference in seeking treatment from one's healthcare provider between age groups, participants

<sup>&</sup>lt;sup>21</sup> Comparing participants answering "yes" with participants answering "no" to the respective questions.

<sup>&</sup>lt;sup>22</sup>  $X^{2}(4, N = 854) = 26.7631, p < .001$ 

 $<sup>^{23}</sup>$  X<sup>2</sup>(4,  $\mathcal{N} = 851$ ) = 12.6716, p = .013

<sup>&</sup>lt;sup>24</sup> X<sup>2</sup>(4,  $\mathcal{N} = 847$ ) = 12.1819, p = .016



between 18-24 years also had the lowest percentage (25%) for this type of help-seeking behavior.

#### 6.3. Summary of findings

Considering data from 2,519 participants revealed that 35% experienced heavy menstrual bleeding (HMB) and using 2023 population data from the Netherlands' Central Bureau of Statistics for women and girls aged 15-49, our report estimates that more than one million menstruating people in the Netherlands experienced heavy menstrual bleeding (HMB) in the 12 months prior to our study.

Using the same extrapolation, the data indicates that of this group, 350,000 people – one third – struggled with or were unable to afford the needed period products.

People with HMB are significantly more likely to experience period poverty, and significantly more likely to report negative outcomes of period poverty on mental and physical health, work, school and social life. Additionally:

- Only one third of people with HMB contacted (38%) or actively sought treatment (34%) from a healthcare provider.
- An even lower percentage of people with HMB sought over the counter treatment in drug stores (24%) and pharmacies (20%).
- ▶ Over half the people with HMB (64%) asked for advice from people close to them, which is the most commonly reported health seeking behavior.
- > Younger people with HMB show a higher tendency to seek help and support from people close to them, when compared to older participants.
- People with HMB aged 18-24 report the lowest rates of contacting healthcare providers or seeking treatment from pharmacies.

#### 7. Contextual analysis and implications

The results show that **people experiencing HMB are also affected by period poverty to a significantly higher degree.** The data collected in the **CODE RED** Study mirrors the findings from prior studies,<sup>25</sup> showing that the many people experiencing HMB in the Netherlands may *not* seek out help from medical professionals, and only roughly half of the people with HMB seek help from people close to them.

Although the survey addressed absence at school and work specifically tied to period poverty (as opposed to general menstruation-related absence), the results align with findings on the economic and academic consequences of other menstruation related complications, such as dysmenorrhea, or severe menstrual pain.<sup>26,27</sup> These findings underscore the need for further research to more precisely determine the effects of HMB on work and school attendance in the Netherlands.

Our results indicate differences in help-seeking behaviors between age groups that are worth further exploration. Regarding the rate of participants seeking help from family and friends, we can see a relative decline, as younger participants reported a higher rate of this behavior. There is the possibility that younger people perceive fewer hurdles to talking with close others about menstruation, as research insights show that younger people have a somewhat more open attitude to menstruation as a topic of conversation.<sup>28</sup> However, the difference may also lie in the different types of people sought out for support, as teenagers may be more prone to turn to their parents, caregivers or peers for help, for example. Future research could help provide more differentiated insights into whom people seek support from, and why. We also need a more detailed understanding of the low rates of contacting healthcare providers and seeking treatment options in pharmacies among those aged 18-24.

Our results pose a number of questions that deserve additional attention and investigation, to further clarify the reasons and barriers that prevent people experiencing HMB from seeking needed medical help and social support from others. There is also value in further exploring the quality of the support that people with HMB actually receive, the financial and health costs of delayed diagnosis and treatment, and the education being provided to medical professionals on HMB. To ensure people who menstruate and experience HMB have improved menstrual health, we call for focus on the following:

<sup>&</sup>lt;sup>25</sup> Fraser et al., 2015, NVOG et al., 2023.

<sup>&</sup>lt;sup>26</sup> Armour et al., 2019.

<sup>&</sup>lt;sup>27</sup> Schoep et al., 2019.

<sup>&</sup>lt;sup>28</sup> Eyring et al., 2023.



