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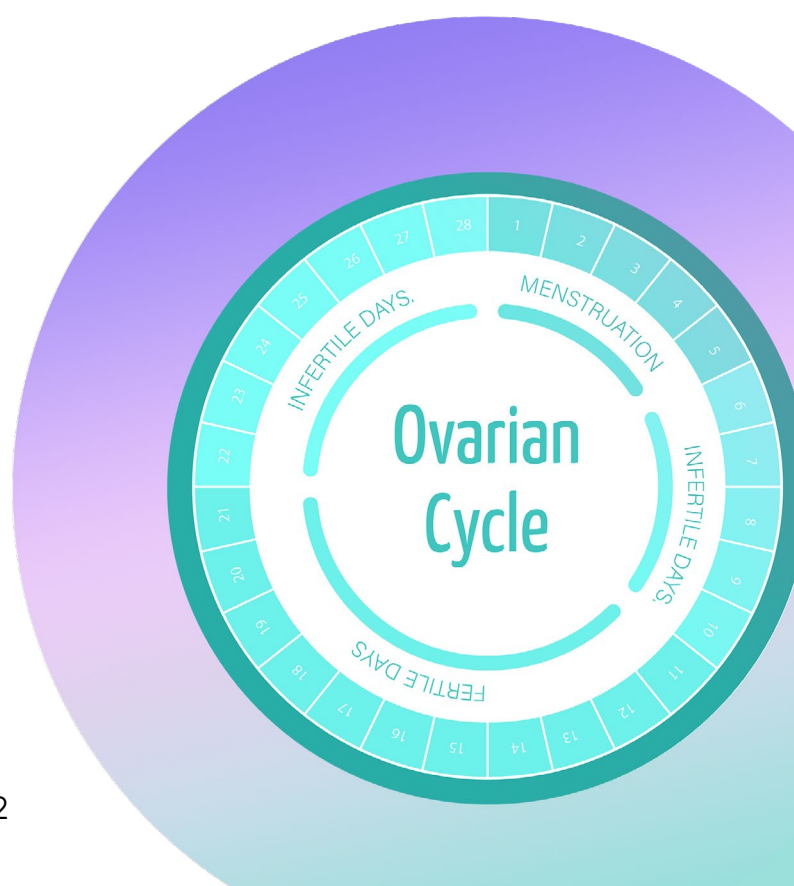
PREMENSTRUAL DYSPHORIC DISORDER (PMDD)

The UK Research Agenda

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Summary

Why is the research agenda needed?

Premenstrual Dysphoric Disorder (PMDD) is a severe hormone-based mood disorder. It causes debilitating symptoms in the latter half of the menstrual cycle. PMDD affects 1 in 20 women and individuals assigned female at birth*.^{1,2} In the UK, approximately 824,000 people have PMDD, of which 593,600 will experience suicidal ideation, 412,000 will self-harm and 275,000 will attempt suicide.³ It is, therefore, vital that future research targets issues that meaningfully support people with PMDD.

What did we do?

We gathered insight from important stakeholders to identify the research priorities for PMDD. We did this in three stages:

1. We held **focus groups** with five different groups of stakeholders. These gathered insight from 25 individuals, including people with PMDD, health professionals, researchers, support organisations, and emergency crisis professionals.
2. Based on their insight we launched a **UK-wide consultation**. This gathered feedback from 208 individuals about future research priorities. Responses were given by people with PMDD, their families, health professionals, researchers, policy decision-makers, support organisations and emergency crisis professionals.
3. We created a draft research agenda and shared this in a final **workshop** with a small group of six stakeholders. Their insight helped finalise the research agenda published in this report.

Overall, our stakeholders provided insight from a variety of helpful perspectives, including different ethnicities, gender identities, and UK health board areas.



What did we find?

