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# **PREMENSTRUAL DYSPHORIC DISORDER**

**THE WELFARE STATE:  
RECOMMENDATIONS FOR REFORM**

**FINAL REPORT**

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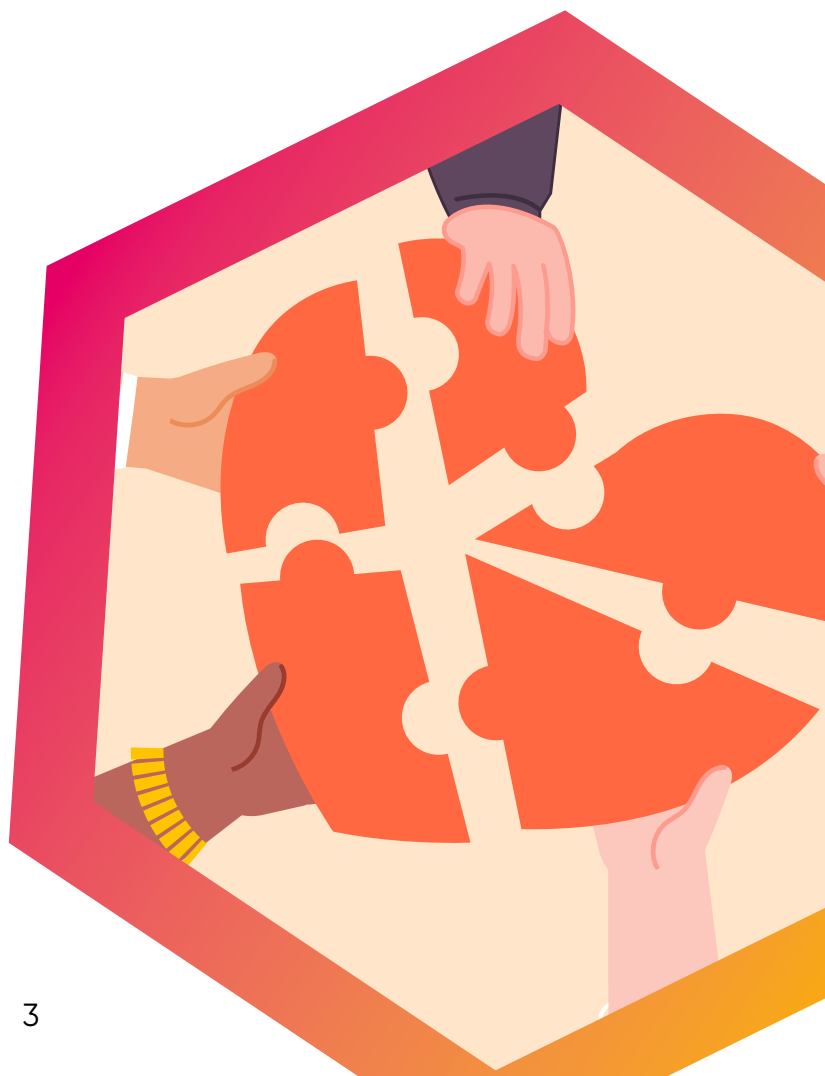
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# Summary

## 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 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) **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 final analysis identified four key findings:

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

## Final recommendations

1. Embed trauma-informed approaches across all systems, processes and organisational practices
2. Provide mandatory trauma-informed training and resources for all decision-making personnel within Social Security Scotland and the Department of Work and Pensions
3. Implement trauma-informed decision letter templates as standard practice
4. Reform eligibility criteria for fairer assessment of mental health related symptoms
5. Reform eligibility criteria for fairer assessment of fluctuating conditions
6. Apply the social model of disability to the assessment of fluctuating conditions
7. Enhance training on fluctuating conditions for decision-makers
8. Strengthen the outreach and promotion of available support services for applicants
9. Provide clear, accessible, and supportive application guidance
10. Establish peer support and independent advocacy services

# Why was this study needed?

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'). A recent study explains that living costs for those living with a disability are, on average, £1067 extra a month compared with someone who does not have one.<sup>3</sup>

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>4</sup>

The introduction of ADP marked a shift toward the social model of disability; in practice, however, many eligibility criteria and regulatory structures remain aligned with PIP.<sup>5</sup> This includes the 'over 50% rule',<sup>6</sup> which creates systemic barriers for people living with conditions characterised by variability.