## 7.1 General awareness-building, accessibility of information & menstrual health education

Given the low level of health-seeking behaviors among participants with HMB symptoms, the question arises to what extent people with HMB are aware that their menstrual symptoms are beyond what is considered a 'normal' menstruation, and if there is sufficient awareness about which symptoms require medical attention.<sup>29</sup>

# I just thought this is normal ... I've just got to stick with it until the menopause, it never really occurred to me to try and seek help.<sup>30</sup>

Before contact with medical professionals, people who menstruate (and those close to them) must first be able to identify abnormal menstrual symptoms requiring medical attention. Previous research on help-seeking behavior among people with HMB indicated that many are unaware that their condition could be treatable, and tend to consider the impacts of heavy bleeding as 'normal'.<sup>31</sup> When information on menstrual issues is sought out, it occurs most often through online help-seeking behavior.<sup>32</sup>

Although information is available online for people living in the Netherlands, the question arises whether the information is sufficiently visible, known, or accessible. For example, platforms specifically addressing HMB such as *hevigbloedverlies.nl* provide symptoms, causes, and potential medical interventions, general health platform *thuisarts.nl* and as well as *degynaecoloog.nl* provide information on heavy bleeding, and suggests tracking the severity of the bleeding with a calendar or chart.<sup>33,34</sup> Some organizations provide additional information about menstruation symptoms through social media awareness campaigns.<sup>35</sup> And yet, awareness is low. As cited on *hevigbloeverlies.nl:* 75% of women surveyed in the Benelux did not know that HMB is a medically recognized, treatable condition. Given this general lack of awareness of HMB as a legitimate medical issue, people with symptoms may not even begin searching for information on these or other healthcare websites. Another factor impacting accessibility is that Netherlands-focused information is only offered in Dutch.

<sup>&</sup>lt;sup>29</sup> Seear, 2009.

<sup>&</sup>lt;sup>30</sup> Dutton & Kai (e294), 2023.

<sup>&</sup>lt;sup>31</sup> Dutton & Kai, 2023.

<sup>&</sup>lt;sup>32</sup> Özberk et al., 2023.

<sup>&</sup>lt;sup>33</sup> Ongesteld En Veel Bloedverlies, 2024.

<sup>&</sup>lt;sup>34</sup> *HevigBloedverlies.nl*, 2024.

<sup>&</sup>lt;sup>35</sup> Doorbreek de Cyclus, 2023.



In our culture, we are quite strict towards women. 'Just bite the bullet', mothers tell their daughters complaining about her period. It is what it is. So women are tough, which is nice, but you can also be too tough. And practitioners think: 'that won't kill you, biting through is part of life'. – Dr. Fedde Scheele, gynecologist<sup>36</sup>

Menstruation knowledge can reduce and even counteract the normalization and trivialization of challenging menstrual symptoms. As our results indicate that roughly half of the people with HMB turn to those close to them for advice and help, people who are not themselves affected – whether parents, carers or peers – should also have a general understanding of symptoms and treatment options. If, when seeking advice, a person with HMB is told that their bleeding is 'normal' or not medically relevant, it can discourage them from seeking needed help from medical professionals, leading to further potential delays for appropriate diagnosis and treatment.<sup>37</sup>

Questions assessing denial of menstrual symptoms from the Modified Menstrual Attitudes Scale (MMAS)

Higher agreement to the following statements expresses higher levels of denial of menstrual symptoms:

- > "Cramps are bothersome only if one pays attention to them."
- Most women make too much of the minor physiological effects of menstruation."

The effect of the denial of menstrual symptoms on the menstruating person can be significant.<sup>38</sup> Education and awareness-building can make a real difference. Research shows that higher levels of general knowledge about menstruation are related to reduced denial of menstrual symptoms (see MMAS info above), meaning people with more accurate knowledge about menstruation are less likely to trivialize and deny challenging menstrual symptoms and their effects.<sup>39</sup> Improving knowledge about menstruation (and menstrual complications) is one significant pathway to reducing trivialization and denial of severe menstruation symptoms.<sup>40</sup>

<sup>&</sup>lt;sup>36</sup> *RD Redactie* podcast, 2024.

<sup>&</sup>lt;sup>37</sup> Ballard et al., 2006.

