



ⓂENSTRUAL MATTERS

ANNUAL REPORT FY2021

ANNUAL REPORT FY2021

THE MISSION

To provide independent, accessible, and evidence-based information for the public, clinicians, and researchers:

- To improve the diagnosis and treatment of menstrual cycle-related ill health
- To help people improve their health & wellbeing
- To save the NHS unnecessary time and expense
- To bust myths that only serve to marginalise people who menstruate

THE VISION

- To raise awareness about the role of the menstrual cycle (and/ or hormonal medications) in triggering or worsening female-prevalent symptoms.
- To promote effective symptom management, through healthy diet and lifestyle changes, rather than immediately resorting to medication (which may result in side effects).
- To prove that tracking symptoms over time is a necessary and efficient way to improve the quality of diagnosis, and health outcomes, of patients who menstruate (e.g. by reducing the costs associated with repeat consultations, or the prescription of unnecessary or ineffective medications).
- To reduce the stigma attached to the menstrual cycle because it contributes to human rights inequalities.
- To create new data, and review existing clinical research, to provide the necessary evidence base to pursue the above goals.



CONTENTS

The mission - 1

The vision- 1

About MM- 2

People- 6

Supporters- 6

Governance- 6

Progress report- 7-9

Finances- 9

How you can help-10

FY2022- 11

Contact- 11

ABOUT MENSTRUAL MATTERS

What is Menstrual Matters?

Menstrual-Matters is a non-profit online information hub where you can;

- find out if your health may be affected by the menstrual cycle, or hormonal medications
- find evidenced-based ways to improve your health and wellbeing through simple lifestyle changes
- and learn how menstrual myths and taboos help to perpetuate gender inequalities

A note for Clinicians and Researchers:

We will eventually develop clinician and researcher areas on the Menstrual Matters website. Please sign up to the clinician or researcher email lists to receive relevant news updates.

In collaboration with several UK-based clinicians, health associations, and leading research organisations, we work hard to ensure that products and information are as evidence-based as possible, in line with relevant professional guidelines, and meet with the NHS Information Standard.

Why is Menstrual Matters needed?

1. Inadequate diagnostic practice

A combination of social, economic, and political factors have resulted in an inadequate diagnostic process to differentiate between the symptoms of various female-prevalent health issues, and those triggered, worsened, or caused by the menstrual cycle (and/ or hormonal medication).

For example, female people of reproductive age are known to be disproportionately affected (at least 2:1) by chronic health issues that share many of the same symptoms as PMS (Premenstrual Syndrome) [1];

- IBS (Irritable Bowel Syndrome)
- Migraine
- Chronic Fatigue Syndrome
- Depression
- Anxiety
- Anaemia

However, menstruating patients are not typically asked to track their symptoms over time (at least 2 cycles), to enable a fully-informed differential diagnosis.

In fact, several factors have combined to effectively obscure the role of the menstrual cycle in triggering, worsening, or causing such symptoms;

- The menstruation taboo (linked to the bleeding part of the cycle) can prevent doctors and patients from mentioning, or adequately considering, the menstrual cycle as a potential factor in, ill health [2] [3].
- Cyclical symptoms and other female-prevalent chronic health issues are more likely to be misunderstood, disbelieved, or dismissed by others, including clinicians [4-6].

“I don’t consult [a doctor]... I haven’t bothered again- I don’t feel they understand the problem and it’s so hard to explain.” - Research participant from menstrual symptoms help-seeking behaviour study [7].

“We have evidence that over half of our patients have to see three clinicians before somebody takes them seriously.” -Lawrence Nelson, a gynaecologist at the US National Institute of Health (NIH) [8].

- Time limited (and, therefore, economically pressured) appointments typically force a prioritisation of symptoms to inform a ‘most likely’ differential diagnosis, rather than allowing the clinician to understand the full range, and changing severity, of symptoms, as experienced over time i.e. in relation to the menstrual cycle [9-10].
- A clinical (and public) focus on the psychological causes and effects of PMS, obscures the role of the menstrual cycle in triggering, affecting numerous physical symptoms [11-12]. Additionally, the lack of any medical specialisation in the menstrual cycle (other than in relation to fertility, or as a signifier of gynaecological disease or abnormality) undermines its role in female-prevalent symptoms.

So, patients may be misdiagnosed with a chronic health issue (or left without a diagnosis), when, in fact, their symptoms are triggered by their (healthy) menstrual cycle.

What is the impact of misdiagnosis?

