

MENSTRUAL MATTERS

ANNUAL REPORT FY2019

THE MISSION

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

THE VISION

- To raise awareness about the role of the menstrual cycle (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.



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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 about 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.

We hope to become a certified member of the Information Standard.

Why is Menstrual Matters needed?

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 (or hormonal medication).

For example, women 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);

- IBS (Irritable Bowel Syndrome) 2:1 (80% symptoms are shared with PMS)
- Migraine 3:1 (80%)
- Chronic Fatigue Syndrome 2:1 (86%)
- Depression 2:1 (91%)
- Anxiety 2:1 (81%)

Symptom	PMS/ Hormone- related	Anxiety	Depression	IBS	CFS/ME	Migraine
Difficulty concentrating/ Forgetfulness	Yellow	Dark Green				
Fatigue	Yellow	Dark Green				
Nausea/ Vomiting	Yellow	Dark Green				
Sensitivity to light, loud noise, alcohol or certain foods	Yellow	Dark Green				
Abdominal pain	Yellow	Dark Green				
Bloating/ Constipation	Yellow	Dark Green				
Diarrhoea	Yellow	Dark Green				
Excessive sweating/ Poor body temperature control	Yellow	Dark Green				
Headache/ Migraine	Yellow	Dark Green				
Irritability	Yellow	Dark Green				
Low mood/ self esteem	Yellow	Dark Green				
Muscle and joint pain	Yellow	Dark Green				
Sleeping problems	Yellow	Dark Green				
Anxiety/ tension	Yellow	Dark Green				
Restlessness/ Pins and needles	Yellow	Dark Green				
Backache	Yellow	Dark Green				
Dizziness	Yellow	Dark Green				
Low libido	Yellow	Dark Green				
Shortness of breath	Yellow	Dark Green				
Tearful	Yellow	Dark Green				
Abdominal (period) pain	Yellow	Dark Green				
Bladder urgency	Yellow	Dark Green				
Breast tenderness	Yellow	Dark Green				
Clumsiness	Yellow	Dark Green				
Dry mouth	Yellow	Dark Green				
Painful lymph nodes	Yellow	Dark Green				
Passing mucus (in stool)	Yellow	Dark Green				
Sore throat	Yellow	Dark Green				
Suicidal thoughts	Yellow	Dark Green				
Trembling or shaking	Yellow	Dark Green				
visual/sensory problems	Yellow	Dark Green				
% shared PMS/ hormonal symptoms	100%	81%	91%	80%	86%	80%

Symptoms as listed under each health condition on www.nhs.uk– retrieved 14 November 2016

So, between 80-91% of the symptoms involved in a diagnosis of any one of these chronic ill-health conditions could potentially be triggered/ affected by the menstrual cycle.

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;

1. 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].
2. Cyclical symptoms and other female-prevalent chronic health issues are more likely to be misunderstood, disbelieved, or dismissed by others, including clinicians [4] [5] [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].

3. 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].
4. 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 [13].

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 [14]:

- 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 [15];

- 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] [5] [6], even if the patient is male...

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PEOPLE



Sally King- Director/ Founder/ Myth-Buster

In 2013, I 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 I faced in trying to find evidence-based and unbiased information on this ‘taboo’ topic led to the creation of Menstrual Matters.

I have over a decade’s experience in various research/ programme quality assurance roles within human rights organisations. I have a Master’s degree in Research Methods (qualitative & quantitative) and I’m a big fan of evidence-based knowledge. I am currently also doing a PhD on the topic of cyclical symptoms at King’s College London.



Dr Catriona Murray- Medical Adviser

Catriona works as a Family Planning doctor. In her clinical work she directly observes how the menstrual cycle and contraceptive medications have a huge impact on many aspects of health and well-being. Catriona has always had a strong interest in Women’s Health. She worked as a junior doctor in Obstetrics and Gynaecology and currently works in New Zealand as a specialist in Family Planning and Reproductive Health. She has a Master’s degree in Natural Sciences from the University of Cambridge, and a medical degree from the University of Oxford.

Informal partners:



The [IBS Network](#) is the UK’s national charity for IBS, offering information, advice and support to patients and health care professionals.



The [PANDAS](#) Foundation gives support to people coping with Pre and *Postnatal* Mental Illnesses, as well as their families, friends and carers.



The ME Association is a British charity that provides information to patients and raises funds for research into ME and chronic fatigue syndrome.



