



University  
of Glasgow



# PREMENSTRUAL DYSPHORIC DISORDER

## THE WELFARE STATE: RECOMMENDATIONS FOR REFORM (INTERIM REPORT)

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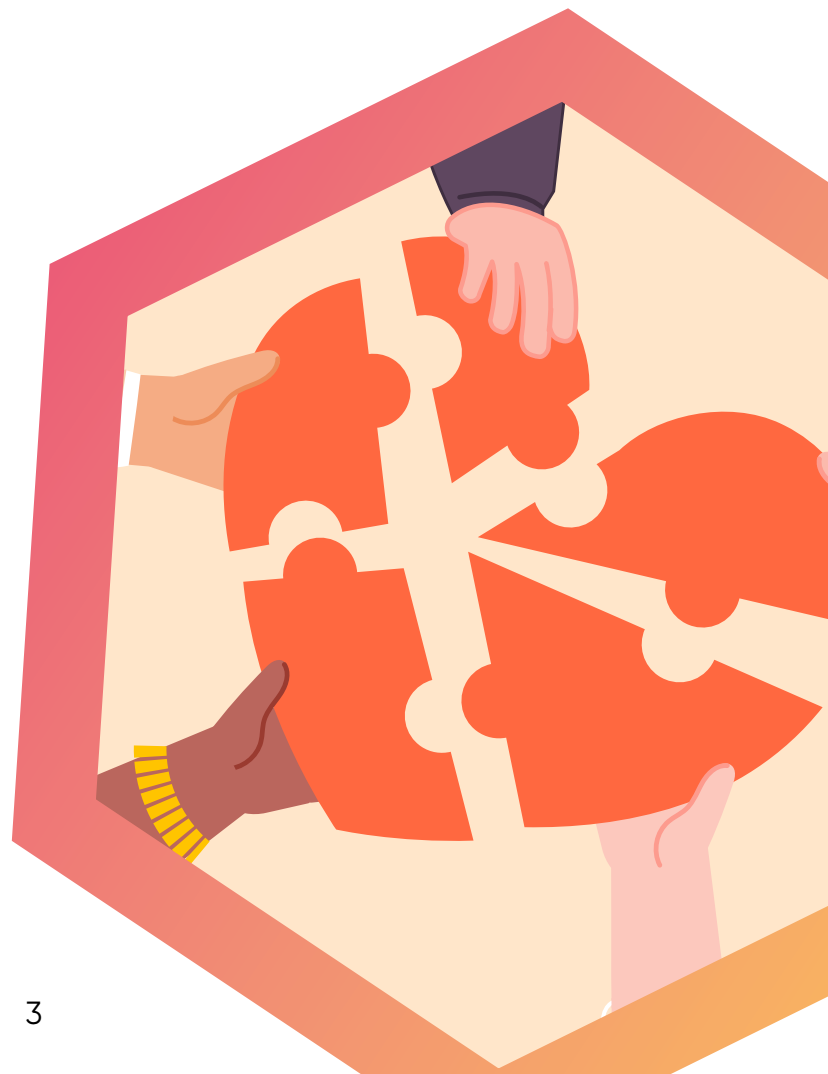
# Acknowledgements

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Content warning. This report describes experiences of suicidality.



# Summary

## **Our study**

This study explored the experiences of people with Premenstrual Dysphoric Disorder (PMDD) who applied for a social security benefit e.g. Adult Disability Payment (ADP) or Personal Independence Payment (PIP). Insight was also gathered from several professional stakeholders with experience of the welfare benefits system.

## **Why was this research needed?**

PMDD is a severe hormone-based mood disorder. It causes debilitating symptoms in the latter half of the menstrual cycle. It affects 1 in 20 women and people who menstruate. The majority of people with PMDD have suicidal thoughts, 1 in 2 self-harm and 1 in 3 attempt suicide. PMDD impacts on all aspects of life. Some people with PMDD need support for daily living.

## **What did we do?**

We delivered four focus groups:

(1) Three of the focus groups included people with PMDD. In total we gathered insight from 17 people. We asked them to describe their experience of applying for support.

(2) and one focus group with three professional stakeholders. We asked them to describe their experience of supporting people through the application process.

