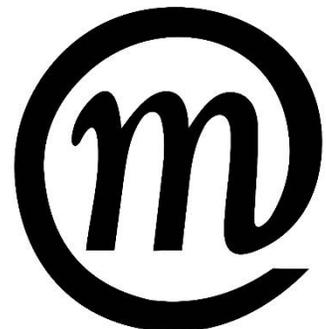


**Check. Track. Manage.
Your health.**



MENSTRUAL MATTERS

ANNUAL REPORT FY2017



MENSTRUAL MATTERS

ANNUAL REPORT FY2017

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.

Our website is for three different audiences:

- **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*). Clinicians can also keep up with the latest in menstrual cycle-related research developments by signing up to our newsletter.
- **Researchers** can keep up with the latest in menstrual cycle-related research news by signing up to our newsletter. We are also developing the 'research' area of the website, where individuals will shortly be able to share their work, collaborate with others, and access information on relevant funding opportunities and conferences.

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

A note for Clinicians and Researchers:

We are developing the clinician and researcher areas of the Menstrual Matters website throughout 2017/18.

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 2018.

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

Based in London, Sally has over ten years' experience working in human rights and international development organisations, and a Master's degree in Social Research Methods (Qualitative and Quantitative) from the University of Manchester.

In 2013, Sally started researching the role of the menstrual cycle in ill health after experiencing a severe reaction to her own menstrual cycle (nausea and vomiting), and then to the hormonal medication used to deal with this problem (asthma). 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 New Zealand. 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. After moving to New Zealand in 2010 and having two children, Catriona is training to become a specialist in Family Planning and is due to complete this at the end of 2017. 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:

Anne King, Anthony King, Mike McCarthy, Denis McCarthy, Mary McCarthy, Denebo Wario, Les & John Brown, and the estate of Joan Griffith.

Moral support:

Swiss Family King, Trish King, the Maxwell-Gadds, the McCarthy clan, Helen Counihan, Naomi Bourne, Hell's bells & family, Hackney Marsh Parkrunners, 'Hoops there it is' netballers, the Barrett family, Oxfammers, CARE givers, Amnesty Internationalists, Westminster Impact Hubbers, and everyone else...

Professional support:

Rich Edwards & all at Paavo Media, Catriona Murray, Douglas Murray, Lizzie Jones, Eleanor Laidlaw, Sophie Rivett, Mark Carswell, Jo Barrett, Jo Broughton, Alistair Whitson, Rich King, Ashley Goldstein, Gratisography, Unsplash, Pexels, Good Women Network, Women's Environmental Network, Mooncup, the Society for Menstrual Cycle Research, Clue Ambassadors, Scott Vrecko, Olivia Knapton, the Wellcome Library, the British Library, and Pubmed!

THANKS!

A year can seem like a long time, but not when you have just quit your job to start up a not-for-profit! I am truly amazed by what has been possible to achieve in twelve months- with just a bit of hard work, and the support of wonderful family, friends, and professional contacts.

Writing this annual report has been a real joy. Whilst I must admit to being an eternal optimist, I never imagined that the future of Menstrual Matters would already look so bright... Thanks for your support, together we can really make a difference to the lives of so many people needlessly struggling with hormone-related ill health.



Sally King - Director

GOVERNANCE

Note: This was our first year of operation, and so for FY2017, the Director of Menstrual Matters acted as 'sole trader' for UK tax purposes. Since we operated at a loss (see financial section), we were tax-exempt.

However, Menstrual Matters is in the process of becoming a UK-registered CIC (Community Interest Company). A community interest company is a business with primarily social objectives whose surpluses are principally reinvested for that purpose in the business, or in the community, rather than being driven by the need to maximise profit for shareholders and owners.

Being a CIC, rather than a charity, or profit-making company, brings a range of governance benefits;

1. The CiC brand provides:

- reassurance to stakeholders, as the asset lock and community purpose are regulated
- a higher profile for social enterprises and not-for-profit companies
- a growing network and voice within the social enterprise and third sector.

2. Transparency of operation.

An annual CIC report is placed on the public record for public scrutiny. The CIC report describes:

- the CIC's activities and the benefit provided to the community
- the remuneration paid to its directors
- the assets transferred other than for full consideration
- dividends paid
- performance-related interest paid
- the steps taken to consult stakeholders and the outcome.

3. Statutory clauses, which cannot be removed.

- The asset lock ensures the assets are used for the benefit of the community and there are other clauses to ensure members retain control.
- These clauses set it apart from other companies and prevent demutualisation and windfall profits being paid to directors and members without the balances and checks of mutuality and charitable status.

4. Continuity of purpose.

- Once a CIC is incorporated it will continue providing benefit to the community until it is dissolved or converted into a charity.
- If it is wound up under the Insolvency Act 1986 any residual assets, after satisfying its creditors, will be transferred to another asset-locked body, such as a charity or another CIC.