Migraine Action is the leading support and advisory charity for people affected by migraine in the UK, whether individuals, families, employees or medics.

SUPPORTERS

Financial support:

Denis McCarthy, Anthony King, Anne King, Matt and Hannah King, & Trish King- and all my lovely friends who have bought me beverages and meals throughout the year.

Professional support:

Mette Hatorp- the wonderful communications volunteer; Clarissa Mascheroni and Dave Thackeray - the expert SEO volunteers; Lucia Sanchez- the fantastically kind volunteer Wordpress expert; Louisa Hardinge and Noemi Ponzoni – the volunteer data crunching experts; Uncle Paul the crazy website magician; Hannah Whelan- top menstrual health activist and swimming buddy; Dr Catriona Murray- the medical consultant; Lizzie Jones- the legal advisor; the Society for Menstrual Cycle Research and the ever-growing and totally rad London/ UK/ European/ Global community of menstrual health researchers and activists; Dr Olivia Knapton, & Prof. Bronwyn Parry and the GHSM massive at King's College London; the Wellcome Library, the British Library, and Pubmed... and the kind folk at Sotheran's bookshop who let me touch and read priceless historical artefacts without ever buying anything.

THANK YOU ALL VERY MUCH.

GOVERNANCE

Note: This was the third year of operation, and for FY2019, I continued to act as 'sole trader' for UK tax purposes. Since MM operated at a loss (see financial section), 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).

Menstrual Matters might be eligible for a wider range of funding opportunities as a charity, but this status requires a greater administrative burden.

OBJECTIVES AND ACTIVITIES

Objectives

The objectives for FY2019 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 (with help from a communications volunteer)
2. Continue to invest in partnerships with others working in this area
3. Start to 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 their management
5. Become a registered charity or CIC in order to access funding opportunities
6. Finalize monitoring and evaluation processes to enable transparent progress reporting

Progress made...

1. I had a wonderful communications volunteer for the first few months of this financial year. However, a subsequent change in their paid employment cut short the implementation of the communications strategy. Since then, I recruited three more volunteers; two who are experts in website Search Engine Optimization (SEO) and a Wordpress website expert who is willing to help fix any bugs or technical issues that crop up from time to time (pew!).

Despite a distinct lack of promotional activities and a significant reduction in the amount of time I have to attend events (due to the PhD), the number of website visits has grown exponentially (by **800%** compared to last year)! It just goes to show that evidence-based information on menstrual health is much needed. This is a big relief, since I was worried that the website might lose traction during my PhD studies.

40 symptom management pages are currently online and the website structure has been updated to respond to user activity patterns. In this financial year, the symptom management page traffic increased from a monthly average of 600 up to approx. 6000 page views... **An increase of 900%!**

42 blogs are currently online. In this financial year, the blog pages traffic increased from an average of 900 up to 2358 page views per month... **An increase of 162%!**

Overall, the website has been attracting more than **15,000 visitors per month** towards the end of this financial year... Without any promotional activities, and limited new content. I hope this upward trend continues in FY2020.

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

Top 10 blogs: depression & anxiety; asthma; cycle length; virginity myth; hormone balancing diet; moon myth; irritable not irrational; top 10 period myths; menstrual management products; period pain-what's normal?

2. Due to workload constraints, I was unable to create website sections for clinicians and researchers, although this is something that I hope to do once I complete my PhD.

I continue to hold informal partnership agreements with PANDAS (postnatal depression), the IBS Network, the ME association, and Migraine Action. I have also established links with various menstrual research and activism contacts and organisations, especially through my involvement as a volunteer technical adviser for Plan UK menstrual health campaigns (together with No More Taboo, Hey Girls, The cup effect, period positive, the real period project, Bloody Good Period, World Menstrual Network, Freedom 4girls, and Robyn Steward).

I am an active member of various networks including the Clue Ambassadors group (period tracking app with over 10 million users), UK menstruation educators group, the Menstrual Health Hub, European Menstrual Health Collective (administrator), the Society for Menstrual Cycle Research, and the Gender and Development Network (feminist forum coordinator). I am also establishing new clinical and academic links through my PhD research at King's College London.

3. The 'symptom checker' web application was launched (as part of the website) in April 2017. This year I decided to remove the logging-in process, partly to encourage greater user uptake, but also to comply with GDPR data protection legislation (much thanks must go to 'Uncle' Paul, my website developer who sorted this out and kept me entertained throughout the process).