## **What did we find?**

Our interim analysis has identified four key findings: These are:

1. A lack of trauma-informed practice
2. Inconsistent assessment and decision outcomes
3. Difficulty evidencing a fluctuating condition
4. Lack (or unaware) of support for the application process

## **Interim recommendations**

1. Align all processes with trauma informed practice
2. Refine eligibility criteria for fairer assessment of mental health related symptoms
3. Improve training of fluctuating conditions for health care practitioners and case managers
4. Improve promotion of support services available for applicants

# What led to our study

In the UK, people can apply for financial support if they live with a condition that impacts their daily living. This is known as Adult Disability Payment (ADP) in Scotland,<sup>1</sup> and Personal Independence Payment (PIP) in England, Wales and Northern Ireland.<sup>2</sup> People may receive these benefits regardless of whether they have a job, how much they earn or whether they are in receipt of other benefits ('non means tested').

Applications are assessed against twelve daily living activities and two mobility activities. People are awarded points if they meet or exceed the 'descriptors' for each activity.

To receive points, a condition must impact someone more than 50% of the time. However, this approach has been criticised for not fairly assessing people who live with a fluctuating condition (i.e., a condition that is not present all of the time).<sup>3</sup>

People with fluctuating conditions may experience physical, cognitive and/or emotional symptoms that impact their daily living.<sup>4</sup> This is typically the case for people who live with Premenstrual Dysphoric Disorder (PMDD). They experience symptoms in the luteal phase of the menstrual cycle, typically for 1–2 weeks per month. However, outside of the luteal phase they continue to navigate trauma responses (e.g., post-traumatic stress disorder, PTSD): other mood disorders; tiring recovery time; and ongoing management issues such as counselling and/or health service appointments.

Our study aimed to explore the experiences of people with PMDD who applied for ADP or PIP support. The timing of our study aligned with the Scottish Government's consultation on reform of the ADP system. ADP is based on a social model of disability, in contrast with PIP, which is based on a medical model of disability.<sup>5</sup>

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1. Social Security Scotland. Information on benefits. 2024. Accessed from <https://socialsecurity.gov.scot/benefits>

2. Department for Work and Pensions. Personal Independence Payment (PIP). 2024. Accessed from: <https://www.gov.uk/PIP>

3. Gray, P. An Independent Review of the Personal Independence Payment Assessment. 2014; page 61. Accessed from: <https://assets.publishing.service.gov.uk/media/5a756f9ded915d7314959efd/PIP-assessment-first-independent-review-print.pdf>

4. Department for Work and Pensions. The Impact of Fluctuating Conditions on Assessment. 2024; page 9. Accessed from: [https://assets.publishing.service.gov.uk/media/66fbc4b6c71e42688b65ef50/the\\_impact\\_of\\_fluctuating\\_health\\_conditions\\_on\\_assessment.pdf](https://assets.publishing.service.gov.uk/media/66fbc4b6c71e42688b65ef50/the_impact_of_fluctuating_health_conditions_on_assessment.pdf)

5. Scottish Government. Adult Disability Payment: Independent Review. 2024. Accessed from: <https://www.gov.scot/groups/adult-disability-payment-independent-review/>

# Who did we speak to?

## People who applied for support

We spoke with 17 people, ranging in age from 21-50+ years

- 16 identified as female, one identified as non-binary
- 15 identified as White British/Scottish, one as Indian and one as Black Caribbean
- 13 were diagnosed with PMDD, 3 diagnosed with severe PMS and one was self-diagnosed with PMDD

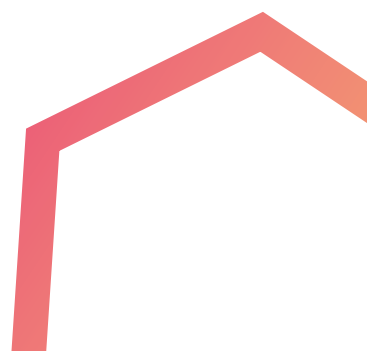
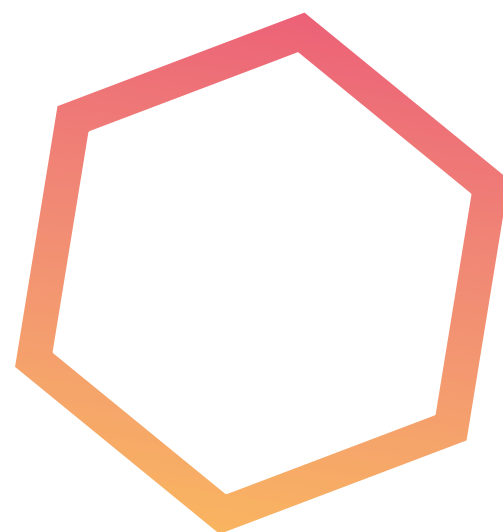
Four people were based in Scotland and had applied for ADP. Thirteen were based in England and had applied for PIP (Appendix 1).

