Department
for Work &
Pensions

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Social Research

Experiences of PIP Applicants Who Received Zero Points at Assessment

A report by Basis Social

October 2024

DWP research report no. 1070

A report of research carried out by Basis Social on behalf of the Department for Work and Pensions.

This document/publication is also available on our website at: https://www.gov.uk/government/organisations/department-for-work-pensions/about/research#research-and-analysis-publications

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Executive summary

Introduction

Personal Independence Payment (PIP) is a benefit which can help with extra living costs where someone has both:

- a long-term physical or mental health condition or disability
- difficulty doing certain everyday tasks or getting around because of their condition

DWP commissioned Basis Social to conduct qualitative research with PIP applicants that had received a zero point outcome after DWP decision to explore their understanding, expectations and experience of applying for PIP.

Method

Between 16 February and 7 March 2023, in-depth interviews were conducted with 29 PIP applicants, with coverage of a wide range of disabilities and health conditions.

Through this research, Basis Social set out to explore the following research questions:

- How do applicants understand the PIP eligibility criteria?
- What information do applicants receive before, during, and after assessment? And how does this impact their decision to apply?
- What are applicants’ reflections on the assessment process? For example, is there information that would have been beneficial to have known at the start of the process? Or would they have done anything differently if they had earlier advice?
- What is applicants’ level of confidence when applying to PIP? Did this change during the process (and if so, how), and did individuals with low confidence consider dropping out?

Zero point outcome

How much a PIP applicant is entitled to depends on how difficult they find everyday tasks and getting around. This is determined based on the information provided on an application form, any additional evidence provided such as care plans or information from a doctor, and through assessment by a qualified health care practitioner. PIP uses a points system where points are allocated based on the level of need associated with each activity assessed (e.g., washing, dressing, moving around)[1] measured against a list of standard statements ("descriptors") describing what someone can do.

Whether a claimant scores points against a descriptor is based on their ability to carry activities "safely, to an acceptable standard, repeatedly and in a reasonable time period".[2] The PIP criteria consider an individual's ability over a 12-month period, ensuring that fluctuations are taken into account. For each activity, if a descriptor applies on more than 50 per cent of the days in the 12-month period, that descriptor should be chosen.[3]

The term 'zero points' or 'zero point outcome' describes an outcome in which an applicant receives no points against any of the twelve activities. This could be either because a customer's disability does not affect their function sufficiently to score points against a descriptor, or because their disability does not affect their function sufficiently regularly to the fluctuation criteria etc.

A high-level description of the PIP application and decision making process is included in Appendix 1 for reference.

Key takeaways

- Participants had a range of conditions that they feel significantly impact their lives. They therefore broadly felt eligible and deserving of PIP, although some went into the process more confident in their outcome than others. Levels of confidence impacted how participants went on to seek information or support, their experience with the PIP application and assessment process, and how they responded to the zero point outcome.

- Participants reported being encouraged by others to apply for PIP. This included family, friends, and peers as well as service providers such as Citizens Advice and DWP. Their understanding of PIP eligibility was vague but relatively accurate, aligning to that detailed on gov.uk which many reviewed in advance of deciding to submit an application.

- Participants who were more confident tended to find the application easier than those who were less confident and those who had more anxiety and fluctuations in their conditions. Participants had varied experiences of assessment: some had a positive experience, some struggled to make their case, some felt they were not understood by the assessor, and some felt unprepared for the process of being interviewed. All participants were unhappy when receiving a zero point outcome given they felt eligible though some had lower expectations of getting PIP (due to

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[1] See https://www.gov.uk/pip for full list of activities covered. Further information on the assessment criteria can be found here: https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-2-the-assessment-criteria

[2] The Social Security (Personal Independence Payment) Regulations 2013 (legislation.gov.uk) – regulation 4

[3] The Social Security (Personal Independence Payment) Regulations 2013 (legislation.gov.uk) – regulation 7

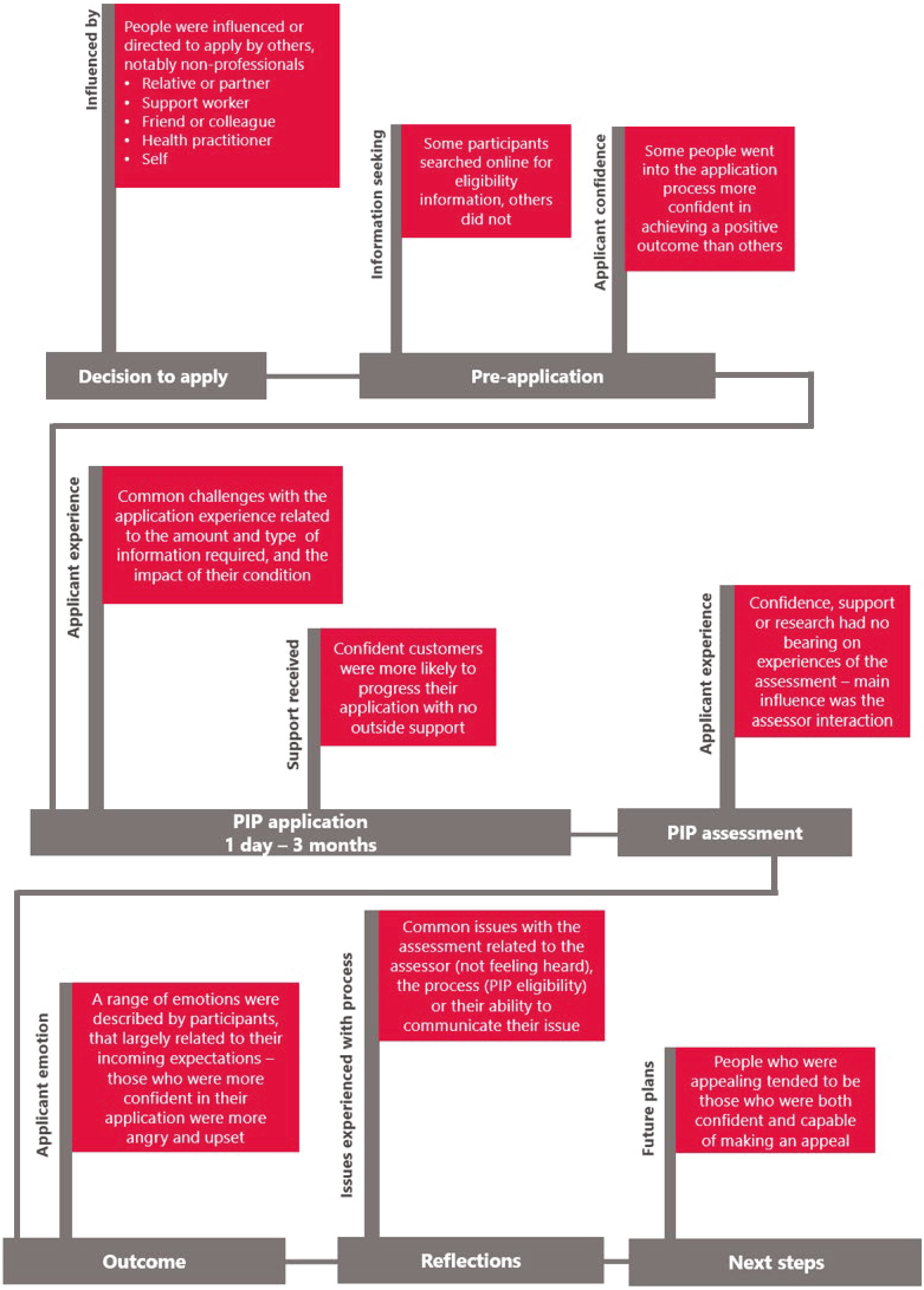
lower levels of confidence in their applications and expectations having been set by others).

- Participants wished they had done a number of things differently during their application and assessment process. Notably these included:
    - Seeking support with application and assessment
    - Providing (more) medical evidence in support of their claim
    - More fully making their case by focusing on their worst days
    - Being more directive in their assessment in terms of what they wanted the assessor to hear about
- Participants wished they had more information throughout the process including:
    - Concrete information on eligibility to inform decision, such as case studies or eligibility pre-checker
    - What evidence should be included in their application
    - Signposting to more detail on how their case was scored in the outcomes letter
    - Signposting to information on the appeals process in the outcomes letter
- Participants also wished for:
    - The ability to request a different mode of assessment, e.g., in-person, telephone, or video call.
    - To be able to speak directly with someone at DWP during the application and post-decision to better understand eligibility.

Summary of findings

The diagram overleaf (Figure 1) illustrates the findings of this research aligned to different stages in the PIP application and assessment process. These are expanded on in the body of this report.

Figure 1 Diagram providing overview of findings



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Acknowledgements

We would like to thank Department for Work and Pensions colleagues, particularly Bridie Lavender and Hugo Dale-Rivas who managed the project and provided valuable input and support throughout. We would also like to thank all the people who gave up their time to participate in this research and share their experiences with us.

Abbreviations

DWP	Department for Work and Pensions
ESA	Employment and Support Allowance
GP	General Practitioner
MS	Multiple sclerosis
PIP	Personal Independence Payment
UC	Universal Credit

1. Research context and methodology

1.1. Background

Personal Independence Payment (PIP) is a benefit which can help with extra living costs where someone has both:

- a long-term physical or mental health condition or disability
- difficulty doing certain everyday tasks or getting around because of their condition

There are 2 parts to PIP:

- a daily living part (if someone needs help undertaking everyday tasks)
- a mobility part (if someone needs help with getting around)

How much a PIP applicant is entitled to depends on how difficult they find everyday tasks and getting around. This is determined based on the information provided on an application form, any additional evidence provided such as care plans or information from a doctor, and through assessment by a qualified health care practitioner. PIP uses a points system where points are allocated based on the level of need associated with each activity assessed (e.g., washing, dressing, moving around)[4] measured against a list of standard statements ("descriptors") describing what someone can do.

Whether a claimant scores points against a descriptor is based on their ability to carry activities "safely, to an acceptable standard, repeatedly and in a reasonable time period".[5] The PIP criteria consider an individual's ability over a 12-month period, ensuring that fluctuations are taken into account. For each activity, if a descriptor applies on more than 50 per cent of the days in the 12-month period, that descriptor should be chosen.[6]

The term 'zero points' or 'zero point outcome' describes an outcome in which an applicant receives no points against any of the twelve activities. This could be either

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[4] See https://www.gov.uk/pip for full list of activities covered. Further information on the assessment criteria can be found here: https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-2-the-assessment-criteria

[5] The Social Security (Personal Independence Payment) Regulations 2013 (legislation.gov.uk) – regulation 4

[6] The Social Security (Personal Independence Payment) Regulations 2013 (legislation.gov.uk) – regulation 7

because a customer’s disability does not affect their function sufficiently to score points against a descriptor, or because their disability does not affect their function sufficiently regularly to satisfy the fluctuation criteria etc.

A high-level description of the PIP application and decision making process is included in Appendix 1 for reference.