Five key research priorities were identified. These are:

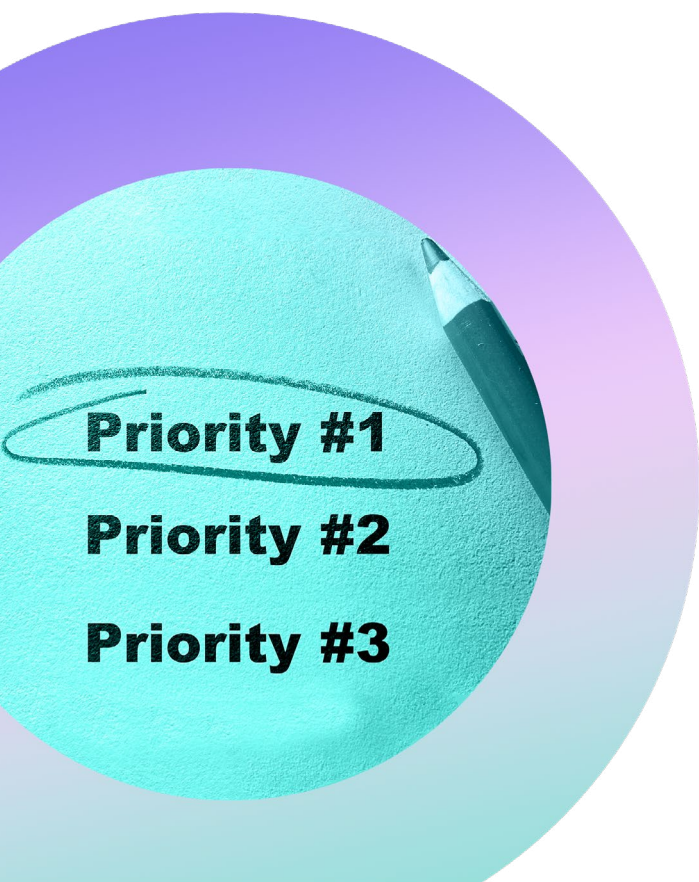
1. Diagnosis and management of PMDD
2. Best approaches for psychological support
3. Suicide and self-harm prevention
4. Impact of PMDD on life
5. Support for hormonal 'trigger' events

Alongside the 'top 5', other areas were identified as important. These include: (a) causes and biology of PMDD; (b) destructive behaviour; (c) surgery and post-surgery support; (d) barriers to support; (e) the 'cost' of PMDD; (f) premenstrual exacerbation of existing disorders; (g) neurodivergence; (h) support from the welfare system; and (i) PMDD education and training.

What happens next?

The research agenda will now help shape the future of PMDD research in the UK. We recommend the agenda be used in four ways.

1. Researchers should use the agenda to focus their funding bids.
2. Lecturers and researchers should use the agenda to identify topics for student teaching and research.
3. Policy decision-makers should use the agenda to identify and implement policy initiatives in their local areas.
4. Not-for-profit groups may find the agenda useful to develop grassroots initiatives.

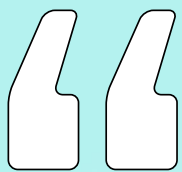




RESEARCH PRIORITY NO. 1

Diagnosis and management of PMDD

Summary: People with PMDD visited health professionals for 4-14 years before receiving a correct diagnosis. Many described misdiagnoses and inappropriate medications. People with PMDD felt frustrated by health professionals' lack of awareness and knowledge of PMDD. Health professionals also felt frustrated by the lack of training on PMDD and the lack of multidisciplinary teams to support their patients.



"I'd been in mental health services for ten years, and no one had mentioned periods [or] asked me about my cycle. I'd been diagnosed with borderline personality disorder first ... and then bipolar disorder, and it hadn't occurred to the psychiatrist, female and male, to ask about my menstrual cycles"

(Person with PMDD)

"A great multidisciplinary approach, I think that would make my life so much easier to have a team where I could speak to a GP, a psychiatrist, even nutritionist trained people, a dietician, more holistic approach to PMDD, psychologist, a counsellor, where there is space to discuss what's happening for each person, and then that person then also has input from that wide team. I think that would be the dream"

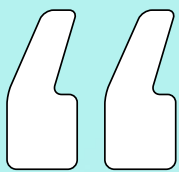
(Health professional)



RESEARCH PRIORITY NO. 2

Best approaches for psychological support

Summary: PMDD typically impacts people for decades. People with PMDD therefore need life-long coping skills to navigate daily life. Although several options were identified, including dialectical behavioural therapy (DBT) and cognitive behavioural therapy (CBT), research is lacking on what are the best approaches, and how these might work for PMDD. Understanding the best psychological techniques (and how to access and fund them) is a key priority for future research.