5. A CiC is quick, easy and inexpensive to set up and specifically designed for social enterprise.

6. A CiC provides limited liability for its members.

7. A CiC uses the company form that can be tailored to a specific organisational structure, governance, or membership, and can be anything from a co-operative providing benefit to a wider community to a single member company.

8. A CiC can take advantage of a company's risk-taking features by accessing the debt markets for loans and bonds.

9. A CiC limited by shares may expand by selling its shares.

10. A CiC may find community development finance institutions a valuable source of funds.

11. Company legislation (with which a CiC must comply) and the company form are familiar and well understood by the business community.

12. Compared with a charitable company the CiC has:

- greater flexibility in terms of activities
- no trustees and no trustee control
- directors who can be paid, but this is regulated
- light-touch regulation, but no tax incentives
- fewer reporting requirements and administration – a charitable company has to complete the Charities SORP, for example.

13. Compared with an ordinary company the CiC has:

- an asset lock, which is inexpensive and easy to set up
- statutory provisions that prevent the members of the CIC removing the asset lock by special resolution
- regulation to ensure the CIC maintains its asset lock and provides benefit to the community it was set up to serve
- checks and balances provided by CIC legislation
- a community benefit report open to public scrutiny
- transparency of directors' remuneration and use of assets
- legal protection from demutualisation and windfall profits being paid to directors and members

OUR OBJECTIVES AND ACTIVITIES

Objectives

In line with our overall aim, our objectives for FY2017 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. Set up online information hub for patients, clinicians and researchers
2. Set up partnerships with others working in this area
3. Set up an application to capture hormonal health data
4. Create communications products to raise awareness- blogs, articles, presentations etc.
5. Conduct research to provide evidence-base for hub/ communications content
6. Secure financial support

Progress made...

1. The blog has been online since June 2016, and the full website was launched in April 2017. However, the researcher and clinician areas of the website will now be developed at a later stage (due to financial restraints).
2. We have made informal partnership agreements with PANDAS (postnatal depression), the IBS Network, the ME association, and Migraine Action. We have also established links with other potential partners e.g. Clue, Mooncup, Period Positive, Pelvic Health, & the National Association for PMS...
3. Our 'symptom checker' web application was launched (part of the website) in April 2017. This is how we hope to create the world's first database of hormone-related symptom occurrence.
4. 30 blog posts, 1 published article in the Journal of Occupational Health at Work, 8 presentations at conferences, and 3 national radio station interviews.
5. All blog posts and website pages are fully referenced and based on the latest available clinical research.
6. After several failed applications for social enterprise start-up funding, and charitable grants, we realised that Menstrual Matters was a little difficult to 'sell' to donors before the full website was launched... However, generous financial donations from family and friends covered most of the business expenses for FY2017, and the Director covered the balance, plus her own living expenses.

Menstrual Matters will continue to look for relevant funding streams and opportunities to create a more sustainable business model. Now that the website is online, and the 'symptom checker' application is generating new data that may be of interest to other research organisations, we are hopeful that future funding applications will be more successful.

Some early outcomes...

Communications - Listed as a BBC expert on menstrual health; our social media accounts have attracted over 500 followers (without any promotional work); blog posts are now also published in an external 'Medium' publication called '*ask me about my uterus*'- boosting our US audiences (they have over 1000 followers); our director was commissioned to write a journal article on 'menstrual leave' after a BBC radio appearance; and the blog has been accessed by over 1700 different visitors, with over 570 returning regularly...

Health - Several people have already been in touch to tell us how they realised that their health issues were hormone-related after reading a blog, or hearing us speak at an event- with positive results in terms of their health and wellbeing.

Research- Work carried out for the online information hub and blog helped to secure a PhD research position for our Director, at King's College London- due to start in October 2017.

OUR FINANCES:

[**Note:** This was our first year of operation, and so for FY2017, the Director of Menstrual Matters covered her own living expenses and the balance of business expenses- coming to around £12, 000 in total.]

Income

Donations from friends and family: £5,375.00

FY2017 Total income: £5,375.00

Expenses

| Expense | Amount |
|--------------------|------------------|
| Postage | £9.19 |
| Photos for website | 16.83 |
| Talks/events | £50.88 |
| Printing | £51.19 |
| Memberships | £67.52 |
| Testing products | £75.52 |
| Travel | £76.57 |
| Trademark etc | £170.00 |
| phone | £205.00 |
| Web hosting | £224.35 |
| Books | £454.51 |
| Web development | £4,013.00 |
| Total: | £5,414.56 |

FY2017 Total expenses: £5,414.56

[Balance covered by Director- £39.56!]

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 2017/18). 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

FY2018- LOOKING TO THE FUTURE

Objectives

In line with our overall aim, our objectives for FY2018 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 online information hub for patients
2. Develop website sections for clinicians and researchers
3. Set up more in/formal partnerships with others working in this area
4. Start to analyse the data captured by our 'symptom checker' application
5. Continue to create communications products to raise awareness of the role of sex hormones in ill health- blogs, articles, presentations etc.
6. Secure on-going financial support
7. Set up monitoring and evaluation processes to enable transparent progress reporting

CONTACT US

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