1.2. Research aims

DWP is interested in understanding more about applicants who apply for PIP and receive a zero point outcome. Specifically, through this research DWP sought to answer the following research questions:

- How do applicants understand the PIP eligibility criteria?
- What information do applicants receive before, during, and after assessment? And how does this impact their decision to apply?
- What are applicants’ reflections on the assessment process? For example, is there information that would have been beneficial to have known at the start of the process? Or would they have done anything differently if they had earlier advice?
- What is applicants’ level of confidence when applying to PIP? Did this change during the process (and if so, how), and did individuals with low confidence consider dropping out?

1.3. Methodology

Between 16 February and 7 March 2023 in-depth interviews were undertaken by researchers from Basis Social with applicants who had received a zero points outcome on a PIP assessment in the past 3 months. A total of 29 interviews were conducted by telephone or over MS Teams, depending on the preference of the participant, and each lasted approximately 60 minutes. Though hard quotas were not set for the recruitment of applicants, demographics were monitored to ensure a spread within the sample. The sample itself was drawn by DWP and provided to Basis Social to recruit from. All participants received a £40 shopping voucher in recognition of their time.

Table 1 provides a breakdown of the demographic characteristics of the achieved sample. Note that Basis Social subscribe to a model of thinking about disability developed by Open Inclusion[7], which holds that we all move, sense, think, feel, and communicate differently, and that ‘disability’ is an outcome of failures in the system to support these differences. We adopt a categorisation which relates to the social

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[7] Open Inclusion is a disability and age-inclusive research, design and innovation organisation who work in partnership with Basis Social on the design and delivery of research projects

model of disability. Details of the range of the primary health conditions and medical types of disability reported by participants are included in Appendix 2.

Table 1 Sample breakdown by demographic characteristics

Characteristics		Achieved
Diversity in ability	Move differently	19
	Sense differently	1
	Think/feel differently	9
Age	18-30	9
	31-45	10
	46-65	10
Gender	Male	12
	Female	17
Ethnicity	White	22
	All other ethnic groups combined	7

A standardised discussion guide was developed for use with applicants in conjunction with DWP. This is included in Appendix 3 of this report. The themes covered included:

- Motivations and expectations when applying for PIP
- Information needed, and sources of information used at different stages of the application process
- Support accessed (and needed) at different stages of the application process
- Experiences of completing the PIP application, and PIP assessment
- Views toward zero point outcome, including how this was communicated
- Reflections on the process of applying for PIP

All interviews were recorded and transcribed. The research team used framework analysis[8] as a method for organising and managing data through a process of summation and synthesis, resulting in a series of themed matrices tied to the topic guide (and aims for the research).

1.4. How to interpret the information in this report

This research report includes findings from interviews and follows the flow of the PIP process: starting before the application begins, through the application and assessment process, to outcomes, and then includes participants' reflections across the entire process. The final section includes a summary and implications of the research.

Qualitative research typically involves small sample sizes and is designed to be exploratory and provide insight into people's perceptions, feelings, and behaviours. In reviewing the findings it is important to acknowledge that the evidence and insights highlighted here are not intended to be representative of the views of all PIP applicants receiving zero points outcomes, but instead to highlight a range of experiences and perspectives that may provide learnings for DWP.

It is also important to note that participant views and the accuracy of their recall of aspects of the application and assessment process may not fully align with the way in which the process works in practice. For example, there are occasions where participants report views on the qualifications or experience of assessors, or the content of DWP communications, which are not accurate according to the policy or process of how PIP should be delivered. These are still helpful as they reflect participant perspectives and priorities.

Anonymised verbatim quotes have been used to help illustrate key findings. For each quote, details are provided about the participants' age, gender and type of presenting health condition or disability. In order to anonymise participants, pseudonyms are used in customer pen portraits.

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[8] Ritchie, J., Lewis, J., Nichols, C.M. and Ormston, R. (2014). Qualitative Research in Practice. Sage: London. (2nd Edition).

2. Before applying for PIP

Key takeaways

- Participants had a range of conditions that were felt to significantly impact their lives.
- Participants broadly felt eligible and deserving of PIP, although some went into the process more confident in their outcome than others.
- Participants reported being encouraged by others to apply for PIP. This includes family, friends, and peers as well as service providers such as Citizens Advice and DWP.
- Participants' understanding of PIP eligibility was vague but relatively accurate.

2.1. Key drivers for applying for PIP

Motivations for applying

Participants involved in this research applied for PIP because they had a health condition or disability that impacted their daily life, and they needed extra money to support themselves. Participants in this research had a wide variety of different health conditions and/or disabilities, many of which overlapped and compounded one another. All felt that their condition had a significant impact on their daily life.

> I've literally gone from trail running and rock climbing to not being able to walk to the shop or bathe and it's affected my daily activities massively.
>
> (Male, 31-45, cerebrovascular accident (stroke))

The trigger to move from a stage of consideration to then applying for PIP was often a change in situation which resulted in additional financial pressures. This included losing a job or having to reduce hours, or a change in circumstances such as being released from prison.

> “I’ve had to cut all my overtime out… that’s time and a half’s pay and the company sort of expect you to help out a little bit when they’ve got problems, but I haven’t been able to do that with them.”
>
> (Male, 46-65, bronchiectasis)
>
> “I've got a genuine disability that cost me my career and that broke my heart.”
>
> (Male, 18-30, multiple sclerosis)

Finding out about PIP

Learning about PIP typically came through others (rather than through participant’s own information-finding activities). This ranged from informal networks, such as family, friends, and colleagues, to more formal sources such as Citizen’s Advice, GPs or healthcare professionals, and DWP. Participants reported that conversations about their illness or health conditions had prompted others to recommend they look into and apply for PIP as a disability benefit.

> “[A friend] said he gets PIP because of his autism as well… I hadn’t realised I was able to claim for it [before then].
>
> (Female, 18-30, autism)”

Informal networks such as family, friends and colleagues often included individuals that were receiving PIP themselves or who provide informal support helping people in their neighbourhood apply for disability benefits.

Online forums were also used as sources of information regarding PIP. These were spaces where participants were able to learn from individuals with similar conditions to themselves, who had often been through the PIP assessment.

More formal sources, such as service providers (including voluntary advice services, social care services, healthcare services, and DWP), also played a large part in participants’ decision to apply for PIP. These organisations and service providers were seen most often to signpost individuals directly to PIP, and less frequently they signposted PIP alongside other benefits.

> “They said it might be worth looking into financial help and then they listed a few different options and PIP was one of them… I was just doing it one at a time to see how it pans out.”
>
> (Male, 18-30, anxiety disorders)

Of the organisations, the most frequently mentioned were Citizens Advice and local disability advice services and charities. University support services (e.g., mental health services) were also mentioned, as well as healthcare professionals such as GPs, nurses, therapists, and social workers, who were also seen to encourage individuals to apply for PIP.

DWP was also seen to encourage participants to apply for PIP during conversations about other benefits, such as Universal Credit or Employment and Support Allowance (ESA). Several participants recall being told by a DWP advisor that if they had qualified for ESA they should qualify for PIP.[9] Participants also mentioned being recommended to apply for PIP through Jobcentre Plus Work Coaches.

> “I rang DWP up because I was on ESA, and she said ‘everyone on ESA should be going for PIP’ like if you’re on the one you should be on the other.”
>
> (Male, 31-45, schizophrenia)
>
> "I would never have gone to claim [before UC encouragement] ... I didn't think I qualified."
>
> (Female, 46-65, breast cancer)

Participants recalled that many formal and informal sources of referral to PIP had flagged how difficult PIP would be to qualify for. Some even told them that while they would be unlikely to be awarded PIP the first time, they should go on to appeal as they would be more likely to then receive an award. This led to some participants feeling less confident in their application, as well as being less surprised by their outcome.

> “When I went to Citizens Advice, they advised me that with PIP you’ll probably not get it on the first application, appeal against that, you’ll probably not get that, then go through the independent panel.
>
> (Male, 46-65, ischaemic heart disease)”

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[9] It should be noted that there is no official guidance from DWP that customers that qualify for ESA would qualify for PIP.

> “Somebody at the Jobcentre suggested that I apply for PIP, they gave me a printout with information on it. A couple of friends said you would be turned down because they turn everybody down first time but to appeal the decision.”
>
> (Female, 46-65, blocked arteries)

Researching PIP

After initially learning about PIP, the next step for some participants involved in this research was reviewing the PIP section of the GOV.UK website to check their eligibility and learn how to apply for PIP. The information on the website was felt to be vague and providing little information beyond confirming their basic understanding of PIP. Some participants reported seeing their specific conditions named on the website which boosted their confidence in their eligibility.

> "It actually listed bronchiectasis as something you can claim for… I'd never looked at it as a disability before.”
>
> (Male, 46-65, bronchiectasis)
>
> “All the information online helped make my decision to go for it. I know people who get PIP who are healthier than me.”
>
> (Male, 46-65, hypothyroidism (myxoedema))

2.2. PIP eligibility

PIP assesses the functional impact of a disability or health condition as defined in law; it is not a clinical diagnosis. As such many people with a genuine disability or health condition may not be eligible for the benefit.

PIP is scored in two parts: daily living and mobility. Each of these sections has a set of activities and descriptors which are scored based on whether and how someone can perform that activity. This is scored using a submitted application, which is usually followed by either an in-person, video, or telephone assessment to assign these points. Applicants scoring between 8 and 11 points on either the daily living or the mobility component will get these components of PIP at the standard rate, while those scoring at least 12 points in total will get the enhanced rate.

To qualify for PIP, needs arising from a condition or disability must last for at least 12 months from when they first started. Conditions and disabilities often fluctuate, for example someone with chronic pain may be able to leave their house one day and be bound to their bed the next. To account for this in PIP, a condition is expected to impact an individual on the “majority of days” over a 12-month period (the 50 percent rule). All needs must be assessed against whether someone can do the activities “safely, to an acceptable standard, repeatedly and in a reasonable time period”.[10]

PIP eligibility is unrelated to whether someone is in or out of work, or levels of existing income.

Understanding of PIP eligibility, including misconceptions

Participants recalled that, at the point of applying for PIP, their understanding of PIP was relatively vague and basic. Although vague, participants’ understanding was typically correct. They understood PIP to be a support benefit for individuals with health conditions or disabilities that impacted their daily life and ability to function. Beyond this, there was little understanding of the nuances of PIP such as the scoring criteria, how long a condition should impact them to be considered long-term, and how fluctuating conditions are considered.

> [PIP is] for people who have a disability and to help them maintain a normal quality of life.
>
> (Female, 31-45, multiple sclerosis)

Broadly, participants had a solid grasp of the basics of PIP eligibility, with only a few misconceptions. The largest misconception included employment, with some participants believing that those who were unemployed may be more qualified for PIP (as they were more impacted by their disability).[11] But at the same time, participants also commonly reported that they understood that there were separate benefits related to employment and the ability to work. Some thought that individuals on a lower income are more eligible for PIP, as they are more in need of help.

> "PIP is just another way to get financial support… for those unable to work."
>
> (Female, 18-30, post-traumatic stress disorder)

Other misconceptions included believing that condition alone could make you eligible for PIP, for example, by being diagnosed with Multiple Sclerosis they should qualify for PIP. One participant reported a belief that work history, such as working in physically laborious jobs, makes you more eligible. This work history was seen as part of the evidence of a condition’s onset and potentially its impact, so was felt that it would be considered during the PIP process.