The misdiagnosis, or a lack of diagnosis, of cyclical symptoms can have a serious impact on patients and the healthcare sector; especially in terms of costs, health outcomes, patient well-being, and societal perceptions of female-prevalent conditions.

Misdiagnosis can have a serious impact on patients [13]:

- Lack of efficacy of prescribed medication or treatment
- Prolonged inability to work, or maintain a social life
- Inability to understand, predict, or manage symptoms
- Poor well-being, low mood

For the healthcare sector, this can result in [14]:

- Repeat consultation and treatment costs

- A loss of trust between patient and clinician/health service
- Incorrect clinical data
- Inappropriate resource allocation

What's more, cyclical symptoms are often quite simple to treat, without necessarily requiring prescription medication. Plus, there is a big psychological difference between a diagnosis of a chronic ill-health condition, and one of 'cyclical symptoms', especially in terms of long term patient health and well-being...

Finally, by ignoring the physiological causes of symptoms, female-prevalent conditions will continue to be dismissed as somehow entirely 'psychological in origin' i.e. the "it's all in her head" mentality. Studies show that female-prevalent health issues (such as IBS, anxiety, depression, migraine, chronic fatigue syndrome, fibromyalgia, and auto-immune conditions) are more likely to be dismissed as 'not real' or thought to be 'exaggerated' by sufferers [4- 6], even if the patient is male...

2. The simultaneous *medicalisation* of normal menstruation and *normalisation* of severe menstrual health experiences

The social and political factors described above have also resulted in a strange paradoxical situation. Many clinical guidelines and research articles unintentionally reinforce the sexist idea that the menstrual cycle is somehow pathological in itself. They may do this by vastly exaggerating the prevalence of a menstrual health issue, or by implying that such extreme symptoms are merely the severe end of a 'normal curve' of menstrual experiences, rather than due to an underlying health issue in that individual [15].

At the same time, people who do experience severe symptoms are often positioned in a way to suggest that they are exaggerating, or are simply less able to handle the natural and healthy changes associated with the menstrual cycle, even though they typically have some sort of underlying condition in need of medical treatment [4-6].

These twin assumptions are incredibly pervasive and so it is only with careful and critical evidence-based research that we can unpick and redefine menstrual health in a way that does not unintentionally reinforce problematic gender stereotypes. This is why the social and natural sciences are combined in the Menstrual Matters research approach and blogs.

3. The rise of problematic interpretations of menstrual experiences

Recent years have seen significant growth in alternative therapies and mystical descriptions of menstrual health. While some are harmless and can provide useful alternative cultural perspectives and treatment options, others are simply selling products and services that are ineffective at best, or very harmful at their worst [16]. Beyond the financial and physical threats such practices pose, the accompanying narratives around menstrual health typically reproduce sexist beliefs that position people who menstruate as 'other', or 'inferior' types of humans [17]. Again, it is only with careful and critical social and medical research that we can effectively counter such narratives.

At the same time, there has been a rise in gender discrimination against transgender and non-binary people. Sadly, such discrimination has also gained traction within supposedly human rights-based political

movements, including feminism(s). Misinformed and exclusionary beliefs based on pseudo-scientific premises underpin much of the debates surrounding sex/ gender. For example, people often confuse the terms sex/ gender, female/woman, feminist/ female supremacist.

My own deep political belief in equal human rights (regardless of sex or gender identity, or any other intersecting social identity) provides further motivation to help counter this disturbing trend with evidence-based and inclusive research approaches and content. Menstrual health matters, language matters and fighting social and political discrimination also matters.

References:

