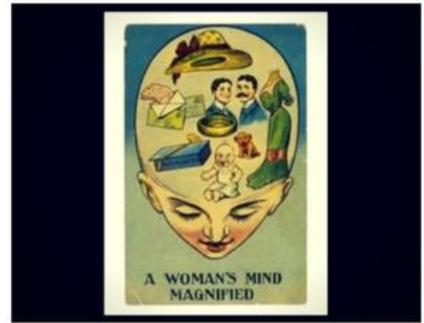


Check. Track. Manage.
Your health.



MENSTRUAL MATTERS

ANNUAL REPORT FY2018



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ANNUAL REPORT FY2018

OUR MISSION

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

OUR VISION

- To raise awareness about the role of the menstrual cycle (or hormonal medications) in causing, triggering, or worsening symptoms associated with a range of female-prevalent chronic ill health conditions.
- To promote effective symptom management, through healthy diet and lifestyle changes, rather than immediately resorting to medication (which cannot fix any underlying hormonal problem, and may result in negative 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 medications).
- To reduce the stigma attached to the menstrual cycle so that it can no longer negatively impact the health and wellbeing of all those who menstruate.
- To create new data, and collate existing clinical research, to provide the necessary evidence base to pursue the above goals.



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ABOUT US

What is Menstrual Matters?

Menstrual-Matters is non-profit research and information hub that aims to raise awareness about the role of the menstrual cycle (or hormonal medications) in a variety of symptoms associated with a range of female-prevalent chronic ill-health conditions.

- **Patients** can use our simple 'Check. Track. Manage' approach to find out if their symptoms are likely to be hormone-related, and, if so, how to manage them through tried and tested dietary and lifestyle changes, before resorting to hormonal, or other forms of medication (which can cause unwanted side-effects).
- **Clinicians** can make more informed diagnoses, and consider a wider range of treatment options, for a range of female-prevalent chronic ill-health conditions; simply by asking patients to track their symptoms over time (at least 2 menstrual cycles*).

* As advised by RCOG (Royal College of Obstetricians and Gynaecologists) Guidelines [1].

A note for Clinicians and Researchers:

We will be developing clinician and researcher areas of the Menstrual Matters website in the future.

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

We hope to become a certified member of the [Information Standard](#) by 2020.

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 caused/ 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 (i.e. changing levels of sex hormones) as a potential cause of, or factor in, ill health [2] [3].
2. PMS (Premenstrual Syndrome) and other female-prevalent chronic health issue symptoms 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, or causing numerous physical symptoms of ill health [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 chronic ill health [13].

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

What is the impact of misdiagnosis?

The misdiagnosis, or a lack of diagnosis, of hormone-related 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 chronic ill-health 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, hormone-related symptoms are often quite simple to treat, without the need to resort to prescription medication. For example, it is possible to manage even severe cyclical symptoms through diet and lifestyle changes, alone.

Plus, there is a big psychological difference between a diagnosis of a chronic ill-health condition, and one of 'hormone-related symptoms', especially in terms of long term patient health and well-being...

Finally, by ignoring the physiological (hormonal) causes of symptoms, female-prevalent chronic ill-health conditions will continue to be dismissed as 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 'exaggerated' by sufferers [4] [5] [6], even if the patient is male...

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OUR PEOPLE



Sally King- Director and Founder

Sally has over ten years' experience working in human rights organisations, a Master's degree in Social Research Methods (Qualitative and Quantitative) from the University of Manchester, and is currently undertaking a PhD on the topic of Premenstrual Syndrome at King's College London.

In 2013, Sally started researching the role of the menstrual cycle in ill health after experiencing severe cyclical 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.



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 and started specialist training in Obstetrics and Gynaecology in 2008, passing MRCOG part 1. Catriona is training to become a specialist in Family Planning and is due to complete this soon. She also has a Master's degree in Natural Sciences from the University of Cambridge, and a medical degree from the University of Oxford.

We have informal partnerships with:



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.

OUR SUPPORTERS

Financial support:

The estate of Joan Griffith, Denis McCarthy, Anne King, Anthony King, and Rachel Dale.