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[10] The Social Security (Personal Independence Payment) Regulations 2013 (legislation.gov.uk) – regulation 4

[11] Note that employment does not affect eligibility for PIP, neither do income or savings

> “You do kind of expect that someone would recognise or acknowledge that I have a condition (MS) that requires some assistance.”
>
> (Female, 31-45, multiple sclerosis)

Confidence in application at start of application process

Based on their basic understanding, participants in this research felt that they qualified for PIP. In our sample, all participants felt they had a genuine case to apply for PIP and told us they were not looking to try and ‘play the system’. In this respect, while there did not appear to be any ‘speculative’ applications, there were plenty of people who were unsure of whether they would qualify and therefore put forward an application to see if they were eligible.

> I'm not confident… I’m not sure if I'm eligible.
>
> (Male, 18-30, anxiety and depressive disorders)

Those that were less confident tended to be those with mental health conditions (notably depression and anxiety, which could co-occur with physical disabilities) and those who had been led to believe that PIP was difficult to be awarded by others (including friends, family, and support organisations).

3. Experience of PIP application and assessment

Key takeaways

- Participants who were more confident tended to find the application easier than those who were less confident and had more anxiety and fluctuations in their conditions.
- Participants had varied experiences of assessment: some had a positive experience, some struggled to make their case, some felt they were not understood by the assessor, and some were unprepared.

3.1. Experience of the application process

The ‘PIP2: How your disability affects you’ application form is available for completion via a paper form, or in some cases online. In paper-form it is a 50-page form that has sections relating to disabilities and health conditions, medical support received, and how an applicant’s disability or health condition impacts their day-to-day living. Applicants have a one-month window in which to complete and return this form, although extensions and exceptions apply.

Completing the PIP application form

The most common reaction to commencing the PIP application form process, for the participants interviewed as part of this research, was one of being overwhelmed. The size of the form and the number of questions to be completed were reported as being daunting for some of the participants. For some, this could lead to putting the form to one side and not starting to complete it until they received a prompt from DWP.

> “I thought it was daunting until I started doing it and then it wasn’t as bad as I thought it would be.”
>
> (Female, 46-65, blocked arteries)

> You can't digest all that information… it's very difficult to understand.
>
> (Female, 46-65, breast cancer)

Within the sample, participants reported a range of health conditions and disabilities. These differed in the degree to which they were known and understood by both the applicant and medical professionals (e.g., conditions like myalgic encephalomyelitis also known as chronic fatigue syndrome (ME/CFS) do not have biomarkers, which makes identifying and diagnosing this condition very difficult) and varied in the impact that they had on people's ability to engage in cognitively demanding tasks such as completing their PIP application. Participants in the research also had differences in English language capabilities, literacy levels, and their wider contextual circumstances (notably relating to their financial circumstances and social support structures) all of which impacted their experience of the application process.

Participants that found the application relatively 'straightforward' were able to navigate to the sections of the application that were most relevant to them, interpret and respond to the questions asked, and to provide medical evidence in support of their claim. These participants tended to be those with higher literacy and with one primary condition, typically impacting movement rather than cognitive functioning. In these cases, the form was often completed in 1-2 days.

> "Doing the application wasn't really difficult.. It was a lot.. I had typed it up… the form in itself is quite simple."
>
> (Female, 31-45, multiple sclerosis)

For participants that found the application more challenging, there was a range of reasons for this. Some participants had relatively low levels of literacy, dyslexia, or low levels of English proficiency which meant that they could struggle to fully understand the questions that were contained within the PIP application form or to articulate themselves as they might have liked. For some, wider contextual circumstances such as financial circumstances and social support structures, made the application process more difficult.

> "I thought I answered wrong because English is not my first language and some of the questions were tricky. I don't know if my answering was 100%."
>
> (Male, 46-65, HIV/AIDs)

> It took me a while to get my head around what I needed to put…I don’t think it’s very dyslexic friendly.
>
> (Female, 31-45, back pain)

Other participants struggled to complete the form because of the impact of their condition. Examples here included:

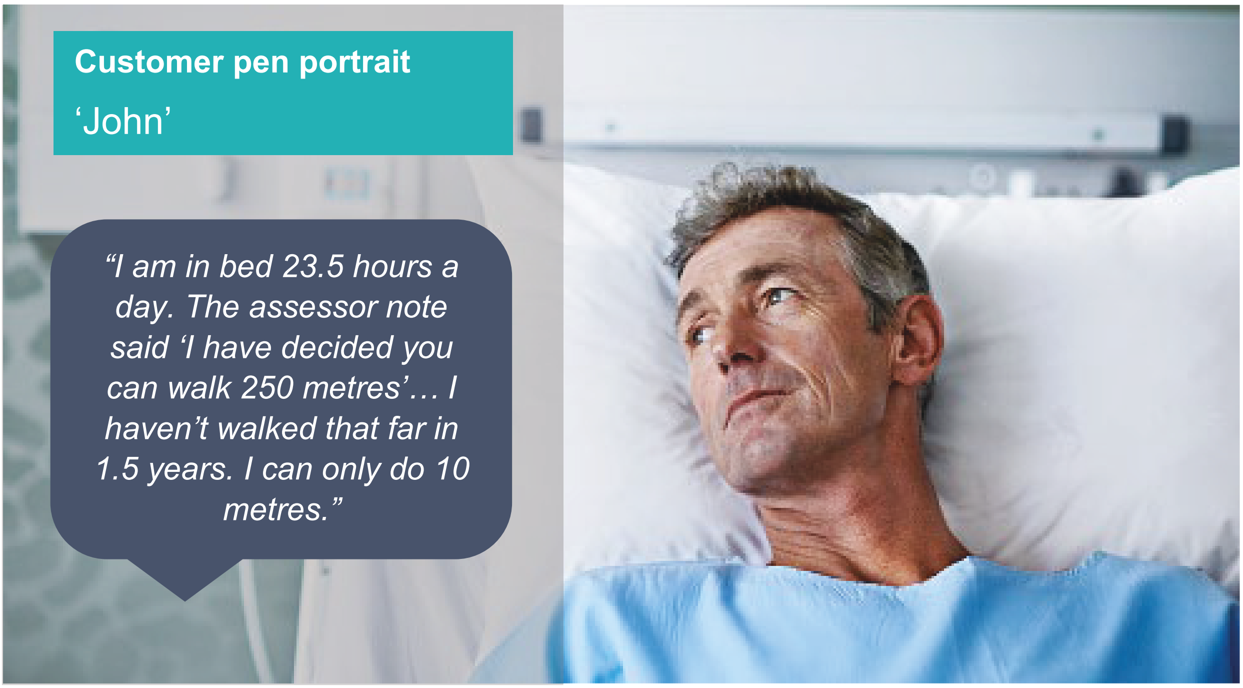
- Conditions which led to fatigue could make the process of completing the form laborious, protracted, and tiresome, in some instances taking people several months to complete.
- Conditions which were a result of traumatic past events could mean that emotional responses were triggered through completing the application and detailing the background and causes to the condition.
- Conditions which impacted individuals’ ability to write (or type) – for example, some participants did not foresee issues they would have completing the online form because of challenges with spending long periods viewing a screen.

> “It was difficult and stressful because of some of things I had to put in there about the background information to why I have the disability.”
>
> (Female, 18-30, personality disorder)

In these instances, the process of completing a form could take weeks or even months. One participant reportedly took around three months, having to use a voice dictator for about five minutes a day due to the impact of chronic fatigue (See Case Study: John, p.24). It should be emphasised that this was on the most extreme end of how long applicants took to complete their application.

Customer pen portrait

‘John’



> *“I am in bed 23.5 hours a day. The assessor note said ‘I have decided you can walk 250 metres’… I haven’t walked that far in 1.5 years. I can only do 10 metres.”*

'John’ was 40 years old and had chronic fatigue that has progressively got worse over time. He had full-time carers, lived in his mother's home, and was in bed 23.5 hours a day. He was unable to read, watch TV, listen to music, or eat on his own. His interview with Basis Social was conducted over two, 30-minute sessions to accommodate his fatigue. He heard from friends and online forums that he may qualify for PIP. He did his own research which took a lot of time for him. From this, he felt he had a good understanding of PIP eligibility, confirmed through the research interview.

It took him 3 months to complete the PIP application as he had to use voice dictation and could only manage about 5-minutes of this per day. He was not able to review his responses, as this was too laborious for him. In his application, he included a letter of diagnosis, a letter from his occupational therapist, and a 7-day diary he wrote by hand. He struggled with answering some questions, for example, he reported a question being posed on how far he can walk in a day, in metres. He can walk only about 100 steps per day, so he had to try to figure out what that is in metres.

His assessment was held via telephone, although he requested video so they could see him. He was feeling particularly drained and unwell during his assessment, but he was unable to reschedule as he had done so once already. John felt some of the questions from the assessor lacked relevance (e.g., “are you right or left-handed?”). The assessor was not reported as probing on any questions, and when John tried to explain more about his case, the assessor reportedly cut him off and said, “I am getting a lot of information” and moved on.

He received his outcome, and the notes were not felt to align with his situation and what he had shared with DWP. At the time of interview John was going through the appeals process. This time he was seeking the advice of Citizens Advice and the Disability Support Service. He wishes he had their support the first time but was unaware they could help him.

Support in completing the PIP application

It was not common for participants to have accessed support in completing their PIP application form, and where support was received this tended to be through a partner or relative rather than a formal support agency (in one case Citizens Advice was mentioned as supporting someone who was severely dyslexic). Furthermore, this support tended to be *ad hoc*, helping them to understand or complete specific parts of the form (typically the more factual parts to do with medical history), rather than the whole form. In speaking with participants there was a view that the questions relating to how a condition impacts them were relatively straightforward to respond to honestly without the need for another person to be involved.

> "I had support from my baby's father and my auntie in explaining the questions. They let me write what I would write in then obviously so the assessor can understand or see how I did things."
>
> (Female, 46-65, joint hypermobility syndrome)
>
> "I could have never filled it in on my own."
>
> (Male, 31-45, cerebrovascular accident (stroke))

Some participants said they would have felt uncomfortable having a "random" external person involved at this point given the personal and subjective nature of the questions. Others completed it alone because they felt they had little other choice due to limited social support networks and lack of any involvement with support services beyond those relating to their health condition.

> I was all on my own with it… I got given a form and I filled it out.
>
> (Female, 18-30, post-traumatic stress disorder)

Similarly, it was not common for participants to have done any research or sought any information online when completing their application. A couple of people mentioned having had the PIP information webpage on GOV.UK open while completing their application, recalling that this included a checklist of things to remember to include. While the PIP application form was seen as dense, it was also relatively straightforward in terms of the information requested, so at this stage of the process, participants commonly reported they did not feel like they required further information.

> "I had the website up, the GOV one [website]… it had like a checklist to make sure you had your letters from the hospital and the doctors."
>
> (Female, 46-65, atherosclerosis (PVD/claudication))

Providing medical evidence alongside PIP application

Participants varied considerably in the extent to which they were able to provide supporting medical evidence. Some participants had no medical evidence as they either had not discussed their condition with a medical professional, had no formal diagnosis, or were unable to access or collate records due to changes in living circumstances (e.g., moving areas, release from prison), or not knowing how to access these records. Some participants mentioned that they did not provide evidence because they assumed if this was necessary then it would be explicitly requested of them, and they did not recall that this was the case.