<sup>&</sup>lt;sup>38</sup> Eyring et al., 2023.

<sup>&</sup>lt;sup>39</sup> Eyring et al., 2023.

<sup>&</sup>lt;sup>40</sup> Seksuelevorming.nl, 2023.



#### 7.2. Addressing menstrual stigma

Seeking advice and support from close others or healthcare professionals can be difficult because menstruation is often seen as a "taboo" topic of discussion,<sup>41</sup> and broaching it can be perceived as violating a social norm. A related sense of shame can be an additional barrier for people seeking advice and support for their HMB.

In 2023, the Dutch Society for Obstetrics and Gynecology (NVOG) published a qualitative analysis of 'Social Acceptance of Female-Specific Conditions'. The report outlines the far-reaching impact of stigma on society, underscoring a lack of adequate comprehensive education and awareness, meaning the ability to make informed decisions and seek appropriate care is affected, impacting opportunities and incurring enormous costs in healthcare and sick leave every year.

"Many gynecological complaints cause women to be unable to perform their school or work activities properly, hindering the career opportunities of women, and increasing male-female differences. In addition, many women work in essential professions such as education or healthcare. If they are unable to do their work, this further contributes to existing and ongoing capacity problems. These findings emphasise the urgent need to take these conditions seriously and to address them adequately."

> - Dr. Judith Huirne, professor of gynecology at Amsterdam UMC, and chair of the Science Committee of the NVOG

Their analysis emphasizes the high prevalence and impact of menstrual disorders such as HMB and cycle-related abdominal pain, which are among the most common menstrual conditions, pointing to studies indicating up to 30% of women experience heavy menstrual bleeding at some point in their lives, significantly impacting daily life, productivity, and overall well-being. The NVOG report goes on to acknowledge significant taboo and underreporting of menstrual health issues, and a resulting reluctance to seek medical help.<sup>42</sup>

The imposing, ongoing stigma around the general topic of menstruation is illustrated by the use of euphemisms, such as "aunt flow", or that "time of the month".<sup>43</sup> Connected to this stigma is a certain menstruation "etiquette" which imposes concealment of menstruation (and any related signals). The attitude that menstruation should be kept secret is

<sup>&</sup>lt;sup>41</sup> Johnston-Robledo & Chrisler, 2011.

<sup>&</sup>lt;sup>42</sup> NVOG et al., 2023.

<sup>&</sup>lt;sup>43</sup> van Lonkhuijzen et al., 2022.



significantly higher among those identifying as male, embracing hostile sexist attitudes, or having inaccurate or inadequate knowledge about menstruation.<sup>44</sup>

...Policy-makers and advocates seemed unprepared to accept that breaking the silence means that "there will be blood". They did not seem ready to make menstruation visible. Menstruators and society at large receive mixed messages: "Yes, let's talk about menstruation. But please do so in a 'respectable' way." <sup>45</sup>

Effectively tackling stigmatizing attitudes towards menstruation involves factoring in the impact of general attitudes toward women and the positive role of menstrual education. Research into the psychological roots of menstruation stigma can further finetune policies and actions. But public awareness campaigns can contribute to the breaking of taboos, just as individuals speaking openly about their own experiences with menstrual conditions, including HMB, can provide valuable visibility and contribute to reducing and dissolving societal norms and stigmas. In particular, campaigns that specifically challenge stigmatizing language used to describe menstruation can be helpful in changing menstrual communication norms, and might also serve as an initial step towards more open communication regarding HMB.<sup>46,47</sup> Being rooted in norms and value systems, for change to occur, menstruation stigma needs to be structurally addressed in different ways and spaces, including at a societal level.<sup>48</sup>

#### 7.3 Optimizing diagnostic procedures and physician engagement

Adequate healthcare for HMB has substantial relevance: medical professionals can set diagnostic processes in motion to investigate possible underlying causes for HMB and provide treatment options. In general, according to medical guidelines, a key step in the diagnosis process is beginning with discussion of the patient history and level of menstrual blood loss, using, for example, a chart/calendar/pbac.<sup>49</sup> In the Netherlands, general practitioners are the first point of contact for non-emergency healthcare. The Dutch College of General Practitioners (*Nederlands Huisartsen Genootschap*, or NHG), provides guidelines regarding menstrual bleeding, including HMB.<sup>50</sup> The Dutch Society for

<sup>&</sup>lt;sup>44</sup> Eyring et al., 2023.