"[We don't have] any specialist psychological service that we can refer patients to after they're seen at our clinic. So, a lot of patients request some sort of specialist psychology, or even specialist support for ongoing support after they're seen at our clinic, and at the moment we don't have anywhere that I'm aware of that we can refer patients to ... it would be really nice to have some sort of either psychoeducation group or specialist psychology service within the NHS that you can refer patients to"

(Health professional)

"One of our main interventions [for adolescent mental health] is Cognitive Behavioural Therapy (CBT) for anxiety and mood disorders, and if there is that underlying possible hormonal influence. Then CBT is recommended as a treatment, but a lot of our CBT therapists probably won't be trained [in PMDD], and offer it [as a tool for supporting PMDD]"

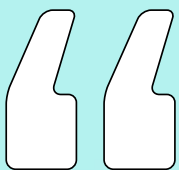
(Health professional)



RESEARCH PRIORITY NO. 3

Suicide and self-harm prevention

Summary: Although one in three people with PMDD attempt suicide, there is minimal PMDD-specific support available. Emergency crisis personnel and support organisations described the challenge of supporting people in PMDD crisis when they themselves have limited options. Additionally, PMDD may not be recognised yet, by either the person with PMDD or those supporting them. This adds additional complexity when providing support.



“Sometimes in a [PMDD] crisis, there will be a lot of self-harm. Normally with calls like that the police are called there first ... Sometimes they’re having suicidal thoughts, which is [frustrating] for us and them in a way, because all we can really do in that case is take them to A&E. That’s pretty much the only pathway we have for them at the moment. So they’re feeling their worst [...] and they say they speak to the mental health team after waiting for hours, and then are sent home, and then the thing will repeat again”

(Emergency crisis personnel)

“There’s definitely things that myself and the people I work with aren’t qualified on, and that would be things like support for suicidal thoughts, people in crisis, and we would refer in cases like that [...] You Google and there’s nothing there (for PMDD related suicide/self-harm support), so it’s really hard to try to keep a positive spin when you’re talking to somebody that’s in crisis”

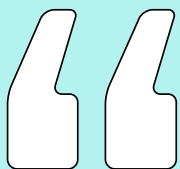
(Support organisation)



RESEARCH PRIORITY NO. 4

Impact of PMDD on life

Summary: People typically live with PMDD for decades. It impacts on all areas of life, including their education, employment, relationships, parenting and more. Understanding the impact of PMDD on life helps create interventions to support people long-term.



"The amount of families that have broken up [...] I'm just thinking, as an example, someone who then had to go into housing and needed council housing, needed extra support. You start counting all those things in, those relationship break ups, the hospitalisation, everything. It really adds up [and takes] a toll on so many levels, financial, emotional ..."

(Health professional)

"I'd like to know what the long term impacts on some people living with PMDD. I don't think people think about that enough. So, for example, how it affects your life and work opportunities, your quality of life, because it's something that you have to live with for 30 years or so. It can have a significant impact, and I don't think that's appreciated"

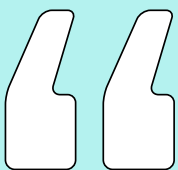
(Researcher)



RESEARCH PRIORITY NO. 5

Hormonal 'triggers' for PMDD

Summary: Research shows that PMDD is linked with hormonal events. These range from menarche (i.e. the first menstrual cycle) to menopause (i.e. the last menstrual cycle), and include events such as starting/stopping hormonal treatment (including birth control), pregnancy, stopping breastfeeding and perimenopause. People with PMDD describe a lack of information and support for these hormonal 'triggers'.



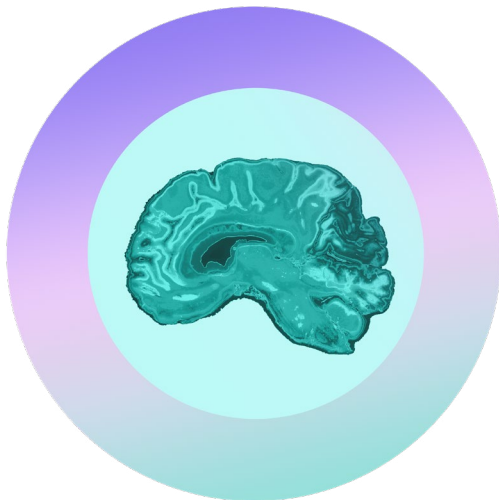
"And also like the impact of some hormonal events, pregnancy, breastfeeding, all of that did have a huge effect. And it affected my relationship with [my partner]"

(Person with PMDD)

"It appeared like she was hyperventilating, a panic attack, and her husband came and said, "It's really weird, she had just started menopause. This happened a month ago, pretty much to the same day, and the month before that you had asthma attacks"

(Emergency crisis personnel)

Other important areas for future research



Alongside the top 5 research priorities, other areas were identified for future research.