1 Social Security Scotland. [Information on benefits](#). 2024.

2 Department for Work and Pensions. [Personal Independence Payment \(PIP\)](#). 2024.

3 Dr Serena Wright et al, [Disability Price Tag 2024: Living with the extra cost of disability](#) (Scope, 2024)

4 Gray, P. [An Independent Review of the Personal Independence Payment Assessment](#). 2014; page 61.

5 [The Disability Assistance for Working Age People \(Scotland\) Regulations 2022](#)

6 Regulation 10, [The Disability Assistance for Working Age People](#) (Scotland) 2022

People with fluctuating conditions may experience physical, cognitive and/or emotional symptoms that impact their daily living.<sup>7</sup> This is typically the case for people who live with Premenstrual Dysphoric Disorder (PMDD). They experience physical, cognitive and emotional impairments during 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. These lived realities are, therefore, not adequately captured by static eligibility descriptors or rigid thresholds such as the 'over 50% rule'.

When no single descriptor is met over 50% of the time, points may still be awarded if two or more descriptors are met.<sup>8</sup> However, this provision remains difficult to evidence and is inconsistently applied. Moreover, because ADP continues to rely on descriptors and definitions similar to those in PIP, there is a risk that the same inequalities will be reproduced despite intentions to move toward a fairer, rights-based model.

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>9</sup> Both the UK Government and the Scottish Government are obligated under the Convention on the Rights of Persons with Disabilities to provide adequate standard of living and social protection for those who live with a disability,<sup>10</sup> yet only the Scottish Government has explicitly recognised Social Security as a human right.<sup>11</sup>

Within the UK, there are approximately 22 million people of reproductive age, with approximately 1.2 million living within Scotland. We know that 1 in 20 people who menstruate will be living with PMDD, meaning around 1.1 million people in the UK (60,000 people in Scotland) will be living with PMDD. This is similar to the number living with bipolar disorder. Based on Scottish Census data (2022)<sup>12</sup>, we know that around 1 in 4 women (n=225700) aged 16–49 reported living with a mental health condition. If everyone with PMDD reported having a mental health condition, then about 1 in 4 people with a mental health condition could actually have PMDD. This highlights the scale of a largely invisible issue, with the number of people living with PMDD comparable to those diagnosed with bipolar disorder.

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7 Department for Work and Pensions. [The Impact of Fluctuating Conditions on Assessment](#). 2024; page 9.

8 The Social Security [\(Personal Independence Payment Regulations 2013, Regulation 7\(c\), The Disability Assistance for Working Aged People \(Scotland\) Regulations 2022](#), Regulation 10 (c)

9 Scottish Government, Interim Report – [Independent Review of Adult Disability Payment](#), 2024.

10 United Nation Convention on the [Rights of Persons with Disabilities 2008, Article 28](#)

11 [Social Security \(Scotland\) Act 2018](#), s. 1

12 [Scottish Census Data](#) (2022)

# 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, 1 identified as non-binary
- 15 identified as White British/Scottish, 1 as Indian and 1 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 1

## Lack of a trauma-informed approach

**Summary:** Trauma-informed practice aims to prevent re-traumatisation for people with previous experience of trauma in their life.<sup>13</sup> 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>14</sup>

Our participants described experiences that did not align with trauma-informed care. Lack of trauma-informed approaches were 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>15</sup>

*"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)

<sup>13</sup> Substance Abuse and Mental Health Services Administration. **SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach**. HHS Publication No. (SMA) 14-4884. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014

<sup>14</sup> National Trauma Transformation Programme. **A Roadmap for Creating Trauma-Informed and Responsive Change: Guidance for Organisations, Systems and Workforces in Scotland**. 2023.

<sup>15</sup> 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.



## Themes Related To Key Finding 1: Lack of a trauma-informed approach

### Trauma from the Application Process

People found the application process to be challenging, distressing and traumatic. They described collating and documenting the impact of their symptoms, only to find the process did not cater appropriately for mental health conditions. They also felt fear and anxiety about repeating the process again in several years' time.

*"It has, you know, plunged people into mental health crisis, because they have found it so traumatic and difficult"* (Professional stakeholder, England)

### Trauma-Informed Vocabulary and Processes

A lack of trauma-informed documentation and processes negatively impacted people with PMDD. They spoke about detailing their experiences of suicidality within the application (and assessment) process. There were instances of this being followed by inappropriate responses from decision-makers and poorly worded decision letters.

*"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)

### Recurrent Cyclical Trauma from PMDD

PMDD is characterised by severe, recurring symptoms. People typically experience these symptoms for decades. This leads to a debilitating impact on everyday life, with people living in fear of the next menstrual cycle.