Professional support:

Rich Edwards & all at Paavo Media; Guy, Will & all at Long Run Works; Dr Catriona Murray; Gratisography, Unsplash, Pexels; the Society for Menstrual Cycle Research and the ever-growing community of menstrual researchers and activists; Dr Scott Vrecko, Dr Olivia Knapton, & Prof. Bronwyn Parry from King's College London; the Wellcome Library, the British Library, and Pubmed!

THANKS SO MUCH!

GOVERNANCE

Note: This was our second year of operation, and so for FY2018, the Director of Menstrual Matters acted as 'sole trader' for UK tax purposes. Since we operated at a loss (see financial section), we are tax-exempt.

At some point in the future (when we are 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. So, in FY2019, we hope to finally decide which legal status we wish to pursue and to recruit appropriate directors/ trustees, as required.

OUR OBJECTIVES AND ACTIVITIES

Objectives

In line with our overall aim, our objectives for FY2018 were to make progress on all four elements of our 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. Finalise and promote patient-focused content on the website
2. Develop website sections for clinicians and researchers
3. Develop research/ activism partnerships with others working in this area
4. Analyse hormonal health data from the Menstrual Matters web app
5. Create communications products to raise awareness- blogs, articles, presentations etc.
6. Secure financial support
7. Set up monitoring and evaluation processes to enable transparent progress reporting

Progress made...

1. The blog has been online since June 2016, and the full website was launched in April 2017. All symptom management pages have now been finalized (37 pages of evidence-based content) and the website structure has been updated to respond to user activity patterns. In this financial year, we have increased our symptom management page traffic from an average of 100 up to 600 page views per month (and this trend is continuing; in March 2018, our symptom pages attracted over 1200 views).

Top 10 symptom management pages: [restlessness](#), [chronic fatigue syndrome](#), [abnormal bleeding](#), [fuzzy-brain](#), [all-symptoms](#), [depression](#), [asthma](#), [diarrhoea](#), [bladder issues](#), [polycystic ovary syndrome \(PCOS\)](#)

2. Due to workload difficulties, we were unable to create website sections for clinicians and researchers, although this is something that we hope to do in the future.

3. We continue to hold informal partnership agreements with PANDAS (postnatal depression), the IBS Network, the ME association, and Migraine Action. We have also established links with various menstrual research and activism contacts and organisations, especially through our involvement as a technical adviser for the Plan UK 'Breaking Barriers' report on the state of sex and menstruation education (together with No More Taboo, The Cup Effect, Period Positive, The Real Period Project, Bloody Good Period, World Menstrual Network, Freedom 4girls, and Robyn Steward. We are active members of various networks including the Clue Ambassadors group (period tracking app with over 10 million users) (London group administrator), 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). We are also establishing clinical and academic links through our Director's PhD research project on Premenstrual Syndrome (PMS) at King's College London.

4. Our 'symptom checker' web application was launched (as part of the website) in April 2017. It appears that the logging in process is discouraging people from using it, so we will be removing the log in requirements and promoting the app more widely, in FY 2019. However, even though we only have around 50 completed questionnaires, this is already some of the most comprehensive data ever recorded in relation to a wide range of female-prevalent symptoms and their relationship with the menstrual cycle. We hope to be able to start sharing some app data-informed content in FY 2019.

5. A chapter in the forthcoming (2019) Palgrave/MacMillan Handbook of Critical Menstruation Studies: 'PMS and the myth of the irrational female', advisory role in the Plan UK 'Breaking Barriers' report, a presentation at the biannual Society for Menstrual Cycle Research conference held in Atlanta, Georgia, speaker at the 'Break the Barriers' event in Leeds, a presentation to the KCL Society for Obstetrics & Gynaecology, and 1 online magazine interview (flux magazine). We also have an on-going relationship with a brand consultancy (Long Run Works) and have recently recruited a communications volunteer, to help promote the website. Fewer blog posts were written (due to other work commitments) but we are committed to producing a monthly blog in FY 2019. In this financial year, we have increased our blog traffic from an average of 200 up to 900 page views per month (and this trend is continuing; in March 2018, our blogs attracted over 1100 views).