- 7 were successful the first time they applied
- 7 were unsuccessful
- 2 were successful after a mandatory reconsideration/appeal
- 1 person started but did not complete the application

## Professional stakeholders

We also spoke with three professional stakeholders. These were people with experience of supporting people at different stages of the application process. They had different types of experiences including:

- Case worker for the Citizens Advice Bureau
- Project worker for a disability/poverty coalition
- Tribunal representative
- Academic researcher



# Key findings no.1

## Lack of trauma informed practice

**Summary:** Trauma informed practice aims to prevent re-traumatisation for people with previous experience of trauma in their life. The importance of this approach is reflected in government supported guidelines such as the roadmap launched by the National Trauma Transformation Programme in 2023<sup>6</sup>

Our participants described experiences that did not align with trauma informed care. A lack of trauma informed practice was evident in all aspects of the process, including application, assessment, written and verbal communications.

**Why is this important?** People with PMDD are known to have a higher prevalence of past trauma than people without PMDD.<sup>7</sup>

*"I think [reading] the report was probably like the worst bit for me. I was reading it, and I was just like, "No..." Like I literally felt like it was just lies {...} when I stated that I had been like suicidal, I actually got asked 'Why I didn't... why I didn't do it?' And I was like, "Wow...". It was horrendous'" (Person with PMDD, England)*

*"I know from my experience, I had early childhood trauma, and I have a flashback every time I have my PMDD phase" (Person with PMDD, Scotland)*

*"I have clients that ended up with more mental health issues, or new mental health issues that they hadn't had before. Some of them to the point of being suicidal from this process" (Professional stakeholder, England).*

6. National Trauma Transformation Programme. A Roadmap for Creating Trauma-Informed and Responsive Change: Guidance for Organisations, Systems and Workforces in Scotland. 2023. Accessed from: <https://www.traumatransformation.scot/implementation/>

7. Girdler SS, Leserman J, Bunevicius R, Klatzkin R, Pedersen CA, Light KC. Persistent alterations in biological profiles in women with abuse histories: influence of Premenstrual Dysphoric Disorder. *Health Psychol.* 2007; 26(2):201-13. doi: 10.1037/0278-6133.26.2.201

# Key findings no.2

## Inconsistent assessment and decision outcomes

**Summary:** Although it was acknowledged that people assessing applications could not be trained in all medical conditions, there was a lack of transparency and consistency between assessments and decision outcomes. People described a big difference in how their physical versus mental health symptoms were assessed, despite the psychological symptoms of PMDD having the most detrimental impact on their life. In some cases, PMDD was not mentioned on the final decision letter despite it being a focus of the application.

**Why is this important?** PMDD is a severe hormone-based mood disorder, with internationally recognised diagnostic criteria and treatment guidelines.<sup>8</sup> However, it remains an unrecognised and unfamiliar diagnosis for many professionals. This adds a burden to applicants when they are in need of support.

*"Despite my doctor's diagnosis and letter, and me clearly struggling, the assessor wrote in my decision letter that I was able to look on Facebook so I could function fine"*  
(Person with PMDD, England)

*"The letter said that 'I laughed' so was clearly not depressed"*  
(Person with PMDD, Scotland)

*"I was successful in getting PIP [Personal Independence Payment], but not because of the PMDD, because of my other health conditions. So, when I got my decision it just wasn't even mentioned, it was only focused on my other health condition, which is more physical in nature"* (Person with PMDD, England)

*"I think there's a real issue in terms of how assessments are carried out [in-person or phone or video]. I've found anecdotally there seems to be more inaccurate decisions reached when there's been a phone assessment"* (Professional stakeholder, England)

8. American Psychiatric Association. Premenstrual Dysphoric Disorder. 2013. Diagnostic and Statistical manual of Mental Health Disorders, 5th edition. Washington D.C.