*"Now I think the PTSD [post-traumatic stress disorder] is quite important, because I feel traumatised as a person going through what I go through every month, and gone through it for so many years as well"* (Person with PMDD, England)

### Long-Term Impact of Trauma

In addition to the recurring trauma, people with PMDD typically had a history of trauma from adverse life experiences. This was exacerbated by trauma from the application process, sometimes leading to further deterioration in their wellbeing.

*"And in the end, by the time the process had finished, she had to move back in with her parents, and still now lives with her parents, because she's never recovered from the kind of trauma of that, that then impacted her already existing conditions"* (Professional stakeholder, England)

# Key findings 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>16</sup> However, it remains an unrecognised and unfamiliar diagnosis for many professionals. This adds a burden to applicants when they need 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 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)

<sup>16</sup> American Psychiatric Association. Premenstrual Dysphoric Disorder. 2013. Diagnostic and Statistical Manual of Mental Health Disorders, 5th edition. Washington D.C.

## Themes Related To Key Finding 2: Inconsistent assessment and decision outcomes

### Arbitrary and Inconsistent Assessments

Participants expressed concerns about inconsistency in the decision-making process. They felt the criteria used to evaluate their applications were arbitrary and applied unevenly, resulting in unpredictable outcomes.

*"I've had personal experience where, for example, you get kind of caught out on the most arbitrary of things in the interview assessment"* (Professional stakeholder, England)

### Inconsistencies in Assessment Reports

Participants often felt that the information in the decision letters did not accurately reflect their applications or assessments. Many noted that PMDD, the central focus of their submissions, was not mentioned at all in the letters. They found this omission both unprofessional and confusing.

*"So it's only about January that I applied and, you know, sort of getting the, the 'no' from that {...} I got to sort of like a real crisis point, and then getting the 'no' after that {...} it was a real downward spiral {...} I'm only sort of just picking myself up, you know, in the last sort of two or three months"* (Person with PMDD, Scotland)

### Lack of Understanding of PMDD

Assessors often misinterpreted or misunderstood the symptoms of PMDD, leading to incorrect assessments and decisions. Although PMDD is internationally classified as a mood disorder, people felt that the decision makers lacked understanding of the significant impact PMDD had on daily life. This highlighted a need for training around PMDD.

*"Because we are complex, because they don't understand what our condition is {...} so one of the things I did for the next interview [assessment] was to break down things... break it down, like I put depression and anxiety as separate things. I started getting more diagnosis [evidence] for the symptoms of PMDD, but getting them diagnosed as individual conditions"* (Person with PMDD, England)

# Key findings 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 over 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>17</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)

*"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)

<sup>17</sup> 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.



## Themes Related To Key Finding 3: Challenge of evidencing fluctuating conditions

### Challenge of Proving Fluctuating Symptoms

The burden was on applicants to prove their fluctuating symptoms. However, they were met with significant barriers in obtaining evidence from relevant services. The structure of the application form made it especially difficult to convey the cyclical and variable nature of their condition.

*"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)

### Inadequate Recognition of Fluctuating Conditions

Assessors appeared to overlook the significant impact that PMDD had on claimants' daily lives. In contrast, physical health conditions were more consistently acknowledged and cited in decision letters as justification for awarding benefits.

*"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, Scotland)

### Impact on Daily Living Activities

The wording of the daily living descriptors is more suited to assessing physical disabilities, focusing on the ability to perform tasks in a fixed, measurable way. This presents a barrier for individuals with fluctuating mental health conditions, as the descriptors fail to capture the variable and often invisible nature of their impairments. As a result, applicants feel discouraged or disadvantaged during the application process.

*"When I was looking at the criteria it seemed so physical, that I kind of amped up the physical aspects. So the fatigue, when I was trying to describe how it affects me. And I found it quite difficult within sort of the limitations of the form to get across how bad the kind of mental side is. And I found it quite difficult to kind of evidence a lot of it"* (Person with PMDD, England)

### Impact of the over 50% of the time Rule

Although PMDD affected participants most severely during symptomatic periods, many continued to struggle with daily living during the 'recovery phase.' They felt that the 'over 50% rule' failed to account for this ongoing impact.

*"I think definitely the PMDD, you're affected for more than ten days most o' the time. You know, even if that's if you're not having symptoms on they days, it's like the kinda aftermath o' that, isn't it, that you're recovering from. And the low self-esteem, you know, it does definitely affect ye more than fortnightly, PMDD. But trying tae, trying tae you know convince people o' that is, is very hard"* (Person with PMDD, Scotland)

# Key findings 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>18</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)*

*"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)*

<sup>18</sup> 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.

