



Department
for Work &
Pensions

Triggers to claiming Personal Independence Payment

Research report

March 2022



Government
Social Research

Executive summary

Background

DWP experienced a noticeable and sustained increase in new PIP claims during October 2021. Using qualitative methodology, the present research sought to investigate the drivers behind this increase.

Findings

- Most people cited multiple health conditions, often a combination of mental and physical conditions.
- People were recently made aware of PIP through contact with formal services (including JCP) friends and family. Few participants mentioned media or social media.
- Health deterioration, financial hardship and employment concerns were the main triggers for PIP application. Few participants mentioned the loss of the £20 UC uplift or the ending of the furlough scheme.
- People cited travel, daily living, utilities and household costs as their intended uses for PIP.

Conclusions

Regarding *which* conditions PIP claimants declare, most people cite multiple health conditions, often a combination of mental and physical conditions. Regarding *where* claimants heard about PIP, people were recently made aware of PIP through contact with formal services (including JCP), friends and family. Few participants mentioned media or social media. Regarding *what* circumstances trigger a claim, health deterioration, financial hardship and employment concerns were the main triggers for PIP application. Finally, regarding *how* claimants think PIP will be helpful, individuals cite daily living, utilities and household costs as primary targets for their potential PIP award.

Key messages

- Claimants are continuing to present with a wide range of conditions.
- Poor mental health was prevalent, and most people relied on multiple carers.
- People were recently made aware of PIP through their contact with formal services including JCP.
- Main triggers for PIP application were health deterioration, financial hardship and employment concerns. Individuals may have been previously eligible, however their claim was triggered by a recent decay in circumstances.

- Individuals were keen to receive validation of their disabled status and saw PIP as a means to achieve this.
- Most individuals cited financial support as the driving 'purpose' of PIP.
- People cited daily living, utilities, household costs and transport as their intended uses for PIP.
- The process of form filling, health assessment, and corresponding wait times provoked anxiety.

Recommendations

1. Continue and expand work by Disability Services Advocacy Team to raise awareness of PIP, with public/third sector services and the general public. This could include:
 - a. Wider publication of distinct travel benefits for disabled people (i.e. separate to PIP and Motability).
 - b. Promote the Access to Work Passports' to facilitate continued employment.
 - c. Promoting the GOV.UK 'Eligibility Checker' for individuals to use prior to applying for PIP.

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Abbreviations

DAD - Disability Analysis Division.

DWP – Department of Work and Pensions.

GP – General Practitioner.

JCP - Job Centre Plus.

PIP - Personal Independence Payment.

ToC – Theory of Change.

UC - Universal Credit.

Main report

Background

The Department for Work and Pensions (DWP) identified a noticeable and sustained increase in new Personal Independence Payment (PIP) claims during Oct-21 and wished to rapidly understand the drivers behind it, in particular whether changes in one part of the welfare system have unintended consequences on other parts. DWP updated guidance¹ on making PIP claims on 4th October which has been widely reported by third sector organisations and both national and local media.

As a concurrent project, Service Delivery colleagues conducted a manual scan of a random sample of e-PIP2 cases for 400 customers, selected from claims made in September and October '21. A significant number of customers were seen to claim for multiple conditions, often a combination of physical/mental health conditions.

Aims and objectives

The overarching aim of this project was to expand our knowledge of PIP claimants' motivations, concerns and opinions on triggering a claim. Our objective was to provide insight into the reasons behind a rise in PIP claims in September/October 2021, in particular we sought to:

- explore *which* conditions PIP claimants declare;
- explore *where* claimants heard about PIP;
- explore *what* circumstances trigger a claim;
- explore *how* claimants think PIP will be helpful.