Exploring the causes and biology of PMDD

Stakeholders want to know more about brain imaging, genetics and physiology of PMDD.

"I think for me the science of it always comes first, because you can't then develop optimal treatments if you don't fully understand the cause"

(Researcher)



Destructive behaviours

People with PMDD described the 'spiral' of other behaviours such as misuse of alcohol, drugs, disordered eating and unhealthy relationships.

"... stuff about restrictive eating and PMDD, because I know that is something I experienced a lot, in that I don't let myself eat, because I don't think I'm worthy of food when I'm experiencing PMDD"

(Person with PMDD)



Surgery (removal of ovaries) and post-surgery menopause support

Researchers and support organisations acknowledged the lack of robust information on surgical management of PMDD.

"[Surgery] it's such a big life change for people to go through [...] but there needs to be a lot more research around it just to make sure that this is the right option to be recommending to people, and is there something that we can do earlier on that's better?"

(Researcher)



Barriers to support

More research is needed to explore insight from people of different cultures, ethnicity, gender identity, disability and socioeconomic status.

"And I talked about PMDD in that group [social group for Black women], and the amount of Black women who [responded] 'No, that's just your emotions. You know, we've all got to keep it down' ... You're always taught you don't talk about these things. It's just women's issues. But the more I talked about it, I've had a lot of [Black] women say to you know, that's something that we don't talk about"

(Person with PMDD)

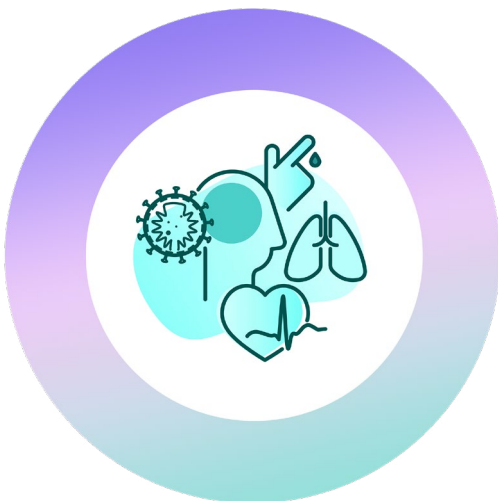


The 'cost' of PMDD

Research is required to demonstrate that PMDD-specific services provide value for money. We need to collect this information to share with policy decision-makers.

"[For] the menopause they [researchers] did those data statistics like 'such and such percent of people will be out of work' [...] and 'that cost the UK economy 'X' amount of money'. It would be really good to have data [for PMDD]"

(Health professional)



Premenstrual exacerbation of existing disorders

Many people with PMDD live with other medical conditions. More information is needed on how their condition is affected by their menstrual cycle and vice-versa.

"We'll have a lot of people that will come and say the exacerbation is what they're asking about. It's like, 'My eating disorder is so much worse in my luteal phase' or, 'I find that my anxiety is heightened' [or] 'My arthritis symptoms are worse'"

(Support organisation)



PMDD and neurodivergence

Stakeholders identified neurodivergence, such as autism and attention deficit hyperactivity disorder (ADHD), as important areas for future research.

"Periods for certain types of neurodivergent people are a nightmare. Like autistic people in particular, from lived experience, the disruption to routine, the sensory issues, the sensitivity, things like that are just they can be very unpleasant and make things even more difficult for autistic people"

(Person with PMDD)



Accessing support from the welfare state

People with PMDD, who are unable to work, experience difficulties accessing support from the welfare state.

"The assessment criteria for Adult Disability Payment [formerly Personal Independence Payment] states that people need to evidence their condition impacts them more than 50% of the month. This is difficult for people with PMDD, as although symptoms may be present less than 50% of the time, the impact and recovery from each episode is ongoing"

(Researcher)



PMDD education and training

Many stakeholders expressed the importance of PMDD education and training for the population as a whole, but particularly for health care professionals. Stakeholders also recognised the value of education for young people (and those who support young people), for example in the school setting.