> “What I didn’t have this time, because of the NHS, was the medical evidence to backup what I was applying for… I didn’t really see anyone for my depression because it was during the pandemic.”
>
> (Female, 46-65, joint hypermobility syndrome)
>
> “I have got all me notes from the doctor and everything if they needed it, but I didn’t send anything in... They should have suggested I send the evidence in. Even on the letter it didn’t mention [evidence].”
>
> (Female, 31-45, back pain)

Participants commonly shared that they had provided medical records (e.g., diagnoses, evidence of medication, sick notes, discharge letters) detailing the history of their condition and did not encounter any challenges in accessing this.

Confidence at point of completing application

Participants generally felt that at application they were able to make their case sufficiently, detailing to the best of their ability their condition(s) and the impact these had on their daily life. However, this did not mean that participants were confident in their application.

> I wasn’t confident. I viewed it as a pot of gold at the end of rainbow. I’d heard things about how difficult it was to get benefits on blogs that I accessed on brain injuries.
>
> (Female, 46-65, head injury; cognitive and sensorimotor impairment cognitive and sensorimotor impairment)

As discussed, while participants felt that they were eligible for PIP based on their understanding of the benefit, they did not always have confidence they would be judged as eligible based on what they had heard about how difficult it was to be awarded PIP.

3.2. Experience of the assessment process

Assessment channel preferences

Participants were typically aware of what the PIP assessment process would involve, having received a letter informing them that they were invited to an assessment with an assessor which would take place by phone, video-conference, or in-person. While some participants were happy to participate in the assessment through the channel allocated, some indicated that they would have preferred an alternative channel (e.g., to be seen in person so that the assessor could 'see' their condition, or to participate by telephone to reduce feelings of anxiety). It was not common among participants to have actively looked to alter the channel through which their assessment took place despite having a clear preference.

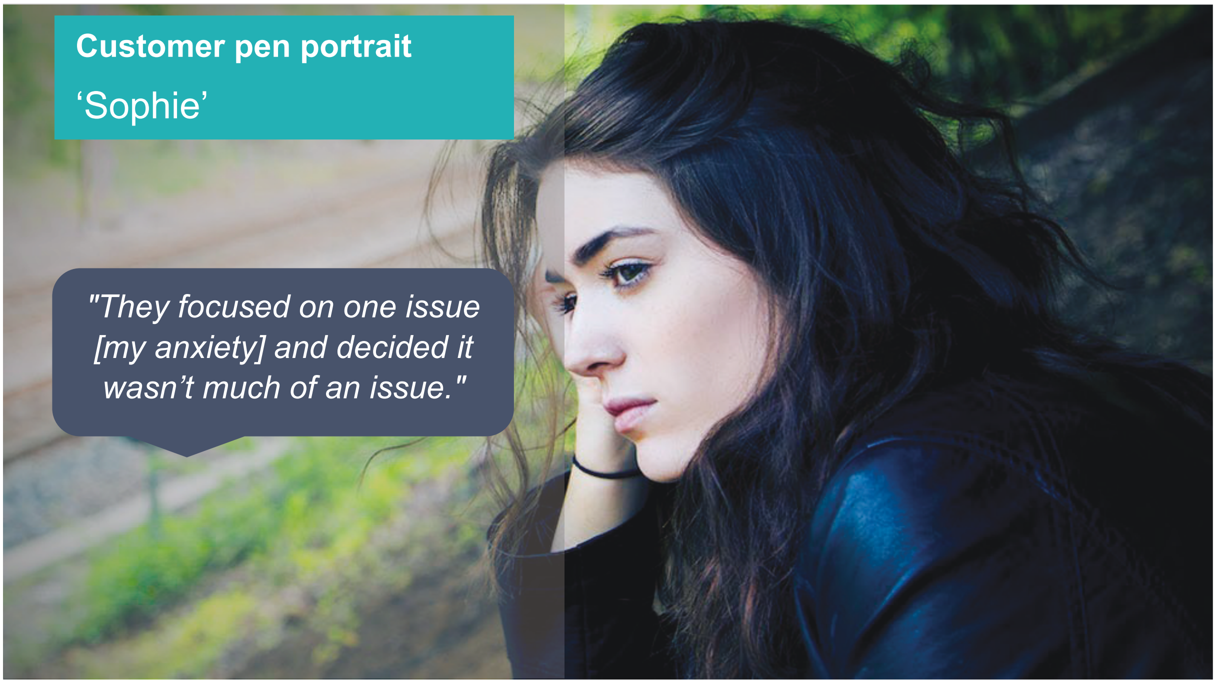
> "It would have been nice to have the option to do a phone call… I am not good with face-to-face stuff… I start to panic."
>
> (Male, 18-30, anxiety disorders)
>
> "If I were to do it again, I would ask for an in-person assessment… [on the phone] they don't see everything."
>
> (Female, 46-65, vision loss)

Preparing for PIP assessments

In advance of their assessment, it was not common for participants to have actively prepared in terms of planning what they might say when talking about their health condition or disability, and how the health condition affects their daily life (specifically in respect of the different PIP descriptors). Participants typically did not prepare, instead believing that they would simply answer the questions asked of them honestly and that this would be all that was necessary.

> I wasn't trying to score points I was trying to be honest.
>
> (Female, 46-65, vision loss)

Some participants went into the assessment feeling ill-prepared. One instance of this was a participant who did not recall receiving any notification of their assessment date (See Case Study: Sophie, p.29); another was a participant who felt ill on the day of their assessment but felt unable to postpone the interview (as it had already been rescheduled once (See Case Study: John, p.24)).



'Sophie' has dissociative identity disorder resulting from childhood trauma. At times of stress, she feels the presence of two other identities: Aisha and Emma. While she receives counselling and takes regular medications to control associated mental health symptoms, Sophie regularly suffers from fluctuating manic-depressive episodes and lethargy. She has very limited social support networks due to her dissociative disorder which has left her isolated.

Sophie has two jobs, working seven days a week, including as a business administration apprentice and in a fast-food chain. She struggles to hold down jobs due to her health conditions and has worked in six different roles over the past year. She applied for PIP at a point where she had left a job following a "manic episode" and needed financial support. This was on the recommendation of her boyfriend's mother who "helps people out with their benefit forms and suggested PIP". Based on the criteria she felt she qualified.

The application process itself was very stressful as it involved detailing historic trauma, so Sophie spread this over a few weeks. Then there came a wait of over a month for the assessment. She received a phone call out of the blue, while at work, and completed her assessment stood outside of the fast-food restaurant where she worked. She reported that she had not received prior notification. The assessment focused specifically on one aspect of her condition – her anxiety – which was confusing, but Sophie did not have the courage to challenge this on the call.

On receiving the outcome Sophie was disappointed and "numb". Having opened up about her traumatic past and the impact that had on her mental state, to receive a zero point outcome felt invalidating. It felt like none of the information on the application form had informed the decision – only what was said during the call. On the recommendation of her boyfriend's mother, she is appealing.

Support during assessment interviews

During the assessment, it was not common for participants to have brought anyone to support them. Some were not comfortable with the idea of other people (notably friends or colleagues) being more aware of the details of their condition and the impact this had on their lives. Some were simply unaware of the types of support available to them having not had formal support services signpost them to PIP. Participants also tended to be reluctant to seek support as they felt that the process was just a case of them stating their issue and answering a set of questions honestly – it was unclear why they would need support to tell the truth.

> "I have a certain level of education…I know how to find things."
>
> (Female, 46-65, joint hypermobility syndrome)
>
> "I don't really know who could help with that sort of thing, the Jobcentre didn't give much advice just said to go and get PIP but didn't say about any charities who could help."
>
> (Male, 31-45, cerebrovascular accident (stroke))
>
> "It's about me and for me so that is fair that you do it yourself."
>
> (Male, 31-45, schizophrenia)

Experiences of the assessment

The experience of the assessment itself was highly variable, with applicants describing both positive and negative experiences. Participants who experienced the assessment more positively tended to reflect on the disposition and conduct of the health and disability benefits assessor. Those who found the assessor to be pleasant tended to be more positive about the assessment overall and saw the zero outcome as a result of the 'system' rather than the 'fault' of the assessor.

> I spoke to a lady she was ever so nice… it's just the way she could understand how I was feeling and the way my body was and the way she was talking to me.
>
> (Male, 46-65, bronchiectasis)

There were a wider variety of reasons for participants having a more negative experience of the assessment process. One of the main reasons for a more negative experience related to issues with the way in which a health and disability benefits assessor was felt to have conducted the interview, ranging from being rushed through the interview to reported unprofessional behaviour (e.g., asking leading questions, seeming disinterested, belittling impact of a condition). Participants reported feeling like the assessor did not understand them or their case. Among these, participants tended to share that the assessor was felt to have focused on only one part of their case (or one of their conditions) without fully exploring what was included within their application form leading applicants to feel that they had not been fairly assessed.

> I felt intimidated to be honest… she wasn't very comforting she seemed like she didn't want to be there… she did talk over me a bit.
>
> (Female, 18-30, autism)

> "He was vile, he didn't understand, he wasn't a health professional[12] and didn't understand changing conditions."
>
> (Female, 31-45, post-traumatic stress disorder)

For applicants that had challenges communicating in English, the experience tended to feel unsatisfactory as they were unable to fully understand the questions or make themselves feel understood. One Romanian participant discussed not feeling comfortable requesting support from a translator due to the prejudices that can exist between different ethnic groups in Romania and a fear that this may influence the assessment process. Others experienced issues resulting from low literacy rather than English as an additional language.

Similarly, some participants felt dissatisfied with the process due to the challenges they faced in responding to questions and stating their case in the way that they would have liked. This was often a result of both the impact of their condition(s), general low levels of confidence, and anxiety going into the assessment, and the pressure of being formally assessed. One participant who has aphasia, inherent to his condition has difficulty speaking and struggled to make his case (See Case Study: Craig, p.33).

> "I felt quite distressed after I got off the phone... I felt like I wasn't getting my point across."

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[12] It should be noted that all assessors are qualified healthcare practitioners, though applicants may not be aware or recall that this is the case.