Evidence gaps addressed

Findings will be used to understand what impact external factors (such as COVID-19 and changes in the associated financial support measures) have on people's health, and their propensity to claim PIP. This will help inform future policy development across the welfare system. The following questions are raised in DWP's internal Evidence Strategy:

- What triggers people to start a disability benefit claim? (DAD8)
- Why is the PIP caseload relatively low and why are claim rates subject to variation? (DAD8)

¹ GOV.UK/PIP/pip

- What can we expect of supply and demand for Disability Benefits (including assessments) following COVID-19 pandemic? (DAD5)

Research methodology

The research methodology was depth telephone interviews. Firstly, we sent out advance letters, explaining the aims of the research, what we expected from participants, and stressing the voluntary nature of the research (see Appendix 1). Individuals were invited to arrange an interview or opt-out of the research by emailing the research inbox. Once the opt-out period had passed, individuals were telephoned by interviewer-notetaker fieldwork pairs to conduct the interview or arrange a suitable time. Interviews lasted approx. 30-40 minutes and were underpinned by a topic guide (see appendix).

The topic guide was structured into four sections. Section 1 'Health conditions' enquired into health conditions related to the individual's PIP application. Section 2 'PIP knowledge and eligibility' explored the individual's knowledge of PIP and asked how they learned about it. Section 3 'Decision to apply for PIP' explored the individual's decision to apply for PIP and probed about the circumstances that led up to their claim. Section 4 'Expectations' looked at the kind of support the individual was hoping for and the changes they were hoping PIP would produce in their life.

Life history: When interviewing we sought to recognise claimants' lives as a whole including the past and present. However, unlike biographical interviews, we did not attempt to elicit whole life stories. Rather, we sought those stories which more narrowly address the research focus and questions, identifying an individual's personal narrative as important in their decision-making.

Sampling

Sample data (400 files) were taken from PIP Administrative Data set. DWP were interested in recent claims, therefore we focused on "ePIP2" forms² registered between 1 September and 31 October 2021. Selection was performed by Service Delivery. Any case declaring an appointee was excluded. It was expected that the claimants using the electronic claim route will have some degree of IT literacy/capability, and so likely not to include the most vulnerable of PIP Claimants.

Participant demographics

From the same sample of 400, interviews were conducted with 21 claimants. These were:

² Alternatively, applications can be started via post, although subject to relative delay.

- Aged 25 – 65.
- 6 were male and 15 were female.
- 8 were employed and 12 were unemployed.
- 8 were living with their partner.
- 11 were living with at least one child.

Analyses (method of)

Thematic analysis: For the qualitative data, an inductive and semantic approach was adopted (only analysing what was said). Initial coding involved labelling interview notes phrase by phrase to conceptualize, compare, and categorize data. This was followed by an iterative process to further define and identify connections between categories in the data.

Grounded theory was used to explore the ways individuals account for and theorise about their actions, and to unveil the relevant factors of the social context. Analysis of each discussion was entered into an emerging analysis framework, allowing sessions to be compared/judgements made about the commonality of experiences. By identifying patterns we were able to establish core themes at a 'whole sample' level.

Limitations

- **Theory:** We acknowledge the limitation of objectivist grounded theory in assuming the construction of data and the relationship of the viewer to the viewed as unproblematic. In reality, our position of interviewer in relation to the interviewee is likely one of power imbalance (DWP versus DWP claimant).
- **Bias:** The research was conducted by DWP researchers, therefore it was not possible to ensure that participants (a) took part and (b) provided honest feedback. We attempted to mitigate this by explaining that we do not have access to their claim.
- **Generalisability:** The low response rate means that there will be an unquantifiable bias in the data. This research is not intended to directly represent or enable generalisability to the general population of PIP claimants; rather, it is designed to encapsulate a relevant range of experiences, characteristics, processes, and examples. Further, our focus on ePIP2 forms means that we may have excluded some of our most vulnerable claimants including those who are digitally excluded.
- **Analysis:** Whilst the interviews were conducted by a team of researchers, analysis was performed by a sole researcher.
- We cannot compare the findings to previous months or years.

Ethical issues

This project involves primary research with PIP claimants – who are inherently vulnerable. The two overarching ethical considerations are:

- How to make the research as inclusive as possible, given the imperative of delivering timely findings
- How to ensure the research does not cause any harm to participants.