<sup>&</sup>lt;sup>45</sup> Olsen et al., 2022.

<sup>&</sup>lt;sup>46</sup> Women Inc., 2024a.

<sup>&</sup>lt;sup>47</sup> Women Inc., 2024b.

<sup>&</sup>lt;sup>48</sup> van Lonkhuijzen et al., 2022.

<sup>&</sup>lt;sup>49</sup> Herman et al, 2016.

<sup>&</sup>lt;sup>50</sup> NHG, 2024.



Obstetrics and Gynecology (*Nederlands Vereniging voor Obstetrie en Gynaecologie*, or NVOG) also provides guidelines and consultation cards for the treatment of HMB.<sup>51</sup>

Although the broader provision of guidelines for medical staff is an important step, there is a further known issue with lack of knowledge and confidence regarding proper diagnosis and management of HMB among physicians.<sup>52</sup> A recent Dutch study<sup>53</sup> analyzing data from adolescents (10-21 years) who sought primary care for HMB showed that, **in 67% of HMB presentations, no diagnostic testing (e.g. tools to quantify blood loss, assessment of quality of life, assessment of family history regarding bleeding disorders) were carried out, and the GP guidelines which recommend laboratory testing were not followed. In cases where diagnostic tests were carried out, adolescents were more likely to be treated for their complaints. The authors of the study further point out that HMB is not always adequately documented in patient files.** 

"The current diagnostic pathway for GPs needs to be improved and future studies should focus on finding the best diagnostic pathway to avoid physical harm by setting a wrong diagnosis and under/overtreatment." <sup>54</sup>

Despite existing medical guidelines for diagnosis and treatment, menstrual complaints may be trivialized by healthcare professionals. Not being taken seriously can prevent people from further pursuing advice and support. Research on people with endometriosis and their experiences with healthcare providers shows that many experience having their symptoms and complaints trivialized, disregarded, or dismissed in non-specific, general practitioner (*huisarts*) care.<sup>55</sup> This research raises the question whether people with HMB seeking help from their GP have experiences similar to those of people with endometriosis.

Being diagnosed with gynecological conditions such as endometriosis and experiencing menstruation-related complaints being taken seriously by medical staff us connected to greater confidence in the legitimacy of treating menstrual disorders and conditions as health issues. Research indicates that people with a medical diagnosis and treatment for a menstrual health condition experience feelings of relief and a sense of control over their symptoms, as well as experiencing relief in finding the adequate language to talk about their experiences,<sup>56</sup> which makes them more likely to disclose their menstrual health issues, for example in the workplace.<sup>57</sup> However, menstruation-related conditions such as

<sup>&</sup>lt;sup>51</sup> Federatie Medisch Specialisten, 2023.

<sup>&</sup>lt;sup>52</sup> Kadir et al., 2024.

<sup>&</sup>lt;sup>53</sup> Van 't Klooster et al., 2023.

<sup>&</sup>lt;sup>54</sup> Van 't Klooster et al. (p.7), 2023.

<sup>&</sup>lt;sup>55</sup> Pettersson & Berterö, 2020.

<sup>&</sup>lt;sup>56</sup> Ballard et al., 2006.

<sup>&</sup>lt;sup>57</sup> Cook & van den Hoek, 2023.

endometriosis are known to have significant diagnostic delays: the median time to receive a diagnosis of endometriosis in the Netherlands is 7.4 years.<sup>58</sup>

There is room for improvement. The UK's National Institute for Health and Care Excellence (NICE) developed guidelines for healthcare professionals in the UK to specifically "investigate the cause of heavy periods that are affecting a woman's quality of life and to offer the right treatments, taking into account the woman's priorities and preferences"<sup>59</sup> to ensure that:

- Symptoms of heavy menstrual bleeding are taken seriously by medical professionals, leading to doctors asking the right questions and using best practices and methods to investigate the causes of heavy menstrual bleeding.
- People with HMB receive access to healthcare professionals with specialist knowledge regarding the diagnosis, and if necessary, treatment of heavy menstrual bleeding.