1. Green LJ, O'Brien PMS, Panay N, Craig M on behalf of the Royal College of Obstetricians and Gynaecologists. (2017) 'Management of premenstrual syndrome'. *BJOG* 124:3 pp.73-105
2. Low EL, Whitaker KL, Simon AE, et al. (2015) 'Women's interpretation of and responses to potential gynaecological cancer symptoms: a qualitative interview study' *BMJ* 2015:5
3. Nnoaham, K. E., Hummelshoj, L., Webster, P. et al. (2011). Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertility and Sterility*, 96(2), 366–373
4. Hoffmann DE., Tarzian AJ. (2001) 'The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain'. *Journal of Law, Medicine & Ethics* 29:13-27.
5. Asbring P, Närvänen AL. (2002) Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qual Health Res.*; 12(2):148-60
6. Leston, S. Dancey, C.P. (1996) 'Nurses Perceptions of Irritable Bowel Syndrome (IBS) and Sufferers of IBS' *Journal of Advanced Nursing*, Volume 23, pp.969-974.
7. Scambler, A. & Scambler, G. (1985) 'Menstrual symptoms, attitudes and consulting behaviour' *Social Science and Medicine* 20 pp.1065-7
8. As quoted in an Al Jazeera news article 'How menstruation stigma puts women in US at risk', January 30th 2015, <http://america.aljazeera.com/articles/2015/1/30/menstruation-stigma-puts-girls-at-risk.html>
9. Heneghan C, Glasziou P, Thompson M, Rose P, Balla J, Lasserson D, Scott C, Perera, R (2009). 'Diagnostic strategies used in primary care'. *BMJ*, vol 338, pp 1003–06
10. Doust J (2009). 'Using probabilistic reasoning'. *BMJ* vol 330 pp 1080–82.
11. Freeman, E. W., Halberstadt, S. M., Rickels, K., Legler, J. M., Lin, H., & Sammel, M. D. (2011). 'Core Symptoms That Discriminate Premenstrual Syndrome' *Women's Health*, 20 (1), 29–35
12. Chrisler, J and Caplan, P. (2002) 'The Strange Case of Dr. Jekyll and Ms. Hyde: How PMS became a Cultural Phenomenon and Psychiatric Disorder.' *Annual Review of Sex Research* 13:274-306
13. Studd, J. (2012) 'Severe premenstrual syndrome and bipolar disorder: a tragic confusion' *Post Reproductive Health* Vol 18, Issue 2, pp. 82 - 86
14. Reid S, Wessely S (2002). 'Frequent attenders with medically unexplained symptoms: service use and costs in secondary care'. *British Journal of Psychiatry*, vol 180, pp 248–53
15. This paradox is very well demonstrated by the way in which Heavy Menstrual Bleeding is described in the clinical literature- see [this blog](#) for more details
16. For example- 'vaginal steaming' which reinforces the idea of menstruation as dirty, can cause burns on the vulva, and result in vaginal infections- see [this blog](#) for more details
17. For example, by promoting the idea that 'all girls' should be taken out of school during menstruation (rather than making the school fit for purpose), or reinforcing myths that make natural cycle length variation seem like a health or spiritual problem.

PEOPLE



Sally King- Founder/ Myth-Buster

In 2013, Sally started researching the role of the menstrual cycle in ill health after experiencing unexplained nausea and vomiting, and then developing asthma after taking hormonal medication to deal with this issue. The difficulty she faced in trying to find evidence-based and unbiased information on this 'taboo' topic led to the creation of Menstrual Matters. Her popular blog looks at how menstrual taboos and gender myths directly contribute to 'bad science', inadequate medical knowledge and training, and wider social inequalities.

Before specialising in menstrual health research, Sally spent nearly a decade reviewing and evaluating human rights interventions and policies, for Oxfam GB, Care International and Amnesty International. Sally has a Master's degree in Research Methods (qualitative & quantitative) and is a big fan of evidence-based critical thinking. She is currently also doing a PhD in Medical Sociology at King's College London.

SUPPORTERS

Financial support:

Denis McCarthy- thanks again for covering the website costs. Michael McCarthy, Anthony King, and Matt King thanks so much for supporting my living costs this year.

Professional support/ collaboration:

Paul Mc (you are a star!), Hannah W (keeping me sane-ish), Radhua Paudel (in solidarity and friendship), Katy Buss (I knew having geeky mates would pay off one day), the US Center for Disease Control and Prevention (CDC) and the US National Hemophilia Foundation, the Society for Menstrual Cycle Research and the ever-growing London/ UK/ European/ Global community of menstrual health and rights researchers and activists; the Wellcome Library, the British Library, SciHub (shhh!) and Pubmed, of course!

THANK YOU ALL SO MUCH.

GOVERNANCE

Note: This was the fifth year of operation, and for FY2021, I continued to act as sole trader for UK tax purposes. Since MM does not make profit and I am also a full-time student, Menstrual Matters is currently tax-exempt.

At some point in the future (when I am able to manage the administrative burden) Menstrual Matters is likely to become a registered charity or a CIC (Community Interest Company).

OBJECTIVES AND ACTIVITIES

Objectives

The objectives for FY2021 were to make progress on all four elements of the mission statement:

To provide independent, accessible, and evidence-based information for the public, clinicians, and researchers:

- To improve the diagnosis and treatment of cyclical ill health
- To help people manage their health & wellbeing
- To save the NHS unnecessary time and expense
- To bust myths that only serve to marginalise people who menstruate

Planned activities

1. Promote website more strategically
2. Continue to invest in partnerships with others working in this area
3. Properly analyse the data captured by the 'symptom checker' application
4. Continue to create original communications products to raise awareness of menstrual cycle-related symptoms and the human rights implications of poor menstrual education/ myths
5. Access funding opportunities
6. Improve monitoring and evaluation processes to enable better progress reporting
7. Complete PhD research!
8. Sell some MM resources!