Top 10 blogs: [asthma](#), [depression-anxiety](#), [top menstrual products](#), [symptom tracking](#), [enviromenstrual-matters](#), [hormone balancing diet](#), [irritable-not-irrational](#), [managing-symptoms](#), [medical taboo](#), [breaking barriers in sex and menstruation education](#)

6. We did not apply for any funding during FY 2018, after our experiences last year i.e. 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'. We hope to become a charity (or Community Interest Company) this year, in order to better access funding, although this depends on the workload of our Director, since this will necessarily involve a fair amount of work on top of existing commitments (PhD research plus Menstrual Matters activities). At least our Director's living expenses are now covered by her PhD scholarship, which significantly reduces the financial pressure on Menstrual Matters!

7. We have some monitoring and evaluation procedures in place e.g. in terms of financial regulation, website analytics, and data protection compliance, but we need to improve our communications and awareness-raising strategy and impact analysis. It is hoped that this will be accomplished in FY2019 with the support of our recently recruited communications volunteer.

Some outcomes...

Communications - Listed as a BBC expert on menstrual health; our Twitter account has attracted over 650 followers; our Facebook group has grown to 266 members (we hope to boost these figures once the communications volunteer is fully in post); our blog posts are still also published in an external 'Medium' publication called '*ask me about my uterus*'- boosting our US audiences (now with over 15,000 followers); our page views have increased substantially, month on month, without any promotional work...

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

OUR FINANCES:

[**Note:** This was our second year of operation, and so for FY2018, the Director of Menstrual Matters covered her own living expenses (in excess of her research scholarship that started in September 2017) and the balance of business expenses- coming to around £5,000 in total.]

Income

Donations from friends and family: £1,400.00

FY2018 Total income: £1,400.00

Expenses

Expense	Amount
SMCR conference	£1,513.12
Books	£229.69
phone	209.94
IT	£205.91
Web hosting	£203.98
Memberships/ subscriptions	£120.05
Other travel	£85.20
Other training/events/conferences	£62.46
Printing/stationary	£61.43
Testing products	£26.74
Postage	£4.75
Total:	£2,723.27

[**All expenses other than participation at the Society for Menstrual Cycle Research Conference at Atlanta, Georgia: £1,210.15**]

FY2018 Total expenses: £2,723.27

[Balance covered by Director- £1,311.70]

HOW YOU CAN HELP

Use the website

By using the 'symptom checker' application, you are helping to improve the diagnosis and treatment of hormone-related health issues... (As well as finding out if there could be a hormonal factor in your own symptoms). We make your answers anonymous and then add them to our secure database (please see our [privacy policy](#) for more information). In time, we hope to find out how best to manage a whole range of hormone-related chronic health problems and symptoms - all thanks to your information!

Tell others about the website

The more people that use the website, the better our evidence-base will be! We need lots of people to use the 'symptom checker' application, and then to tell us how tracking their symptoms over time perhaps improved their diagnosis, or health and wellbeing... We 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

We incur various administrative, research, and web development costs. If you have found the Menstrual Matters website useful, or would simply like to support our cause, you can donate via our PayPal page here- <https://www.menstrual-matters.com/donations/1852/> - 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 us. We will promote it within our professional networks, and add it to our researcher and/or clinician areas of the website (being developed in the future). Join our 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! We are hoping to collaborate with multiple charitable, research, and professional organisations- to raise awareness of the link between the menstrual cycle (and hormonal medications) and symptoms of chronic ill health... Email us 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 our work? We are 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 us at info@menstrual-matters.com

FY2019- LOOKING TO THE FUTURE

Objectives

In line with our overall aim, our objectives for FY2019 are to make further progress on all four elements of our 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 communications volunteer)
2. Continue to invest in partnerships with others working in this area
3. Start to analyse the data captured by our '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. Finalise monitoring and evaluation processes to enable transparent progress reporting

CONTACT US

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