One of the findings of the aforementioned 2023 NVOG report is that there is the need to improve training among Dutch healthcare providers to better recognize and manage menstrual disorders.<sup>60</sup>

In summary, there are several open questions regarding Dutch application of the HMB diagnostic treatment guidelines in practice, as well as the interactions between medical professionals and people with HMB. Given the findings on inadequate or lack of application of the guidelines, insights into actual levels of knowledge and awareness of these guidelines, as well as reasons or motivations regarding adherence to the guidelines, particularly among general practitioners, would be valuable. Also valuable: more detailed insights into the experiences of people with HMB who do contact or seek help from medical professionals, particularly regarding conduct and the degree of communication, and the impact of these interactions on future help-seeking behaviors.

<sup>&</sup>lt;sup>58</sup> Staal et al., 2016.

<sup>&</sup>lt;sup>59</sup> NICE, 2018.

<sup>&</sup>lt;sup>60</sup> NVOG et al., 2023.

#### 8. Recommendations and conclusion

People with heavy menstrual bleeding (HMB) in the Netherlands face significant challenges, with negative impacts on their mental and physical health, education, work, and social lives. Despite these effects, only a minority seek help and support, with younger individuals (aged 18–24) being the least likely to contact healthcare providers. Reasons for this are varied but often include the trivialization of menstruation symptoms, lack of awareness of treatment options, and significant, widespread menstrual stigma.

Effectively addressing barriers and challenges to healthy menstruation healthcare practices, including ensuring timely diagnosis and treatment of HMB and other menstrual issues, falls under three priority areas:

#### Priority 1: MENSTRUAL ACCESS & EQUITY

Menstrual equity includes adequate access to the information needed to maintain healthy menstruation practices. To increase menstrual access and equity, the constraint of stigma must be better identified and tackled.

#### Our recommendations include:

- Acknowledging the problem of menstrual stigma in any menstrual health policies, and directly tackling this contributing factor by actively addressing the norms and systems that keep it alive, through education, awareness-building and research.
- Accounting for menstrual stigma in care standards for menstrual conditions, and providing education to medical professionals about the harm (unconscious or conscious) attitudes of resistance or dismissal can have.
- Applying particular attention to language and the depiction of menstruation to avoid further reinforcing stigmas in policies and measures, since focusing on concealment (rather than openly discussing and naming menstrual complications) can reinforce menstruation stigma.<sup>61</sup> In practice, this means that any policy aiming at destigmatizing heavy menstrual bleeding must also address and directly name symptoms, such as bleeding or passing blood clots.

<sup>&</sup>lt;sup>61</sup> Olsen et al., 2022.



#### **Priority 2: MENSTRUAL EDUCATION**

Public campaigns and better integration of menstrual health into school curricula and physician training are essential components to enabling people, including those with HMB, to seek support and receive the care they need.

#### Our recommendations include:

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- Integrating comprehensive menstrual health education within school sexual education programs as a crucial tool for ensuring an increase in general menstruation knowledge, as well as for more timely medical intervention.
- Developing awareness campaigns for HMB, similar to those that nationally inform the general public and medical professionals about endometriosis, as a useful tool supported by government funding to destigmatize the issue and inform a wide audience.

#### **Priority 3: MENSTRUAL RESEARCH**

The value of robust research and analysis is not only in better identifying issues and solution pathways, but also in challenging popular assumptions of decision makers, educators, medical professionals, and the general public.

#### Our recommendations include:

- Increasing funding for research into the motivations and perceived hurdles when seeking and choosing support. Among other insights, this would provide important starting points for developing effective HMB information campaigns and communication strategies, while reducing the risk of overlooking important psychological factors.
- Reviewing existing medical education and guidelines on HMB and other menstrual conditions to assess their visibility to GPs (as the first point of patient contact), whether they are in line with best-practice, include new evidence and research, and address the psychological aspects of HMB, including stigma.
- Conducting a national analysis of diagnosis and treatment rates of HMB to determine the costs associated with delayed diagnosis and treatment of HMB and related menstrual conditions, such as mistreatment and/or patient safety



## incidents. This could also provide valuable data on the financial impact (including job security) of stigma and inadequate education on the healthcare industry.