The number of people completing the **symptom checker application has increased by 150%** in this FY. I hope to promote the app more widely next year, to encourage people of all genders to help build a picture of the frequency of the most common female-prevalent symptoms in the wider population.

Louisa Hardinge and Noemi Ponzoni have kindly offered to help crunch the data that the app has already collected... I just need to find the time to tell them exactly what I want to find out and they will sort out an automatic reporting mechanism! I look forward to sorting this out as soon as possible.

4. My chapter in the Palgrave/MacMillan Handbook of Critical Menstruation Studies: 'PMS and the myth of the irrational female' is due for publication very soon. Another book chapter on 'menstrual leave' is due for publication in 2020. I wrote 10 new blogs this year, and edited an additional guest blog by an MA student, Elizabeth Goolden, on period poverty. I spoke at a few events, including the inaugural live 'blobcast' podcast, and was interviewed by VICE. I also designed and printed a test run of informative posters. The first one to be disseminated- the top 10 period myths- has been well received by schools and menstrual health activists.

5. I did not apply for any funding during FY 2019, after previous experiences of spending a lot of time and effort on applications, only to be rejected due to 'not being a social enterprise' or a 'not being a registered charity'. I hope to register MM as a charity (or Community Interest Company) soon, in order to better access funding, although this depends on my workload, since this will necessarily involve a fair amount of work on top of existing commitments.

6. Running Google analytics on the website content and writing this annual report is all I am currently doing in regard to the monitoring and evaluation of progress. 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-woman show (and that woman is also doing a PhD)!

Some outcomes...

Communications – The Twitter account has over 1000 followers (an increase of 83% compared to last year); the Facebook group has grown to 349 members (a 40% increase- these figures are likely to substantially increase once a more permanent communications volunteer is in post); and as mentioned above, page views have increased substantially (800%), without any promotional work...

Research- As a result of speaking at the Society for Menstrual Cycle Research biannual conference in June 2017, I was asked to contribute a chapter to an upcoming publication (due out in June 2019), the Palgrave/ MacMillan Handbook of Critical Menstruation Studies. My chapter about 'PMS and the myth of the irrational female' will hopefully inform the work of numerous students for years to come.

I was also asked to write a book chapter on the topic of 'menstrual leave; good intentions, bad solution' for a Sage handbook of 'Organisational policies and gender', which is likely to be published next year.

The 'symptom checker' app data is already proving useful for informing my PhD research on clinical definitions of cyclical symptoms. For example, it is clear that those who experience severe cyclical mood symptoms also feel low, anxious, or irritable throughout the cycle, albeit experiencing 'premenstrual' exacerbation. This suggests an underlying issue that is worsened premenstrually, rather than a distinct cyclical mental health issue; as 'PMDD' is currently clinically defined.

FINANCES:

Income

Donations from family members: £1,786.02

FY2019 Total income: £1,786.02

Expenses

Expense	Amount
SMCR conference	£204.98
Books/ research reports	£311.82
phone	£157.58
IT (mainly GDPR compliance!)	£675.83
Web hosting	£59.99
Memberships/ subscriptions	£127.50
Other training/events/conferences	£39.58
Printing/stationary	£190.88
Donation	£10.00
other conferences	£73.32
Total:	£1,851.48

FY2019 Total expenses: £1,851.48

[Balance covered by Director: £65.46]

HOW YOU CAN HELP

Use the website

By using the 'symptom checker' application, you are helping to improve the diagnosis and treatment of cyclical 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! I need lots of people to use the 'symptom checker' application, and then to tell me how tracking symptoms over time perhaps improved their diagnosis, or health and wellbeing... I need all sorts of people to use the checker app, 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 will 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 symptoms... 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

FY2020- LOOKING TO THE FUTURE

Objectives

In line with the overall aim, the objectives for FY2019 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 more strategically (with help from a communications volunteer)
2. Continue to invest in partnerships with others working in this area
3. Start to 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 their management
5. Become a registered charity or CIC in order to access funding opportunities
6. Improve monitoring and evaluation processes to enable transparent progress reporting
7. Complete PhD research interviews and analysis phase
8. Sell some posters
9. Attend SMCR (Society for Menstrual Cycle Research) conference in Colorado Springs (June 2019)

CONTACT

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