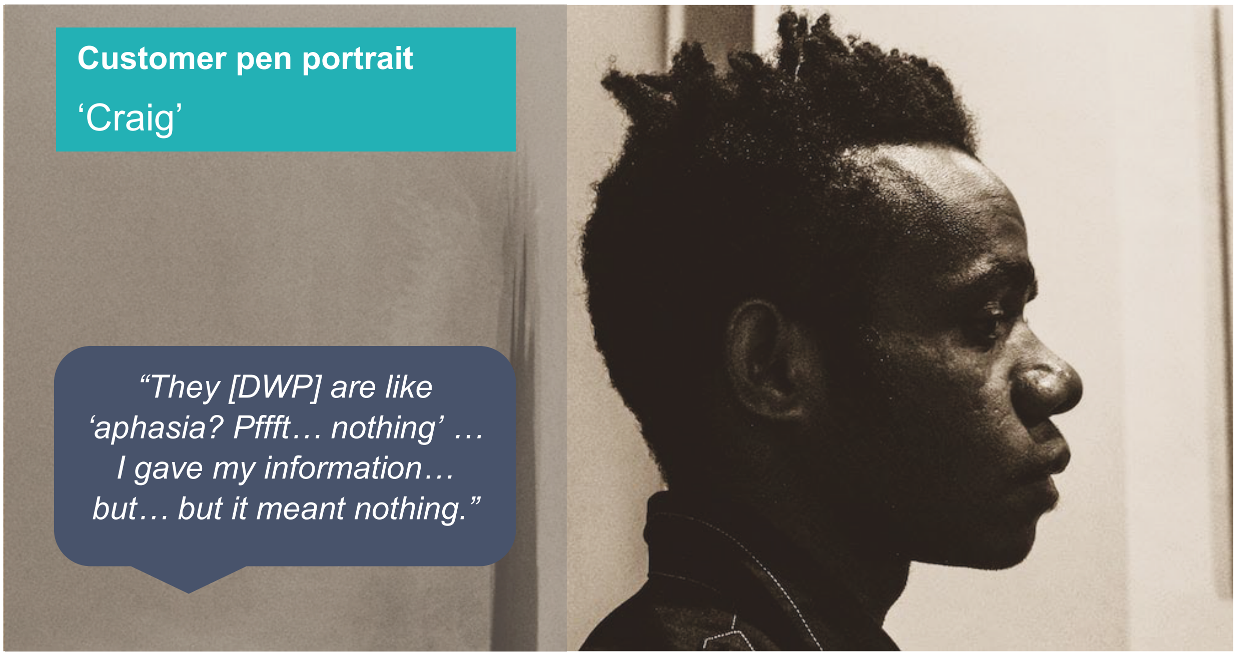
> (Male, 18-30, anxiety and depressive disorders)
>
> "They are asking you to disclose things about yourself, sometimes things my friend doesn't even know, which makes me anxious."
>
> (Female, 31-45, post-traumatic stress disorder)

It was common for participants to therefore feel 'out of control' of the assessment process, including what was discussed and the speed at which the process took place. The formality of the situation meant that people felt unable to direct the interview or question why an assessor hadn't asked for certain information. There was an expectation that they were accounting for what was in the PIP application form and that it was not necessary to repeat much of this in the assessment itself.

Some participants reported that, on reflection, they did not feel they had presented a true reflection of how their condition impacts them, instead putting on a 'brave face' and tending to undersell themselves. For example, this could include focusing on the current day, or better days, rather than their worst days; this was particularly the case for participants that had more fluctuating conditions (often tied to mental health). These participants often shared that they had learned to manage their conditions over a period of time, despite the challenges in doing so, and 'keeping going' necessitated not focusing on how bad things could be for them.

> Does that make me less entitled to PIP because I can dress myself? I struggle with it, but I do it.
>
> (Male, 46-65, hypothyroidism (myxoedema))

> "I felt personally that by me being completely open and honest about bad and good days I really thought that I would get a fair assessment out of it. They [the assessor] gave me the perception that they understood that, and it would be taken into consideration; but clearly it wasn't."
>
> (Male, 18-30, multiple sclerosis)



Customer pen portrait

‘Craig’

> *“They [DWP] are like ‘aphasia? Pffft… nothing’ … I gave my information… but… but it meant nothing.”*

‘Craig’, now in his mid-40s, suffered a series of small strokes at the age of 18. As a result, he has since suffered from aphasia and can struggle to put sentences together. At first glance, Craig appears fit and healthy until he tries to talk. Craig had found ways to disguise his condition through years of speech therapy, by speaking in very small sentences. His condition became increasingly noticeable during the interview with Basis Social as we talked at greater length and depth.

Craig had managed to cultivate a career as a graphic designer, but more recently, Craig had begun to struggle to make ends meet through work, so decided to apply for PIP. He had knowledge of the benefits system, as he had previously received disability benefits in the early 2000s, before the introduction of PIP, for the same condition. He also had experience applying for PIP previously (in 2016). On that occasion, he was turned down and went through the appeal processes, eventually to an independent panel where he was denied PIP. He recalls three judges being “so so sorry” but their hands were tied by criteria which didn’t recognise his disability. Craig felt that the DWP’s behaviour towards him during the appeal process was “nasty”.

He applied again for PIP last year on the advice of Citizens Advice. He had a good understanding and confidence in progressing his application which he found “easy”. Despite his previous zero point outcome, he was still confident he would receive PIP as he had extensive medical evidence and had received disability support in the past.

Craig was booked into a video assessment. The assessment was experienced as “straightforward”, thought as more of a “physical assessment” which Craig did not feel took into account his inability to communicate. They reportedly focused on his physical functioning and asked him yes/no questions that did not showcase his inability to communicate or form sentences. When the zero point outcome came through, he was disappointed. Craig did not blame the assessor for the outcome though, it is the system that he feels does not account for his disability. He will not be appealing the decision again due to low morale and feeling “broken”.

Providing additional medical evidence at point of assessment

It was uncommon among participants to provide any further supporting medical evidence at the assessment stage, either because they had no supporting medical evidence or because this was felt to already have been sufficiently covered at application.

Similarly, it was uncommon that people had support during the actual assessment process as most participants assumed it would be a straightforward process of answering simple questions about the impact of their condition. In those cases where support was provided, this tended to be more emotional support ‘in the room’ or providing input where participants got confused during the interview. Those with more negative experiences of the assessment often reflected that they would have benefited from support in retrospect. This was variously identified as being supported to keep them on track in terms of focusing on the question at hand, at prompting them to reflect on the range of experiences and evidence needed, and in keeping details of what had been asked/said.

> “There were a lot of in-depth questions that I didn’t understand.”
>
> (Female, 18-30, autism)

Confidence at point of completing assessment

Having completed their assessment, those participants that went into the PIP application process feeling confident they would be awarded PIP tended to still feel relatively confident. This was typically because they believed the impact of their condition warranted PIP and that they had explained this in the application and assessment. Those who were less confident going into the application process tended to feel more unconfident following the assessment. This was typically because the experience had been challenging and they were unsure whether they had got their point across clearly enough.

> “When I done the assessment over the phone I knew I wouldn’t get it…. I couldn’t explain myself properly.
>
> (Male, 46-65, ischaemic heart disease)”

4. Outcomes and reflections

Key takeaways

- Participants were unhappy when receiving a zero point outcome given they felt eligible.
- Participants wished they had done things differently:
    - Sought support with application and assessment
    - Provided (more) evidence
    - Made their case stronger by focusing on the worst days
    - Been more directive in their assessment
- Participants wished to have had more information throughout the process including:
    - Concrete information on eligibility to inform decisions, such as case studies or eligibility pre-checker
    - What evidence should be included in their application
    - Signposting to more detail on how their case was scored in the outcomes letter
    - Signposting to information on the appeals process in the outcomes letter
- Participants also wished for:
    - The ability to request a different mode of assessment, e.g., in-person, telephone, or video call.
    - To be able to speak directly with someone at DWP during application and post-decision to better understand eligibility.

4.1. Outcomes and next steps

Reflecting on outcomes of assessment

The outcome of PIP is shared via a letter that contains the score assigned for the mobility and daily living components. The letter also includes some notes from the DWP Decision Maker to justify the scores they had assigned.

Participants in this research were generally unhappy at receiving an outcome letter with a zero point outcome. They reported a mixture of emotions, ranging from shock, anger, and upset at those who were most confident in their application at the outset to disappointment and dejection from those who were less confident. This is unsurprising given the sample of participants felt they were eligible based on their understanding of the eligibility criteria.

> It was like a confidence knock… it felt like a kick in the teeth.
>
> (Male, 18-30, multiple sclerosis)

> “I was fuming I went down there gave an interview and in confidence told her that I struggle with basic things and then for her to say I don’t need any support was kind of like a slap in the face.”
>
> (Female, 18-30, autism)

Some participants were particularly upset because they knew of other people receiving PIP who had similar conditions to them or who they believed were less deserving of PIP.

> “I know people on PIP who are less unhealthy than me.”
>
> (Male, 46-65, hypothyroidism (myxoedema))

Receiving zero points was seen as indicative of a flaw in the benefits system, especially for those who were more confident in their eligibility. Receiving no points at all, rather than at least a few, felt like something must have gone wrong with their assessment or that the broader PIP system was failing, rather than suggesting that they were not entitled to PIP.

> The whole process is degrading. It feels like people are judging you and that the system is set up to refuse people.
>
> (Female, 31-45, post-traumatic stress disorder)

> “I didn’t feel this at first but now I feel that they would find any reason not to give it to you.”
>
> (Male, 18-30, multiple sclerosis)

Self-confidence impacted responses to zero point outcomes

Those who were less confident may have felt their zero point outcome indicated a flaw in the system or process, but they were also more likely to feel the need to move on quickly from the experience. This was particularly the case for those with mental health issues or complex trauma. Less confident individuals recalled wishing to drop out at different points, not because they felt they were not eligible, but because the process was emotionally stressful. Some went so far as to wish they had never gone through the process in the first place.

> I cried and ripped up the letter.
>
> (Female, 18-30, irritable bowel syndrome (IBS))

> “I wish I never applied for it… I haven’t got the help I thought I needed… I feel like I’ve been blacklisted.”
>
> (Female, 31-45, multiple sclerosis)

Within the less confident group, there were some participants that were not surprised by their outcome, as they went into their application believing that PIP was a difficult benefit to be awarded. They had been informed by informal networks or service providers that applying for PIP can be challenging, especially for certain conditions such as mental health.

> “I wasn’t surprised, and I wasn’t shocked… I heard through the grapevine that it’s so hard to get for mental illnesses that I didn’t get my hopes up.”
>
> (Female, 18-30, post-traumatic stress disorder)

Engaging with the outcome letter

Participants differed significantly in the extent to which they had engaged with their outcome letter. For some, notably those who were less confident, they tended not to review it in any detail beyond seeing a ‘lot of zeros’. Others did review their letter in more detail. Within this group, there was a sense that the information shared in the outcomes letter was insufficient in enabling them to understand why they were given zero points. The information was felt to be lacking especially in regard to explaining the nuance of how their case had been scored, and participants expressed wishing they could have known more.

> “What was written felt a bit sh**ty… it felt like everything that I said they thought I was making it up.”
>
> (Male, 18-30, anxiety and depressive disorders)

Some participants also felt that there was a disconnect between what they had said during their assessment and the information contained in the assessor’s notes of the outcomes letter. In these instances, the assessor was felt to have misunderstood or misrepresented what had been said during the assessment.

> “The notes said ‘we determined you can’t do this’, but it was clear he didn’t listen.”
>
> (Male, 18-30, anxiety disorders)”

> “The letter was just lying… it was like she hadn’t read my autism diagnosis. Because I was at university I was perfectly functioning.”
>
> (Female, 18-30, autism)

It was also mentioned that the letter did not contain enough information about appeals, and there was a desire for more details on this process.