Progress made...

1. This year I changed the website hosting and Paul Mc has really helped to improve the speed of the site and its general accessibility, contributing to an increase of 130% in overall page visits compared to last year [up to 160K in total]! I revised the website layout and topline content in December, which also seems to have encouraged higher numbers of visitors [now averaging approx. 20K visitors per month on a regular basis].

Since the PhD thesis continues, I could only manage reactive media engagement over the past year. Due to the publication of two academic book chapters (discussed below), media interest was actually quite good (especially given the massive impact of Covid on health news in general).

- I was quoted in The Lancet blog- [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)32583-6/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)32583-6/fulltext)
- Interviewed by a Sunday Times reporter- <https://www.thetimes.co.uk/article/periods-at-work-should-women-get-menstrual-leave-q1c2w6d0p>
- Quoted in a Health Affairs Journal blog- <https://www.healthaffairs.org/doi/10.1377/hblog20201001.640025/full/>
- Featured in Microsoft News and Refinery 29 blogs <https://www.msn.com/en-gb/health/mindandbody/how-can-we-know-more-about-erectile-dysfunction-than-pms/ar-BB18Xnes>
- And cited in an article in the Social Europe Journal <https://www.socialeurope.eu/trade-unions-and-mainstreaming-menstrual-awareness-in-the-workplacedecent>

40 symptom management pages are currently online. Compared to the last financial year, the symptom management page traffic doubled from approx. 40K to 80K visits [around half of all website traffic].

57 blogs are currently online- 5 uploaded this financial year. The blog pages traffic increased by approx. 18% up to around 2K visits per month.

Overall, the website has been attracting twice as many **visitors per month than last year**... Without any promotional activities. I am reasonably happy with this, especially since I have been conducting full time doctoral research alongside MM activities.

Top 10 symptom management pages: restlessness; muscle & joint pain; fuzzy brain; chronic fatigue syndrome; dizziness; mid-cycle bleeding; sensitivity to light/smell; nausea; ovarian cysts; and vaginismus.

Top 10 blogs: period pain-what's normal; menstrual maths- why we say 'people who menstruate'; blood loss- what's normal; 6 breathtaking facts about the hormones and asthma; mood and the menstrual cycle; hormone balancing diet; washing your lady bits; the physical virginity myth; cycle length- what's normal; and top 10 menstruation myths.

The Twitter account now has 2567 followers (867 more since last year); the Facebook group has grown to 508 followers (a 10% increase).

2. I have maintained links with menstrual research and activism contacts and organisations in the UK and beyond. I am an active member of several networks including the Menstrual Research Network, Clue Ambassadors group (period tracking app with over 10 million users), UK menstruation educator's group, the Menstrual Health Hub, European Menstrual Health Collective (administrator), the Society for Menstrual Cycle Research, Global South Coalition for Dignified Menstruation, and the Gender and Development Network. I am also a member of the UK government's 'women's health' task force.
3. The symptom checker web application was launched (as part of the website) in April 2017. This is the world's first database of cyclical health experiences and will ultimately help build a picture of the most common female-prevalent symptoms. The number of people completing the **symptom checker application has increased by 160%** compared to last year [1000 people have now filled it out- making this one of the large-scale menstrual health studies out there!]. Katy Buss has kindly volunteered her amazing data analysis skills to help improve the accessibility of the data... There are already some interesting patterns relating to iron-deficiency anaemia and cyclical symptoms.
4. My chapter in the Palgrave/MacMillan Handbook of Critical Menstruation Studies: 'PMS and the myth of the irrational female' was finally published in October 2020- the handbook has been downloaded over 750K times and my chapter a further 12K times- https://link.springer.com/chapter/10.1007/978-981-15-0614-7_23. Another book chapter on the topic of menstrual leave was published in the 'aligning perspectives on gender mainstreaming' Springer handbook in January 2021- It is already the most cited reference on the Wikipedia page on the topic! <https://www.springer.com/gp/book/9783030532680>.

I also researched and wrote 4 original blogs this year (reframing the diagnosis of endometriosis, what's normal- mood change, do you have a bleeding disorder, and why do humans menstruate), and edited an additional guest blog about period photography.