The following processes and considerations were put in place:

- **Informed consent.** We sent out advance letters explaining the aims of the research, what we expect from participants, and stressing that it is voluntary, entirely unrelated to their claim, and they can withdraw at any time (Appendix 1). The letters encouraged participants to discuss the research in advance with a friend or carer. The letters gave participants the opportunity to opt out of the research. We also confirmed consent at the start of the interview.
- We did not know participants' health conditions in advance, however we excluded appointees and claimants with a terminal illness.
- Participants could be accompanied by a friend/ carer. Interviews could be re-scheduled so that the friend/carer is present.
- Participants were able to stop the interview at any time, either for a break or to withdraw completely, for any reason. Depending on the extent of participant distress, they were reminded they could take as long as they need, reiterating that they are welcome to stop the interview, that they are welcome to take a break, or that the team could rearrange at a later time to continue if they wish (i.e. giving the interviewee some control over the interview).
- As mentioned, there was a risk that participants may conflate the research with their claim process/outcome and feel compelled to participate. Therefore, it was particularly important that the agreement to participate information was not only as plain and clear as possible to ensure understanding, but also made it very clear to participants the basis on which the research is being conducted and the fact that this is independent of their claim.
- Special category information was a central part of the research questions. 'What conditions do they declare?' and 'What triggers a claim, for example changes in claimants' health or personal circumstances?' It was important that the team carefully considered handling of this data and how to minimise inferred disclosure; however, limited distribution of findings helps mitigate this risk.

- All responses were confidential. Interview notes were stored separately from the sample file, so that it was not possible to identify individuals from the notes. Personal identifiable information raised by the participant during the interview was not recorded in the notes.
- Each interview was conducted by a trained interviewer and a notetaker. All were DWP social researchers. DWP researchers who were inexperienced were allocated to the notetaker role.
- Given the sensitive nature of the research topic and the vulnerable condition of participants, interviewers were given a clear topic guide (Appendix 2) and safeguarding protocol (Appendix 3). Further, weekly interviewer debriefing sessions were held by project manager and support signposted where appropriate.
- As we were interviewing claimants who were in the process of having their claim assessed, there was a risk that asking them to take part in the research would cause additional stress. We sought to manage this by assuring participants that we do not have access to their claim, and by stressing that the research is voluntary.
- We provided training to all interviewers and notetakers, which highlighted the ethical concerns laid out here. This included detailed discussion of the department's 6 point.
- Due to the need for timely findings, we could not offer reasonable adjustments on this occasion.

Findings

In this section of the report, the findings from the interviews are synthesized by theme, so that a particular topic is dealt with in its entirety, drawing on all of the relevant evidence, in a single section.

1. Health conditions

First, we enquired into health conditions related to the individual's PIP application. We asked: **“Could you tell me about the long-term health condition or disability that your PIP application is related to?”**, **“How are you affected by this condition/disability in your day to day life?”**

Summary

Individuals cite a broad array of both physical and mental health conditions in relation to their PIP application. These conditions involve varying degrees of uncertainty and social isolation. Whilst there are a large number of professionals involved in monitoring their care, individuals heavily rely upon informal sources for day to day care, for instance, friends, relatives and spouses. People were reluctant to venture outside of the home for fear of judgement about their condition.

Table 1 Health conditions

Core concepts	Key categories	Representative quotes
Physical health	Pain	"A couple of years ago I was diagnosed, so I was put on really strong medication. It made me really tired and lethargic all the time. They've recently stopped that because it was affecting my blood. At the moment I've started a new medication and that's also made me tired. It's made it difficult to get up in the morning. I'm also trying to
	'Back problems'	
	IBS	
	Inflamed nerves	
	Tendonitis	
	Bursitis	
	Endometriosis	
	Seizures	

	Hysterectomy	lose weight as that's a factor." "Imagine having flu. It's like having flu all your life basically. On bad flares I'm just in bed and I can't move."
	Asthma	
	Overweight	
	Slipped hip	
	Wheelchair	
	Surgery	
	Osteoarthritis	
	Rheumatoid arthritis	
	Amputation	
	Exhaustion	
	Bed ridden	
	Autoimmune	
	Immobile disease	
	Inflammatory Bowel Disease (IBD)	
	Incontinence	
	Heart condition	
Mental health	PTSD	"Lockdown was the biggest factor, being far from family, had a massive emotional toil." "Some people can power through and others can't. There's a bit of a mental health crisis at the moment."
	Anxiety	
	Depression	
	Panic attacks	
	Bipolar	
	Personality disorder	
	Nervous Breakdown	