> “They never told me I could appeal.”
>
> (Female, 18-30, autism)

Preferences for channels notifying outcomes

Receiving a letter explaining outcomes was preferred compared to a phone call. It was felt to allow an individual time to review the detail in their own time, especially given how emotional receiving the outcome can be. As mentioned, there were some individuals, especially those with mental health conditions and trauma, who did not feel they were in a place to handle the information and needed to quickly move on. This may indicate that there may be a better means to communicate or follow up on outcomes for certain individuals to give them the opportunity to appeal if they felt it appropriate. Some participants wished they had a chance to discuss their outcome in depth with someone, especially to clarify questions about how their case had been scored. This could indicate that an option to speak with someone by phone could be referenced more explicitly in the letter.

> “It’s no good speaking to people when they haven’t got good news for you. With a letter you can look at it, read it, put it down and then look at it again.”
>
> (Male, 31-45, schizophrenia)
>
> “Maybe if it is zero then call me a second time and ask about everything. Because only doing one time, maybe he’s not asked me about everything.”
>
> (Male, 31-45, neurological disorders)

Appealing outcomes

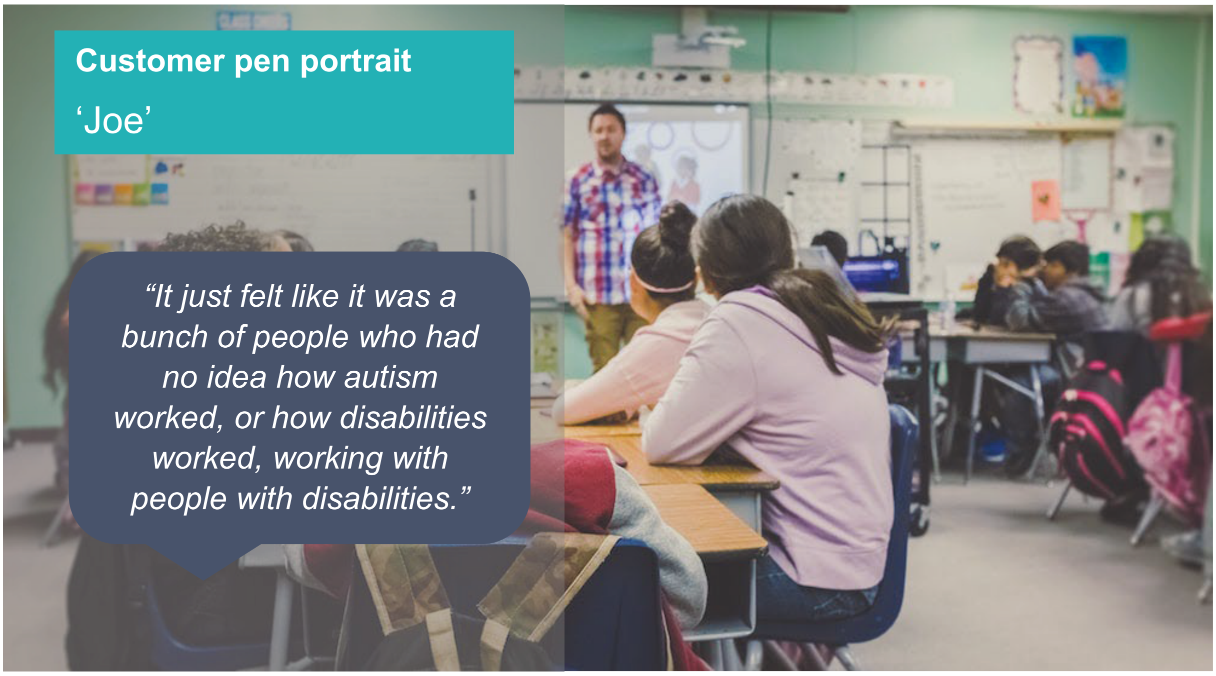
Individuals who felt more confident in their application from the outset, and who had higher capability (in terms of their resilience and cognitive functioning) tended to go on to appeal their case. These participants felt a mistake had been made in their assessment – either by the assessor, or the way they had responded to the assessment questions (See Case Study: Joe, p.41). Individuals who were less confident in their outcome and their own abilities tended not to go on to appeal. The process had been so challenging and stressful that they did not feel they could repeat it. As stated, they had a sense of wanting to move on quickly from the experience.

> “What she said on the letter is not true… I am eligible for this I’m not going to back down.
>
> (Female, 18-30, autism)”

> "I thought about appealing, but I just don't want to go through it again and get spoken to like that."
>
> (Male, 18-30, anxiety and depressive disorders)

The participants appealing their case were more likely to go on to access support at this stage in order to strengthen their case. Those who had not received support during their first attempt felt this would be especially important for improving their chances of being awarded PIP. Although there were also a few that remained uncertain of how to access support.

> "My aunt is helping with my appeals… She should've done the assessment with me because she knows me better than I know myself."
>
> (Male, 18-30, autism)
>
> "I don't know who to talk to [for appeals support]."
>
> (Female, 31-45, back pain)



Customer pen portrait

'Joe'

> *"It just felt like it was a bunch of people who had no idea how autism worked, or how disabilities worked, working with people with disabilities."*

'Joe' was a post-graduate student teacher in his early 20s, training to be an illustrator. Joe is autistic and had managed associated anxiety and depression since his teenage years. As a result of his neurodivergence, Joe had always struggled with "academic" things, like writing and numbers, but was a keen artist. He faced everyday challenges in how he managed things, such as time and money, and his anxiety means that he was unable to travel to unfamiliar places alone.

Joe's friend, who was similarly neurodivergent, was recently awarded PIP. They urged Joe to apply as they experienced similar challenges in their day-to-day lives, and so assumed he was also eligible. After doing some research online, Joe started the application process. Due to his problems with writing, his girlfriend helped him fill in his application form. After some time, they were able to submit his application alongside evidence of his diagnoses.

He was booked into a face-to-face assessment, which was in a nearby town. He was unable to get there on his own, so his girlfriend accompanied him and supported him through the process. Joe found this whole process anxiety-inducing and challenging. He says there "were a lot of in-depth questions that I didn't understand" and he said he struggled to communicate how his condition impacts his day to day because the assessor was unsympathetic and intimidating. Joe said he felt "intimidated" and he "just felt like I wasn't being taken seriously".

When his decision letter arrived, Joe was furious. He felt the assessor had not listened to him and that her assessment contradicted the medical evidence he had submitted. He felt that because the assessor's first impression of him was that of a physically fit young man, they disregarded large sections of his medical evidence. At the point of interview Joe was appealing his decision and remained adamant that he is eligible.

4.2. Reflecting across the PIP application experience

Participants were asked to reflect on their experience applying for PIP to understand what they wished they had known and what, if anything, they might have done differently.

Clarity in eligibility and entitlement criteria

One common reflection was that clearer information on PIP eligibility and entitlement criteria would have been beneficial. The information that is currently available on the GOV.UK website[13] was felt by participants to be sufficiently vague to lead more people to believe they are eligible than may be the case. Participants felt that it would have been beneficial for more specific information around entitlement, alongside scoring information, to enable people to make an informed decision to apply, and to understand what is required of them at application and assessment.

"I just feel like it could've been explained better…I don't remember mention of a scoring system."

(Male, 18-30, anxiety and depressive disorders)

> "You don't know what sort of level you have to be at before you qualify."
>
> (Male, 46-65, bronchiectasis)

There were a variety of suggestions to be able to make PIP eligibility concrete. For example, case studies or examples of claimants who did and who did not qualify for PIP to highlight some of the complexity of how PIP is scored. Some participants wanted a way to check their eligibility in advance of applying, such as through an online eligibility checker or by speaking with someone at DWP who could advise them whether they were eligible to proceed or not and explain any necessary information about the process.

> "They could have some sort of pre-scoring system, where if you suffer from these bits you get these points and you can sort of gauge yourself.… If there was someone to go to preassessment, explain your circumstances to. They know literally all the DWP stuff, they know based on what you are telling them whether it's worth it or not."

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[13] See https://www.gov.uk/pip

> (Male, 46-65, bronchiectasis)

Accessing support

One of the biggest areas where participants wished they had done something differently, was to have sought support (or more support) both in their PIP application (i.e., filling out the form and what evidence they should include) and during the assessment. They wanted to have guidance on how best to respond to the assessment questions and to have someone who could step in and advocate on their behalf when they struggled to respond, for example, if they could not understand the question or form a coherent response themselves.

> I wish I had found out more about it or had help going through the form.
>
> (Female, 18-30, post-traumatic stress disorder)

> “I would have asked Citizens Advice [for support] … I knew that they could help but I didn’t feel that I needed their help. But I now know that they are here to help respond to this, they know the case. And I didn’t know disability advice existed. I would have asked either of those services.”
>
> (Male, 31-45, chronic fatigue syndrome)

Providing additional evidence in support of application

It was a common reflection among participants that they wished they had provided more evidence at assessment. This was less about providing more medical evidence, but about providing a more comprehensive response to questions, including the most negative impacts of their conditions (rather than ‘putting on a brave face’). Especially in the case of fluctuating conditions, participants often spoke about best-case or at least not worst-case scenarios. Reflecting on this, they wished they had instead ‘not held back’ and made the full story clear. (See Case Study Noah, p.45).

There was a belief that more evidence would be asked for by assessors if needed to fully draw out the impact of a condition, but participants reflecting on the process in this research did not identify this as something which took place in their cases. In retrospect, participants felt they should have taken more control in the assessment, and ensured they covered the relevant points to make their case. Some participants had experienced an assessment in which the assessor had focused only on parts of their condition or was felt not to have given them the opportunity to fully explain themselves. Participants wished that they had been directive and assertive in focusing the assessment (particularly where conditions were intersecting) and this was often something that participants said they would do in appealing a decision.

> “I wish I had not held back... Make them believe it’s as serious as it is for you."
>
> (Male, 18-30, anxiety disorders)

Desire for more information on outcome decisions

Lastly, there was a desire to have more information in outcome letters. The letter was felt to be vague and, at times, contradictory when it came to the assessor notes. Participants would like to have more information to explain how their case had been scored, as well as to have more information on appeals.

> “It wasn't necessarily the scores it was the comments… they think I'm a liar. It would've been good to get a proper explanation."
>
> (Male, 18-30, anxiety and depressive disorders)

Customer pen portrait

‘Noah’

> *“If ‘it’ means doing something differently then it means I’m going to lie. I’m not going to lie.”*

‘Noah’ was a college student who developed anxiety when he was 15 which got worse in the past few years. To help manage his anxiety he switched to going to college half remote and half in person.

He was seeing the mental health services at his college, and they recommended he apply for PIP since his mental health had begun to impact his daily life. He spoke with his friend who also had PIP for a similar condition, and she told him it was challenging but he should try. She also received zero points the first time but was awarded PIP on her appeal.

He felt confident in his responses to the application form. His dad helped him from an “outside point of view” as he had seen his condition and its impacts over the years.

His assessment was in person, which was very challenging as he gets very anxious in new environments. Noah felt the assessor “misinterpreted” what he was saying and asked leading questions. For example, when the assessor asked about his ability to travel, he told the assessor that he sticks to the route he knows – the assessor marked this as he was able to travel. His dad helped him during the assessment and jumped in when he struggled with his words. During the assessment, Noah wished to stop the entire thing, but he knew he needed to continue. The assessment was experienced as very rushed, and he struggled to keep up. He said he “needed a minute to get his thoughts together” which he was not offered.