In short, this range of targeted measures involves everyone, from members of national and local government, medical professionals and members of medical associations, to researchers and educators. By working together, we can:

- Improve and increase access to needed information and tools to better determine when menstrual bleeding requires medical attention.
- Increase social safety to talk about menstruation without the fear of stigma to access needed social support.
- Help ensure access to appropriate and timely healthcare, that includes the validation of experiences and symptoms, as well as appropriate provision of diagnostic and treatment options.

As stated in the 2024 **CODE RED** report, "every citizen has a right to *bestaanszekerheid* – alongside the right to housing, work, health care, and a healthy and safe environment." This means every person in the Netherlands should be able to access all the basic necessities for life. By prioritizing menstrual equity and access, menstrual education, and menstrual research – including on the matter of heavy menstrual bleeding – the Netherlands can move from **CODE RED** toward **CODE GREEN**, with improvements in public health and participation in school and work, as well as overall economic benefits for all.



#### Appendix

With a view to pushing back against stigma, this appendix includes additional practical and informational resources on heavy menstrual bleeding:

- An information sheet on heavy menstrual bleeding and talking with a medical professional whether doctor (*huisarts*), nurse or gynecologist also available for download on the NF website.
- A sample pictorial blood assessment chart.



#### I. NF Info Sheet on HMB

# HEAVY MENSTRUAL BLEEDING

TALKING ABOUT HEAVY MENSTRUAL BLEEDING (HMB) WITH MEDICAL PROFESSIONALS & GETTING THE HELP YOU NEED

#### HEAVY MENSTRUAL BLEEDING SYMPTOMS

- BLEEDING FOR 7 DAYS OR MORE
- FLOODING THROUGH CLOTHES OR BEDDING
- NEED TO FREQUENTLY CHANGE PADS OR TAMPONS (EVERY 2 HRS OR LESS, OR USING 12 + PRODUCTS PER 24 HRS)
- NEED FOR DOUBLING UP ON PADS
- BLOOD CLOTS LARGER THAN A 50 CENT COIN

## Be your own champion

Any person who experiences or thinks that they might be experiencing heavy menstrual bleeding (HMB) can benefit from talking with a medical professional, whether doctor (huisarts), nurse or gynecologist.

Opening conversation with a medical professional using clear language, including questions, can be powerful in ensuring you're heard.

Example: "My periods are extremely heavy, I am having to change my pad every hour and this really affects my work/school/life commitments."

Providing specific examples can help the medical professional understand how much and the ways HMB is impacting your life.

Example: "Last month I was unable to leave the home for 3 days because of heavy bleeding and extreme fatigue."

Asking for help – and explaining exactly why you have made the appointment with the medical professional – can ensure you receive the care you need.

Example: "I am here because I need relief and would like to understand my treatment options."



## Tracking your symptoms... knowing your body

Keeping a menstrual diary will be useful in understanding your symptoms over time and providing the details of your experiences and symptoms specific to HMB which the medical professional needs to understand your situation, to support their diagnosis and choice of treatment.

Turn the page to see what can be tracked and brought to your appointment with a medical professional.

## Questions to ask your medical professional

- What could be causing my heavy bleeding?
- Are there any diagnostic tests that you recommend, such as an ultrasound or blood tests?
- Could this be related to another condition like fibroids, endometriosis or PCOS?
- What treatment options are available to me?
- What are the risks and benefits of these treatments?
- Are there lifestyle changes or supplements that might help?
- How often should I follow up if my symptoms continue or worsen?
- What are the next steps if my symptoms don't improve?
- How might my bleeding affect my overall health in the long term?
- If I want to have children, how might my condition or its treatment affect my fertility?
- Should I see a specialist, such as a gynecologist or hematologist?
- Are there patient support/advocacy groups or resources you recommend for more information?

Please keep in mind that while all information provided is based on <u>current Dutch medical guidelines</u>, this is not intended to be comprehensive nor to replace medical opinion.