	Therapy	
	Stressed	
	Triggers	
	Insomnia	
	Social anxiety	
	Struggle	
Professional involvement	Diagnosis	“Nurse asked why aren’t you claiming for it and she was like, ‘that’s what PIP does, it covers you if you’ve got to take some time off work if you’re struggling’.”
	Medication	
	Psychologist	
	Appointments	
	Physiotherapist	
	Midwife	
	Orthopaedic surgeon	
	Rehab	
	Neurologist	
	Mental health support worker	
	Social services	
	Doctor	
	Scans	
	Psychiatrist	
	Therapist	
Variability	‘Flare up’	“I have days where I can manage most things and I
	Sporadic	

	'On and off'	have days where I cannot walk and I cannot move." "My husband and children do a lot of things at home. It depends on the day. They have to peel things for me, they have to lift if I have a pot on the cooker, they bend down if my legs cannot."
	Chronic	
	Recent	
	Precarious	
	Deterioration	
Informal care	Partner	"If I'm having bad days I've got no chance. I had to ring my Mum and say can you get me off the toilet."
	Children	
	Parents	
	Pets	
	Ex-partner	"My girlfriend helps me. She visits 80% of the time. Helps to cook, clean etc. My family are also a stones throw away."
	Mother-in-law	
	Extended family	
	Friends	
Uncertainty	Medical enquiries	"The pain from the endometriosis has brought on a new type of seizure. These are paralysing for hours, and sometimes over 24 hours – it takes time for movement to come back. So I'm unable to work until they can find out what's going on."
	Work search	
	Accommodation	
	PIP award	
	Timing of flare ups	
	Deterioration	
Social isolation	House bound	"I couldn't physically leave the house and chest would tighten... panic
	Social judgement	

		attack and felt like everyone would stare”
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2. PIP knowledge and eligibility

Here we explored the individual’s knowledge of PIP and asked how they learned about it. We asked: **“How did you come to know about PIP?”**, **“Have you ever sought information about PIP?”**

Summary

Most individuals cited financial support as the driving purpose of PIP, with bills and basic survival mentioned prominently. A significant proportion spoke of transport needs that could be alleviated with PIP. There was a common misunderstanding of the role of employment status, with some individuals believing only unemployed people were eligible for PIP and others believing the reverse. Independence was a strong theme mentioned by individuals who felt stigma and shame associated with relying upon informal care.

Table 2 PIP knowledge and eligibility (a)

Core concept	Key categories	Representative quotes
Professional advice	Family Support Officer	“I heard about PIP from my doctor. This was about a year ago. They just said that mental health is being considered as part of it now.”
	Recently	
	Social worker	
	ESA interviewer	
	Employer	“I had to apply for Universal Credit, through that process the chap asked me if I’d applied for PIP. He said I would qualify suggested my carer did so.”
	Mental health charity	
	Job Centre Plus	
	Mental health support worker	
	Hospital consultant	

	Formal carer	
	Doctor	
Family & friends	Father in law	“My mother gets PIP, and obviously now I’m permanently disabled she said I should apply, for help with money situations. My mum has been on PIP back when it was DLA.”
	Grandmother	
	Friend	
	Mother	
	Ex-girlfriend	
	Wife	
	Husband	
Media	Nothing	“I’ve seen in the news recently about some other conditions being added and bits and bobs, but not a big deal of things, no.”
	The Sun (online)	
	Avoids media	
	Articles on phone	
	Negative news	
GOV.UK	Helpful	“I read what I could on the Government website and that was it really. I wanted to see if it would be beneficial for me. I wanted to see if the amount of money would be worth it or whether it was better off going to people that really need it.”
	Unclear timeframes	
	Eligibility	
	Too brief	

We asked: **“What do you think the purpose of PIP is?”**

Table 3 PIP knowledge and eligibility (b)