Having been given zero points, he has now gone through the mandatory reconsideration process, in which he “didn’t hold back” and said to them “Can you listen to me this time?” He felt more information on eligibility for PIP, such as a way to check eligibility ahead of time, would have been useful.

5. Summary of findings

The following section summarises our findings based on the research questions set for this research:

Applicants' understanding of PIP eligibility criteria

Participants' understanding of PIP eligibility was vague but relatively accurate: it was a support benefit for people with health conditions or disabilities that impacted their daily life and ability to function. The most common misconception held was that employment impacted PIP eligibility, with participants believing that people who were unemployed or unable to work were more eligible for PIP than others. Less common misconceptions included that health condition alone could make you eligible for PIP, people with a low-income are more eligible for PIP, and that work history may be considered in PIP eligibility.

What information applicants received before, during, and after assessment and how this impacted their decision to apply

It was commonly reported that the decision to apply was influenced by someone else. This was both through informal and social networks, such as partners, relatives, and friends, as well as more formal networks such as service providers like Citizens Advice.

It was common for participants to report seeking information on the GOV.UK website after initially learning about PIP, to check their eligibility and learn how to apply. The information on this website was felt to be vague and did not provide much more information beyond confirming participants' basic understanding of PIP.

When reflecting on the information that would have been beneficial for them, participants wished to have had more concrete information on eligibility to inform their decision to apply, for example case studies or an eligibility pre-checker.

When receiving their outcome letter which shared their award decision, participants felt the information shared in the letter could be expanded, especially providing more detail on how their case was scored and on the appeals process.

Applicants' reflections on the assessment process

The application process itself varied greatly for participants. Those who were more confident tended to find it easier and more straightforward, whereas those who were less confident had more anxiety and fluctuations in their conditions which meant applications could be drawn-out and tended to be reported as being hard. The conditions themselves could also impact their experience, with people that had health issues which impacted their energy or cognitive ability more likely to find the process exhausting.

The experience of the assessment also varied between participants. Some had positive experiences, mainly when the mode (i.e., phone vs in-person) aligned with their preference, and when the assessor was seen to be polite and considerate. Some participants struggled to make their case at the assessment for many reasons. For example, they were unprepared, they had language or communication barriers, and the assessor was perceived to control the conversation in what was felt to be an unproductive way.

When reflecting on what they wished they had done differently, participants wished that they had sought support, provided (more) evidence, made their case fully, and were more directive in their assessment. They also wished for the ability to choose the channel of their assessment (e.g., phone, video, or face-to-face), and to speak with someone throughout the process.

Applicants' level of confidence when applying to PIP, if (and how) this changed during the process, and whether individuals with low confidence considered dropping out

Participants broadly felt eligible and deserving of PIP, although some went into the process more confident in their outcome than others. Those less confident tended to be participants with mental health conditions and who were told at the outset (by friends, family, or colleagues) that PIP was difficult to get.

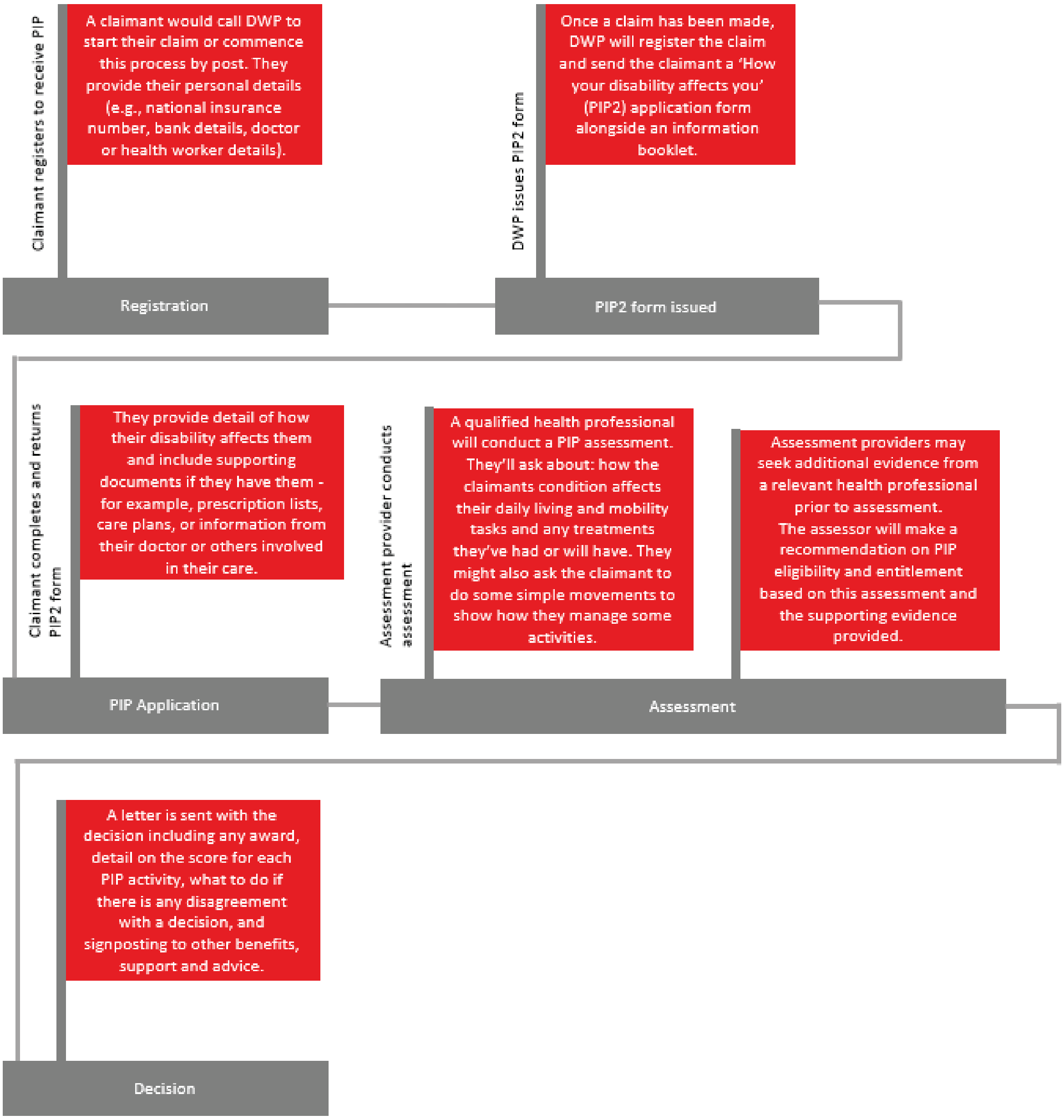
Participants who were more confident tended to be less likely to seek support for their application and assessment. Those who were more confident also tended to find the application process more straightforward. Individuals who were less confident recalled wishing to drop out at different points, not because they felt they were not eligible, but because the process was emotionally stressful.

Individuals who felt more confident in their application from the outset, and who had higher capability (in terms of their resilience and cognitive functioning) were more likely to go on to appeal their case. Individuals who were less confident in their outcome and their own abilities were less likely to go on to appeal.

Appendix 1: the PIP application and decision-making process

What follows is a high-level summary of the how the PIP application and decision-making process should work in practice. This is provided to allow readers to compare and contrast with participant's reported experiences.

Figure 2 Diagram providing summary of PIP application and decision making process



A claimant would call DWP to start their claim or commence this process by post. They provide their personal details (e.g., national insurance number, bank details, doctor or health worker details).

Once a claim has been made, DWP will register the claim and send the claimant a 'How your disability affects you' (PIP2) application form alongside an information booklet.

They provide detail of how their disability affects them and include supporting documents if they have them - for example, prescription lists, care plans, or information from their doctor or others involved in their care.

A qualified health professional will conduct a PIP assessment. They'll ask about: how the claimants condition affects their daily living and mobility tasks and any treatments they've had or will have. They might also ask the claimant to do some simple movements to show how they manage some activities.

Assessment providers may seek additional evidence from a relevant health professional prior to assessment. The assessor will make a recommendation on PIP eligibility and entitlement based on this assessment and the supporting evidence provided.

A letter is sent with the decision including any award, detail on the score for each PIP activity, what to do if there is any disagreement with a decision, and signposting to other benefits, support and advice.

Appendix 2: additional sample information

Within the sample, a wide range of disabilities and/or health conditions were reported by participants, including:

- Anxiety
- Aphasia
- Arthritis
- Asthma
- Atherosclerosis
- Autism
- Back pain
- Bronchiectasis
- Cancer
- Cardiac failure
- Cognitive and sensorimotor impairment
- Chronic obstructive pulmonary disease
- Depression
- Dissociative identity disorder
- HIV/AIDs
- Hernia
- Hypothyroidism
- Irritable bowel syndrome
- Ischaemic heart disease
- Joint hypermobility syndrome
- Manic depression

- Myalgic encephalomyelitis or chronic fatigue syndrome
- Multiple sclerosis
- Neurological disorder
- Osteoporosis
- Personality disorder
- Post-traumatic stress disorder
- Radiation poisoning
- Schizophrenia
- Scoliosis
- Sleep apnoea
- Stroke
- Vision loss

Appendix 3: discussion guide

Introduction and Consent [2 minutes]

My name is […]. I work on behalf of Basis Social. We are an independent research agency who have been asked to carry out this research with you on behalf of DWP.

DWP have commissioned this research to get feedback from individuals who have received zero points on their PIP assessment. The research will be used by DWP to inform decisions that are taken in future about disability assessment processes.

Your responses will be anonymised and treated confidentially. Your involvement in this research will not impact any current or future claims or interactions you have with DWP, and DWP will not be able to identify who has taken part in the research. As mentioned, Basis Social is an independent research agency and we do not work within DWP. What you say will remain confidential, except in the case we are concerned about the safety of yourself or others.

We understand that talking (and hearing) about disabilities and health conditions can be a very personal topic and there may be details about your personal situation you don't want to talk about or questions you don't want to answer. This is completely okay. If there is something you don’t want to talk about then please tell us and we'll move on. However, please be as open and honest as you can. We welcome all views, positive, negative and anything in between.

I would like to audio record and take typed notes of the discussion today. This is purely so we have an accurate record of what you tell us today. The notes and recording will be kept strictly to the Basis Social team and we will only be recording what is said. Any notes and recordings will be deleted at the end of the project. Are you okay with this?

Finally, Basis are a company partner of a body called the Market Research Society and abide by their code of conduct. Participation in this discussion is completely voluntary and you are able to withdraw your consent to participate at any point in the process. This includes during this discussion, or even afterwards.

Are you happy to continue with this interview on this basis? Confirm consent.

Any questions before we start?

Meet the participant [5 minutes]

This section is to become introduced to the participant and learn about their disability and support needs.

- To start off, I would like to find out a little more about you if you don’t mind…

    - Tell me about a typical day in your life. What do you do? *Probe on work, study, leisure activities, family commitments and support networks and care (whether formal or informal)*
- Great, and can you tell me a little more about your particular support needs, health condition or disability, if you are happy to share those?
    - When did your condition start?
    - Has it changed? Does it fluctuate?