I recorded a Facebook Live talk about menstrual leave- good intentions, poor solution - for the Radhwa Paudel foundation <https://fb.watch/4CE0SeZuZR/>

5. I did not apply for any funding during FY 2021, mainly due to working full time on my doctoral thesis.

6. Running Google analytics on the website content and writing this annual report is still all I am doing in regard to the monitoring and evaluation of impact. I am confident that MM actually *is* making progress on its objectives, although this is limited by the fact it is still largely a one-person show (and that person is also doing a PhD)!
7. Unfortunately, my thesis is taking much longer than anticipated but I hope to submit it and pass examination during 2021. The good news is that my findings are very exciting!
8. I am still in the process of sorting out an online shop for resources... Watch this space.

FINANCES:

Income

Donations from Uncle Denis: £2,101.32

FY21 Total income: £2,101.32

Expenses

Expense:	Amount:
Test products	£17.45
Donations	£10.00
Illustrations/ design	£600.00
IT Software/ hardware	£178.52
Books	£117.14
Other events/conferences	£11.37
SMCR conference- not reimbursed	£0.00
Memberships/ subscriptions	£101.88
phone	£234.96
Web hosting/ apps/SSL cert	£381.51
Printing/stationary	£112.74
MM expenses:	£1,765.57

FY21 Total expenses: £1,765.57

FY21 'profit': £335.75

Previous year balance (FY2017-2020): - £649.52

FY 21 Balance: - £313.77

HOW YOU CAN HELP

Use the website

By using the '[symptom checker](#)' application, you are helping to improve the diagnosis and treatment of menstrual cycle-related health issues... (As well as finding out if there could be a cyclical factor in your own symptoms). The app automatically makes your answers anonymous and adds them to a secure database (please see the [privacy policy](#) for more information). In time, this information could help find out how best to manage a whole range of chronic health problems and symptoms - all thanks to you!

Tell others about the website

The more people that use the website, the better the evidence-base will be! We need lots of people to use the 'symptom checker' application... We need all sorts of people to take part, including people who do not have a menstrual cycle, or take hormonal medication- so feel free to share it with everyone.

Make a donation

Menstrual Matters incurs various administrative, research, and web development costs. If you have found the website useful, or would simply like to support the cause, you can donate by contacting me at info@menstrual-matters.com. Many thanks indeed!

Share your research

If you happen to be working in a relevant field of clinical or social research, please feel free to share your work with me. I can promote it within various professional networks, and add it to periodic newsletters sent out to researcher and/or clinician groups. Join the clinician (<https://www.menstrual-matters.com/for-clinicians/>) or researcher (<https://www.menstrual-matters.com/for-researchers/>) newsletter lists to keep updated.

Become a research partner

If you are interested in collaborating on communications, research, or media work- please get in touch! I aim to collaborate with as many charitable, research, and professional organisations as possible- to raise awareness of cyclical experiences... Email me at info@menstrual-matters.com

Become a corporate partner

Perhaps you are keen to become a corporate partner of Menstrual Matters? You may be running a fundraising event, or wanting to find a 'niche' non-profit to support as an organisation- why not consider supporting this work? MM is certainly a talking point, smashing ancient social taboos, and potentially helping to improve the health and wellbeing of billions of menstruating people all over the world (forever)! Be part of something truly revolutionary... Email me at info@menstrual-matters.com

FY2022- LOOKING TO THE FUTURE

Objectives

In line with the overall aim, the objectives for FY2022 are to make further progress on all four elements of the mission statement:

To provide independent, accessible, and evidence-based information for the public, clinicians, and researchers:

- To improve the diagnosis and treatment of sex hormone-related ill health
- To help people improve and take control of their health & wellbeing
- To save the NHS unnecessary time and expense
- To debunk myths that only serve to marginalise people who menstruate

Planned activities

1. Promote website and resources more strategically- to clinicians, employers and patients
2. Continue to invest in partnerships with others working in this area
3. Properly analyse the data captured by the 'symptom checker' application- write up and publish an article
4. Create and sell resources to raise awareness of menstrual cycle-related symptoms and the human rights implications of poor menstrual education/ myths
5. Set up revenue stream from the website- resources and consultancy work
6. Complete PhD research- finally! Apply for postdoc funding for further research.

With thanks,



CONTACT

- <https://www.menstrual-matters.com/contact/>
- info@menstrual-matters.com
- Twitter: @Menstrumatters <https://twitter.com/MenstruMatters>
- Facebook: @MenstruMatters