Core concept	Key categories	Representative quotes
Financial	More money	<p>"I couldn't answer that. I have no idea. It gives you a bit more money. I like to do colouring [mindful colouring] and things like that, helps me to pay for the materials. It gives you a little bit more financial security for yourself. On UC, you don't get an awful lot."</p> <p>"PIP's all about the extras [...] it is so expensive to be disabled"</p>
	Reduces stress	
	Disability expensive	
For the employed	Support to maintain at work	<p>"I didn't realise working people could claim anything like that."</p>
	Support to reduce hours	
Help the unemployed	Incapacity	<p>"The purpose of PIP is to help people who can't go to work or who can work who are severely impacted in certain areas, as a financial help or financial aid, in maybe mobility or other aspects of disability. That would be my best way of describing it."</p>
	Unable to work	
	Limited capacity	
	Sacked	
	Support into work	
Transport/mobility	Taxis	<p>"Generally the purpose is to help you. More than anything what I want from it is a free bus pass – only way I can get a free bus pass is if I get PIP, as I can't walk very far."</p>
	Bus pass	
	Car	
	Petrol	

Bills	Rent	“If I am unable to work it covers some kind of bills and is helpful in taking that pressure off”
	Utilities	
	Reduce stress	
Survive	Live	“In a sense, DWP are helping people like me...survive...”
	Struggling	
	Easier life	
Independence	At my age	“That’s why I applied- to try and get some of independence back. I’m 31 my parents shouldn’t have to bail me out”
	Shame	
	Guilt	
	Rely upon	
	Grow up	“Feels like should have grown up, can’t always rely on Mum.”
	Burden	
	Remain independent	
	Gain independence	
	Stigma	

3. Decision to apply for PIP

Here we explored the individual’s decision to apply for PIP and probed about the circumstances that led up to their claim. We asked: **“Have you considered applying for PIP previously?”**, **“Has anything changed in your life, that made you decide to apply now?”**

Summary

Most of the interviewed individuals had not considered applying for PIP previously, either because of no previous need or because they were previously unaware of the benefit, although they may have been eligible. Main triggers for their current PIP application involved health deterioration, financial hardship and employment concerns. Furlough was not a strong factor in their decision to apply for PIP, in part because it was inapplicable to most individuals interviewed. Removal of the Universal Credit (UC) uplift was experienced by some individuals as a consideration in their PIP application but other individuals were unaware of its existence.

Table 4 Decision to apply (a)

Core concept	Key categories	Representative quotes
Previous consideration	Doubted eligibility	“PIP was mentioned 7 years ago, didn’t apply at the time didn’t think would be eligible.”
	Off putting	
	Lengthy process	
	Unaware of PIP	
	No previous need	
	No previous ‘drive’	
Became unemployed	Sacked/lost job	“It’s only in the past couple of years that this condition has come on and I’ve got severely worse, to the point where I’ve lost my job.”
	Gave up	
	COVID-19	
	Health	
Health deterioration	Mental	“It’s only in the past couple of years that this condition has come on and I’ve got severely worse, to the point where I’ve lost my job and unfortunately can’t work.”
	Physical	
	NHS waiting list	
	Surgery	

	Rapid	
	Worsened	
	Weight gain	
	'Flare up'	
	Recent incident	
	Change	
Financial	Debt	<p>"Erm... I think it's because I'm having to seek more private treatments and stuff so yeah, it's a struggle to financially support that and the NHS wait list is so long so I'm having to seek alternative treatments for my condition."</p>
	Sick pay	
	UC eligibility	
	Low salary	
Furlough	Irrelevant	<p>"I was on furlough for 9 weeks. We had gone quiet and also my knees were playing me about.</p> <p>Furlough scheme ending, no... I wouldn't say it played a part at all. Furlough was irrelevant really."</p>
	No impact	
	Ineligible [for furlough?]	
	Key workers	
UC uplift	UC insufficient	<p>"It has gone £86 a month, so we've lost basically one shop a month, which was money to go to uniforms and shoes. That £86 is an awful lot of money.</p> <p>Will PIP help? – I am hoping so."</p>
	No impact	
	Coping ok	
	No changes	

Learned about PIP	Professional advice	“I didn’t realise working people could claim anything like that.”
	Family Support Worker	
	Doctor	
	Employer	

We asked: **“What are your main reasons for applying for PIP?”**

Summary

Those interviewed cited financial, employment concerns, transport and legitimacy as their main reasons for applying for PIP. Regarding the latter, individuals were keen to receive validation of their disabled status and saw PIP as a means to achieve this. Employment concerns arose in connection to deteriorating health and were encapsulated by a fear of becoming unemployed.