Pre-application [10 minutes]

This section is focused on the participant's experiences before applying to PIP. We are particularly interested in their decision-making for applying including what made them ultimately go ahead with the application. We are interested in learning about what information they received and who they discussed it with. Details are very critical here, so please make sure to probe as much as they can recall.

Please note this that the research is only interested in PIP assessment. Other disability benefits such as WCA are relevant as they may relate to participant's (mis)understanding of PIP processes and eligibility, but ensure the conversation always comes back to PIP.

- When did you first consider applying for disability benefits?
    - *Probe: PIP vs other benefits*
    - What prompted you to consider applying?
    - *Probe: if suggested by someone, probe for who e.g., friend or family, GP, support worker*
    - Thinking back to that point in time, what had you heard about disability benefits and specifically PIP? I.e., in terms of who qualified.
- What were your next steps?
- When you first were learning about PIP, what sort of questions did you have?
    - *Probe: specifically on PIP if they are discussing other benefits as well*
    - *Note: clarify time frame*
- Did you speak to anyone at that time about it?
    - *Probe: all sources*
    - Who? What did they tell you about it?
    - *Probe: GP, nurse, medical practitioners, community / advice organisations*
    - *Probe: family, friends, peers, etc.*
    - Did anyone encourage you to apply? Why?
    - *Note: clarify time frame*
- How else did you get information about PIP?
    - *Probe: gov.uk, videos, online discussion forums, other sources*
- What sources did you find most helpful? Why?
    - Probe: which they found influential in deciding to apply? Why?

Note to moderator: please ensure you get a granular understanding of exactly who was spoken to (or sources of information), in what order and what they learned from each.

- How long was it between first considering applying for PIP and then putting the application in?
- (If not already clear from above) What made you decide to go ahead with applying for PIP?
    - *Probe: fear of assessment process, lack of energy, worry about stigma of applying, don't think PIP is for them*
    - How confident were you that you would get PIP benefits?
    - *Note: clarify time frame*
- Have you applied for other types of disability benefits? *If so, clarify which benefits and when they applied*

Moderator to reconfirm information/support sources used between consideration and PIP application(s)

Understanding of PIP eligibility [10 minutes]

This section is focused on their understanding of PIP. We are most interested in their understanding of eligibility of PIP.

- Can you tell me what your understanding of PIP is?
    - What is PIP meant to support with?
- Who is eligible for PIP?
- How do you think DWP determines whether someone qualifies for PIP?
    - Probe: scoring system (*Score out of 12 on daily living and score out of 12 on mobility component. Researchers to review PIP on a page pre-interview for own reference/understanding)*
    - Being eligible for PIP is based around how your health condition stops you doing daily activities, for example getting out and about or making a meal or eating food. How does this fit with your current understanding of PIP? (*Note to researcher: we hypothesise some Zero point PIP applicants believe they qualify based solely on condition, when in reality PIP is measured based on functionality rather than condition itself. We are interested in testing this hypothesis here)*
    - What is your understand of how long a disability should impact someone in order to qualify for PIP? (*Note to researcher: Their health conditions must be expected to last at least 12 months to qualify as long term. It should have already started at least 3 months before applying, in which case they need to be expected to continue for at least another 9 months)*
    - How do you think employment impacts PIP, if at all? (*Note to researcher: employment status does not impact PIP/is not part of eligibility. We hypothesise there might be misunderstanding around this, and would like to test that here)*
    - What is your understanding of how conditions that fluctuate/change are considered in PIP eligibility? *(Note to researcher: PIP assessment considers how the condition impacts them on "majority of days")*

Application [5 minutes]

This section focuses on the application process itself. It is important to understand what support they did or did not have, and what may have made the application process challenging for them.

- *For researcher reference, the application and assessment process involves:*
    - *Call DWP to begin claim or send a letter requesting a postal application (takes longer)*
    - *Then fill a form "How your disability affects you", either online or in a paper format (to be returned by post) (participants may refer to this form as the PIP2 form)*
    - *Either a 'paper based' decision is made (where there is sufficient evidence in the application to make a decision), or applicants are invited to an assessment if more information is needed. This will cover how the condition impacts daily living and mobility tasks, and any treatments had or will have (Note: some people do not have to fill this form and go straight to assessment)*
    - *The outcome is sent via a letter. This includes whether or not you will get PIP, the scores for each activity and a date of your first payment.*
- Now, I would like to learn a bit more about your experience going through the application and assessment for PIP benefits.
- Could you tell me about the process of filling in the application form?
    - Did you fill the "How your disability affects you form"?
    - Did you fill this in online or in a paper format?
- How confident were you when going through the application? Did you face any difficulties in the process?
    - *Probe ease/barriers across the 2 stages above*
        - *Call or apply via post (probe: ease of making phone call, returning post)*
        - *"How your disability affects your form" (if they did this) (probe: understanding, ability to complete online or paper, returning by post if relevant)*
- Did you have someone supporting you in the application process?
    - If so, how did they help you?
    - If not, what kind of support would have been helpful (if any)?
    - *Probe across the 2 initial stages above*
        - *Call or apply via post*
        - *"How your disability affects your form" (if they did this)*
    - *Probe for barriers in accessing third party support*
- Did you have any other sources of information that you used in helping to put your application together?
- What documents or supporting evidence did you include with your application form?
    - How did you decide to include those documents?
    - Were then any other documents you decided not to include? Why?
    - *Probe for barriers in gathering evidence*
- How long did it take you between starting your application and submitting it? Why?

  - *Probe on potential barriers: filling forms poorly, not enough evidence, organisation*
  - *Did you take breaks? Why/why not?*

Assessment process [5 minutes]

This section covers the assessment process. It is important to understand the support they did or did not have, and what may have made the assessment challenging for them.

- Could you tell me about the assessment?
  - Did you have an assessment?
  - Was this in person, by telephone, or video?
- How confident were you at your assessment? Did you face any difficulties in the process?
- Did you have someone supporting you in the assessment process?
  - *Probe across preparing for the assessment and during the assessment*
  - If so, how did they help you?
  - If not, what kind of support would have been helpful (if any)?
- Did you have any other sources of information that you used in helping at the assessment?
- Did you provide any new information at your assessment that you did not include in your application?
  - *Probe for either offering new information or being asked for it*
  - *If yes:* Why did you not provide this information initially?
- Do you feel that the assessor understood your circumstances?
  - *Probe for health condition, how it impacts daily life*
- At any point from your initial contact with DWP to receiving your decision letter, did you ever wish to stop the application process?
  - If so, why did you wish to stop the process?
  - Why did you not stop? As in, why did you still complete the application process? *Probe: uncertain how to, difficult to reach DWP*

Outcome/Results [10 minutes]

This section focuses on the results of the PIP application. We are interested in how information was received, whether there was confusion at this stage, and what they decided to do next (if anything).

- And, at the end of the application process, how did you learn about the outcome of your application? *(This comes through an outcomes letter)*
- How do you feel about the decision that DWP made? *Probe whether upset/annoyed as believe qualify, or whether accept decision based on the assessment criteria.*

If still feel eligible then ask following questions:

- OK, so take me back to that point of learning about the outcome of your application.
    - What questions did you have when you received the outcome?
    - Was it clear why you had received zero points?
        - Did you understand why you were not thought to be eligible for PIP?
        - And did you understand how your application was scored?
    - Do you think your application was assessed fairly?
        - What makes you this?
    - Was there any information contained in the letter that you wish you had known before you put forward your application? *(e.g., scoring or eligibility criteria)*
    - Knowing what you know now about how you were assessed, is there anything you would have done differently in your application in terms of the information to be included?
    - Do you think there could have been a better or different way to tell you about the outcome of your application? If so, what/how?
- What did you do next having received the outcome letter? Did you speak to anyone? *Probe:*
    - Did you speak again to anyone that you received advice or support from before applying?
    - *Probe: reaching out to DWP, gov.uk, speaking to medical practitioner*
- What were your next steps after you received your outcome?
    - *Probe: apply for other benefits, mandatory reconsideration (or appeal if already at that stage), go to someone for advice, give up*
    - *[If they considered, plan to, or are going through mandatory reconsideration or appeal]* Did you receive advice on this? What advice and from whom? How did this impact your decision to go to request a mandatory reconsideration or appeal?
    - *[If they considered, plan to, or are going through mandatory reconsideration or appeal]* Are you planning to submit any different or additional evidence? If so, what made you decide to include that? Why did you not include it in your original application?

If agree that not eligible then ask following questions:

- OK, so take me back to that point of learning about the outcome of your application.
    - What questions did you have when you received the outcome?
    - Was it clear why you had received zero points?
        - Did you understand why you were not thought to be eligible for PIP?
        - And did you understand how your application was scored?
    - Do you think your application was assessed fairly?
    - Was there any information contained in the letter that you wish you had known before you put forward your application? *(e.g., scoring or eligibility criteria)*
    - Knowing what you know now about how you were assessed, is there anything you would have done differently in your application in terms of

    either the information you included, or whether you would even have submitted the application in the first place?
  - Do you think there could have been a better or different way to tell you about the outcome of your application? If so, what/how?
- What were your next steps after you received your outcome?
  - *Probe: apply for other benefits, mandatory reconsideration (or appeal if already at that stage), go to someone for advice, give up*

Reflections [10 minutes]

This section is to allow the participant to reflect across the assessment process and identify any points where they wish they had information or done something differently.

- Now, I would like to spend the rest of our time reflecting back on the PIP application process as a whole. Now that we have spent time going through your experience with the PIP assessment, what are your thoughts?
- Now that you have completed the application process and received your outcome, looking back is there anything you wish you had known when you were first considering applying for PIP?
  - When would you have liked to have known these things?
  - Who would you like to have told you? *Refer back to trusted sources, and explore role for DWP*
  - Do you wish you had someone to discuss PIP with? Who? *Probe: DWP, independent charity, medical professional*
  - Do you wish you had more opportunity to check your eligibility before applying? If so, how would you like to have been told this?
- Was there anything about PIP and the PIP assessment process that you now realise you did not understand?
  - *Probe: eligibility, application process, the assessment*
  - *How could these best be addressed?*
- If you had received different information earlier, such as about eligibility for PIP, would that have made you make a different decision about applying? If so, what? If not, why?
- Thinking about other people in similar situations to yourself, what advice would you give them about PIP?
  - How would you describe who is eligible for PIP?
  - Who would you advise them to speak with?
- Do you wish you had done anything differently?
  - *Probe: more/different evidence when applying, more/different advice or information*
- [If not already discussed fully above/time allows] A large proportion of people who apply for PIP do not qualify (the overall impact of a health condition or impairment on people's ability to carry out daily tasks is not deemed to justify an award). This is a process which can be difficult and emotional for people making a claim. How do you think DWP can better support people to understand who does/does not qualify?

Thanks and close [2 minutes]

That concludes my questions. Is there anything else you would like to add?

Thank you very much for your time. This has been very helpful and will be used to help inform process improvements for disability assessments in the future.

Again, your responses are confidential and will not impact any of your involvement with DWP going forward.

If you have any questions please email us at social@basisresearch.co.uk

Your payment will be processed in the coming week.