## Themes Related To Key Finding 4: Unaware (or lack) of support for the application process

### Claimants need emotional and practical support

Participants described the application process as both emotionally traumatic and logistically challenging. Many relied on support from friends and family to complete it. However, some chose to complete the application alone, finding the content too personal to share. The practical demands of the application process were especially difficult to manage when applicants were at their most unwell and vulnerable.

*"The task of like filling out all the information as a daily living activity is like impossible, without the important support of other people. And that like cultural capita of like what is required, like all these insider tips of like what is required in order to communicate our symptoms and our struggles in a way that's palatable for the form"* (Person with PMDD, Scotland)

### Claimants are unaware of available support

Most people in this study were unaware that support was available. They described how despite reading all the information they saw no mention of services to support them with their application.

*"I wasn't aware of that [support] {...} it's not on any of the social security documents. It's not on anything that's come through the door"* (Person with PMDD, Scotland)

### Lack of guidance and assistance for claimants

The application process was overwhelming, particularly for those trying to complete it while experiencing symptoms that affected their concentration and comprehension. Participants felt the information provided did not accommodate individuals facing additional barriers, such as cognitive impairments or neurodiversity.

*"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)

### Importance of Advocacy Services

For many participants, the welfare benefits system was unfamiliar. They described how their lack of experience made it difficult to understand what evidence was required and how to present it effectively. This highlighted the value of advocacy services. Several also highlighted that peer support could play an important role for future applicants.

*"I actually reached out to Citizens Advice Bureau, and that's who within England... 'cause they don't have an advocacy service, unfortunately, which I think is fantastic that Scotland does have it. And they're, they're the ones who gave me the pointers, and they're the ones who were my cheerleaders {...} I just found it overwhelming, I found it intimidating... but I know Citizens Advice Bureau can be pot luck. But it's worth a try"* (Person with PMDD, England)



# Recommendations for reform

1. Embed trauma-informed approaches across all systems, processes and organisational practices
2. Provide mandatory trauma-informed training and resources for all decision making personnel within Social Security Scotland and the Department of Work and Pensions
3. Implement trauma-informed decision letter templates as standard practice
4. Reform eligibility criteria for fairer assessment of mental health related symptoms
5. Reform eligibility criteria for fairer assessment of fluctuating conditions
6. Apply the social model of disability to the assessment of fluctuating conditions
7. Enhance training on fluctuating conditions for decision-makers
8. Strengthen the outreach and promotion of available support services for applicants
9. Provide clear, accessible, and supportive application guidance
10. Establish peer support and independent advocacy services



# Ongoing questions for future research

**Based on our 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. This gap was also identified by researchers exploring broader mental health conditions.<sup>19</sup>
- 2. What are the barriers to implementing trauma-informed approaches?**
  - It is important to understand why social security services do not embed trauma-informed approaches, and how they can be supported to adopt 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.
- 4. Are members of the Social Security First and Upper Tier Tribunal adequately trained in trauma-informed practice?**
  - Insights from tribunal personnel were not included in this present study. It is important to explore whether decision-makers at all levels, including tribunal level, are properly trained in trauma-informed practice.
- 5. What is the cost benefit of supporting people with PMDD through the welfare benefits system?**
  - Future policy decisions will be informed by evidence of an economic benefit from successful PMDD applications. Studies are needed to explore the health economics of this.
- 6. Why is there a lack of awareness of entitlement to social security financial support for people with PMDD?**
  - The purpose of providing financial support to individuals with health conditions or disabilities is to help them live independently. More research is needed to understand why people with PMDD may not recognize that they could be entitled to this support.

# Resources

## Support and resources about PMDD

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



To stay updated about our PMDD research please visit

[www.pmddresearch.com](http://www.pmddresearch.com)

Here you can sign up for our PMDD patient insight group or our professionals' special interest group.



# Appendix 1.

## Participant decision outcomes

	Total	Diagnosis	Ethnicity
<b>Successful on first application</b>	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
<b>Successful after mandatory reconsideration / appeal</b>	2 --- ADP = 1 - 1 diagnosed with PMDD  PIP = 1 - 1 diagnosed with PMDD	Diagnosis of PMDD = 2	White British/Scottish = 2
<b>Unsuccessful</b>	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
<b>Did not complete</b>	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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