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# HEAVY MENSTRUAL BLEEDING

## TALKING ABOUT HEAVY MENSTRUAL BLEEDING (HMB) WITH MEDICAL PROFESSIONALS & GETTING THE HELP YOU NEED

#### Keeping a menstrual diary: symptoms to track

#### FLOW DETAILS

- How often do you change your tampon or pad?
- What is the size and frequency of blood clots?

#### DURATION

How many days do you bleed each cycle?

#### IMPACT

What impact does this have on your life? Explain any missed or limited activities, whether at work, school or your free time, or impact on your mood and well-being, and so on.

#### PAIN

What are your experiences with pain rates throughout your period? This could be cramping, dull aches, sharp pain for example. Including information about the location and duration of the pain could also be helpful.

#### **OTHER SYMPTOMS**

Are there any other symptoms or experiences during your period? This could include dizziness, fatigue, anxiety, or nausea, for example.

#### Know when it might be time to seek a second opinion

If you feel that your concerns and experiences are being ignored or not taken seriously:

- Ask for a recommendation or referral (verwijzing) to a gynecologist or hematologist (a internal medicine specialist with training in disorders related to your blood, bone marrow, and lymphatic system).
- Ask for more information about heavy menstrual bleeding, including specialists or associations for resources.
- Bottom line: Trust yourself and your body. If you feel unheard, you do have the right to seek help from another medical professional.

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### Possible causes of heavy menstrual bleeding



- Adenomyosis (when the tissue lining of the uterus grows into the uterine wall)
- Bleeding disorders (when blood does not clot properly)
- Ectopic pregnancy (when the embryo attaches outside the uterus)
- Endometriosis (when tissue similar to the lining of the uterus grows outside of the uterus)
- Fibroids and polyps (different types of abnormal growths, which can sometimes occur with no other symptoms)
- Medications (such as blood thinners or aspirin)
- Miscarriage (when there is a loss of pregnancy in first 23 weeks)
- Pelvic inflammatory disease, or PID (when the reproductive organs are infected, causing chronic pain)
- Polycystic ovary syndrome or PCOS (when a hormonal imbalance affects periods, ovulation, and the ability to get pregnant)

Sometimes, the exact cause is not known.

Because it can reflect a more serious condition, it is important to not delay speaking with a medical professional if you are experiencing symptoms of heavy menstrual bleeding.

Please keep in mind that while all information provided is based on <u>current Dutch medical</u> <u>guidelines</u>, this is not intended to be comprehensive nor to replace medical opinion.



#### II. Pictorial Blood Assessment Chart

(source: The Royal Children's Hospital Melbourne)

Month:										
	Pads			Tampons			Clots		Flooding	Score
Date	Light (1 pt each)	Medium (5 pts each)	Heavy (20 pts each)	(1 pt each)	(5 pts each)	Heavy (10 pts each)	5 cent size (1 pt each)	50 cent size (5 pts each)	1 pt each episode	
1										
Z										
3										
4										
5										
6										
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27										
28										
29										
30										
31										
									Total	



Each row represents a day of the month

Count the number of sanitary pads and/or tampons you use each day (24 hour period).

Calculate a score for each day, then add up the score at the end of the month.

Bleeding between periods - If you also experienced bleeding between periods that required sanitary protection please record this on the relevant days.

Clots – if you pass clots, please indicate this on the relevant days and the approximate size (ie. closer to an Australian 5 cent or 50 cent piece).

Flooding – if you experience any episodes of 'flooding'/overflowing/staining of clothing/underwear please indicate the number of episodes on the relevant days.

**Double protection** – if you have used both a pad and tampon simultaneously and both sanitary items were stained with blood don't forget to include both sanitary items on the PBAC.

Pads								
1 point	For each lightly stained pad							
5 points	For each moderately stained pad							
20 points	For each completely saturated pad							
Tampons								
1 point	For each lightly stained tampon							
5 points	For each moderately stained tampon							
10 points	For each completely saturated tampon							
Clots/Flooding								
1 point	int For each small clot (Australian 5 cent coin)							
5 points	For each large clot (Australian 50 cent coin)							
5 points	For each episode of flooding							

#### PBAC Scoring System



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