# Key findings no.3

## Challenge of evidencing fluctuating conditions

**Summary:** PMDD is a fluctuating condition, meaning symptoms are not present all the time. The prescriptive nature of the application process made it difficult for people with PMDD to evidence the impact of their condition. The application lacked flexibility with people finding it focused on physical symptoms more than mental health symptoms. Obtaining health reports from clinicians or other professionals highlighted several challenges, including: inconsistency in what evidence was available; instances of health professionals refusing to give reports or not responding to requests; and some people receiving documents for free, while others were asked to pay.

**Why is this important?** To be eligible for financial support a person must evidence that their condition affects them more than 50% of the time. Although the symptoms of PMDD are present for 1-2 weeks per month (every month), it is known to have a debilitating impact on all aspects of life, even when symptoms are not present.<sup>9</sup> This, however, can be challenging to evidence.

*"When I was looking at the criteria it seemed so physical, I found it quite difficult within the limitations of the form to get across how bad the mental side is"*  
(Person with PMDD, England)

*"It's very, very quantified. So there's specific boxes and specific points, and if you have a fluctuating condition, trying to convey that is really difficult"* (Professional stakeholder, England)

*"Lots of people with mental health conditions are stepped down from services, not because they don't need it, just because that's been a decision that's made, it's out of their hands, and they're suffering as a result [can't get evidence]"*  
(Professional stakeholder, England)

Conflicting advice was another challenge of evidencing PMDD...

*"The top tip that I was told is to write it from the perspective of **your worst days**"* (Person with PMDD, Scotland)

*"People do always say you should take your worst day. But **actually you shouldn't**. I've been in so many tribunals where people have come across like they've exaggerated"* (Professional stakeholder)

9. Eisenlohr-Moul T, et al. Prevalence of lifetime self-injurious thoughts and behaviors in a global sample of 599 patients reporting prospectively confirmed diagnosis with premenstrual dysphoric disorder. BMC Psychiatry. 2022; 22(1):199. doi: [10.1186/s12888-022-03851-0](https://doi.org/10.1186/s12888-022-03851-0)

# Key findings no.4

## Unaware (or lack) of support for the application process

**Summary:** People were unaware that support existed to help with the application process. On hearing that support was available, some were reluctant to engage, based on concerns about transparency or quality of the support. People described fear, anxiety and panic about applying, with some feeling unable to appeal an application that was rejected. Professionals with experience of supporting people described enormous pressure on support services due to funding cuts and lack of staff.

**Why is this important?** PMDD causes significant cognitive changes, making it difficult to think, concentrate and make decisions.<sup>10</sup> People with PMDD experience exhausting and overwhelming psychological symptoms making it very difficult to begin and complete an application, typically at a time in their life when they need support.

*"If you consider even the task of filling out all the information as a daily living activity is like impossible without the important support of other people" (Person with PMDD, Scotland)*

*"Reasonable adjustments are talked about everywhere, but they seem to be forgotten about in the ADP process. There is no consideration to how the info is presented or worded" (Person with PMDD, Scotland)*

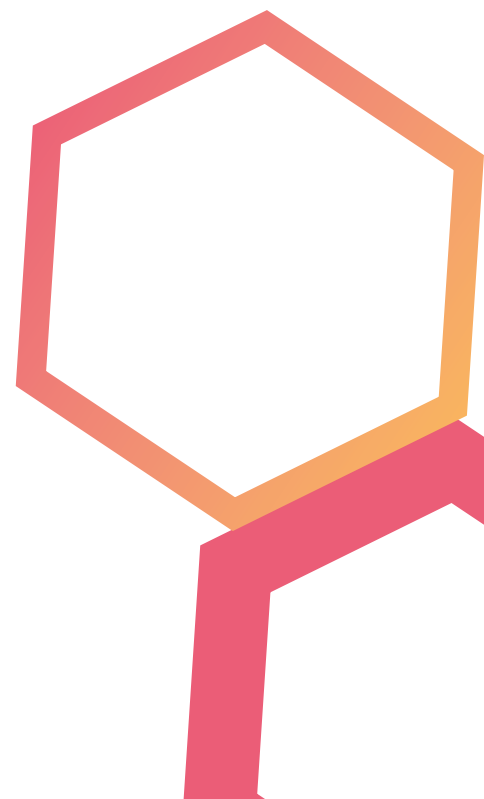
*"The lack of access that disabled people have for face-to-face advice and the pressure that's on those services to be able to support disabled people through this process is absolutely apparent" (Professional stakeholder, England)*