"I don't think that [health professionals] are very curious, and I don't think it's something that [health professionals] have on their radar. When I've given teaching (on PMDD) I've had clinical psychologists with years and years of experience have that "ah-ha moment" for themselves, and I've had loads of people email and ask me questions afterwards"

(Health professional)

What happens now?

How to use the research agenda

This is the UK's first research agenda for PMDD.

It will be a valuable resource as we progress our understanding of PMDD.

We recommend four ways of using the agenda.

1. Researchers should use the agenda to focus their funding bids.
 - This will demonstrate to funders that stakeholders have been central to the research process.
2. Lecturers and researchers, from various disciplines, should use the agenda to identify topics for student learning and research.
 - This will help build awareness of PMDD within trainee practitioners and provide development opportunities for future PMDD researchers.
3. Policy decision-makers should use the agenda to identify and implement policy initiatives in their local areas.
 - When accompanied by appropriate evaluation, this will speed up the delivery of sustainable interventions within various settings (e.g. health service, schools, higher education, employment etc).
4. Other stakeholders may find the agenda useful to develop grassroots initiatives.
 - This will help not-for-profit groups identify appropriate support activities (e.g. support groups about parenting, or disordered eating etc).

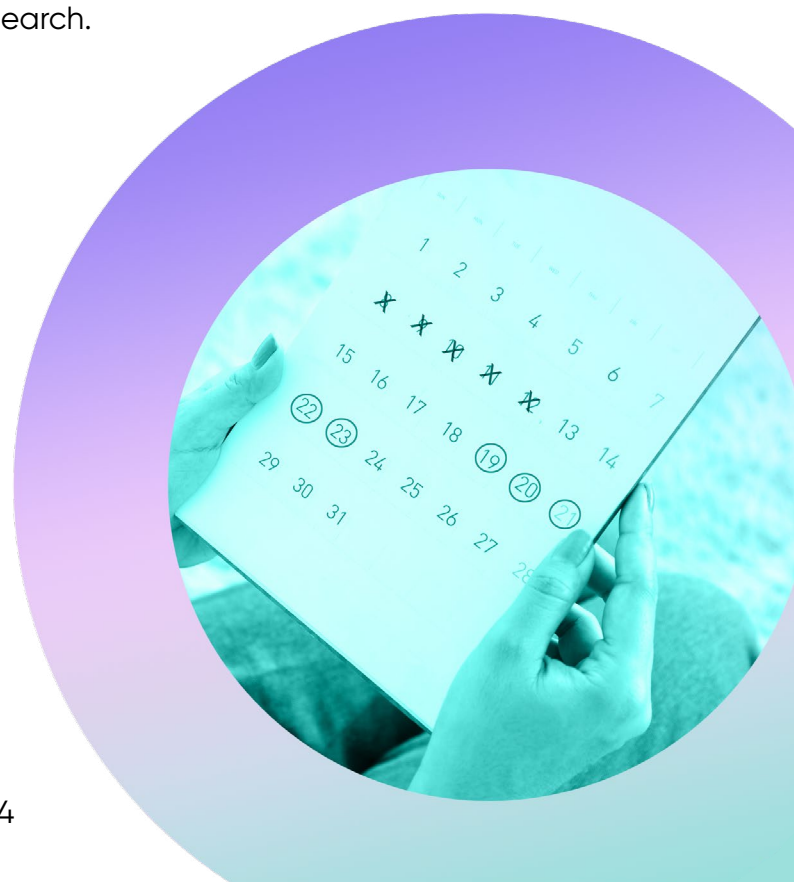
Please consider this document the 'quick access' version of the research agenda. We are working alongside a team of co-authors to publish a detailed version of the agenda in an academic peer-reviewed journal. This will present our findings alongside the current literature on PMDD research.

Thank you for the support

Thank you for engaging with the research agenda. The PMDD community appreciate the support and efforts of everyone working towards improvements for PMDD.

Stay in the loop

Visit www.uws.ac.uk/pmdd for all the latest information.



Resources

Support for people with PMDD

The International Association for Premenstrual Disorders (IAPMD) www.iapmd.org

The National Association for Premenstrual Syndromes (NAPS) www.pms.org

The UK's free Menstrual Cycle Support course <https://menstrualcyclesupport.com/>

Support for health professionals and researchers

The International Association for Premenstrual Disorders (IAPMD) provide helpful guidelines, training, webinars and an online professionals' community.

See www.iapmd.org



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