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10. Schmalenberger KM, Eisenlohr-Moul TA, Surana P, Rubinow DR, Girdler SS. Predictors of premenstrual impairment among women undergoing prospective assessment for premenstrual dysphoric disorder: a cycle-level analysis. *Psychol Med.* 2017; 47(9):1585-1596. doi: [10.1017/S0033291716003524](https://doi.org/10.1017/S0033291716003524)

# Interim recommendations for reform

1. Align all processes with trauma informed practice
2. Refine eligibility criteria for fairer assessment of mental health related symptoms
3. Improve case manager training for fluctuating conditions
4. Improve promotion of support services available for applicants



# Ongoing questions for future research

## Based on our interim findings, the following areas are important to explore further:

1. What are the **experiences of assessors** (i.e., case managers or health care practitioners) of assessing applications that include PMDD?
  - PMDD impacts 1 in 20 women and people who menstruate. It is important to understand the training needs for people who assess these applications.
2. What are the **barriers** to implementing trauma informed practice?
  - It is important to understand why trauma informed practice is not followed, and how social security services can be supported to deliver this.
3. Is trauma informed practice lacking for only women's mental health conditions such as PMDD, or other fluctuating conditions?
  - More information is needed to understand if there are differences in trauma informed practice between genders and/or between different health conditions.



# What happens now?

**This report has outlined our interim findings.**

We will now:

- Finalise our data analysis to produce a final detailed report;
- Share our final recommendations with policy and decision makers;
- Obtain funding to explore the ongoing research questions;
- Liaise with stakeholders to improve relevant support for people with PMDD.



# Resources

## The UK's first research agenda for Premenstrual Dysphoric Disorder

Matthews L, Riddell J. (2025). Premenstrual Dysphoric Disorder (PMDD): The UK research agenda. University of the West of Scotland.

<https://doi.org/10.5281/zenodo.14644017>

## Support and resources about PMDD

The International Association of Premenstrual Disorders (IAPMD) [www.iapmd.org](http://www.iapmd.org)

The National Association for Premenstrual Syndrome (NAPS) [www.pms.org](http://www.pms.org)

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

Further information about the social security system

Department for Work and Pensions: [Personal Independence Payment \(PIP\)](#)

Social Security Scotland: [Adult Disability Payment \(ADP\)](#)

[Consultation](#) by the Scottish Government for Adult Disability Payment

## Stay in the loop



### This report has outlined our interim findings.

To stay updated about our PMDD research please visit [www.pmdresearch.com](http://www.pmdresearch.com) Here you can sign up for the PMDD research newsletter, and/or join the PMDD patient insight group.



# Appendix 1.

## Participant decision outcomes

	Total	Diagnosis	Ethnicity
Successful on first application	7 --- *ADP = 3 - 2 with diagnosis of PMDD - 1 with diagnosis of severe PMS  PIP = 4 - 3 with diagnosis of PMDD - 1 self-diagnosed with PMDD	Diagnosis of PMDD = 5  Diagnosis of severe PMS = 1  Self-diagnosed with PMDD = 1	Black Caribbean = 1  White British/Scottish = 6
Successful after mandatory reconsideration /appeal	2 --- ADP = 1 - 1 diagnosed with PMDD  PIP = 1 - 1 diagnosed with PMDD	Diagnosis of PMDD = 2	White British/Scottish = 2
Unsuccessful	7 --- ADP = 0  PIP = 7 - 5 diagnosed with PMDD - 2 diagnosed with PMS	Diagnosis of PMDD = 5  Diagnosis of severe PMS = 2	Indian = 1  White British/Scottish = 6
Did not complete	1 --- PIP = 1 - 1 diagnosed with PMDD	Diagnosis of PMDD = 1	White British/Scottish = 1
* ADP, Adult Disability Payment (Scotland); PIP, Personal Independence Payment (England)			



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