Table 5 Decision to apply (b)

Core concept	Key categories	Representative quotes
Financial	Extra costs	“Financial help, and maybe help at looking at the mobility scheme if I qualify. That’s my main reasons.”
	Afford to live	
	Skint	
	Extra money	
	Income	
Employment concerns	Uncertainty	“I’m terrified I’m going to lose my job.”
	Threat	
	Protection	
	Disciplinary	
	Warnings	

	Worry	
Legitimacy	Title/label	“More for the protection and also having, as bad as it sounds, a title, and being able to turn around and say I am disabled. I feel like a bit of a liar when I say I’ve got this hip condition.”
	Liar	
	Fraud	
	Stigma	
	Protection	
	Cover	
	Invisible disability	
	‘Make it all up’	
	‘Putting it on’	
Transport	Blue badge	“Main reason is to get a bus pass, but that is what I really need. It would make my life really easier without having to go through all this PIP thing. My sister is epileptic and she gets a bus pass automatically. She walks fine and you are thinking, ‘That is not very fair. I need a bus pass too.’”
	Public transport	
	Expensive	
	Petrol	
	Someone to drive	
	Maintain car	
	Mobility	
	Unfair	

We asked: **“Did you have any concerns about applying?”**

Summary

Individuals were concerned about the PIP application process, specifically form filling, the health assessment, and what they perceived as a lengthy waiting period. Confusion surrounding eligibility was another prominent concern. One individual who had suffered an amputation, cited failure to meet PIP eligibility criteria but was nonetheless awarded PIP. Related to eligibility, a perception of 'deservedness' was fuelled by social comparison with others.

Table 6 Decision to apply (c)

Core concept	Key categories	Representative quotes
Deserve	A fraud	"I've often questioned whether my situation... obviously there's always other people worse than me... I didn't know whether I'd be able to apply for it. So I sent off to see if I was eligible."
	Social comparison	
	Morally	
Wait time	Lengthy	"I found quite repetitive, which sometimes caused a bit of confusion. Felt like they might be doing it to catch people out. Applied 2 months ago, still waiting to hear – heard nothing from them, assume there's a massive back log."
	Decision	
	Uncommunicative	
	Frustrated	
	Worry	
	'Waiting game'	
Form filling	Daunting	"We shouldn't be punishing people because they are unwell or disabled."
	Concentration	
	Difficult	
	Procrastinate	

	Confidence	
	Help with	
	Punishment	
Eligibility	Afraid	<p>"I felt bad and thought was I going to be in trouble for applying. And there was a question on whether you were turned down before. And I thought should I or not or should I leave it until I couldn't do anything? In my head my friend said it was to help you stay independent. Then I'm thinking should I apply now or should I wait till I can't move? I'm still a bit afraid."</p> <p>"My biggest concern I had was that when I applied for physio because I can put my index finger to my thumb I'm not technically disabled according to the DWP literature. Does that mean I'm not eligible, what's the crack?"</p>
	'Get in trouble'	
	Uncertain	
	Doubt	
	Qualify	
	Worry	
Health assessment	Difficult	<p>"I know they've said you go through the application and do health assessment and that's really daunting. And what if they're really funny to me?"</p>
	Criteria	
	Daunting	
	Suspicion	
	Assessors	

4. Expectations

Here we looked at the kind of support the individual was hoping for and the changes they were hoping PIP would produce in their life. We asked: **“If you’re awarded PIP, how do you intend to use it?”**

Summary

The interviewees cited daily living, utilities and household costs as primary targets for their potential PIP award. Transport featured prominently in the discourse, particularly the funding of taxis. Some individuals mentioned the planned purchase of aids and adaptations to assist with their health condition including alternative therapy and private treatment. Savings were viewed as a means to mitigate against the uncertainty of their future health prospects.

Table7 Expectations

Core concept	Key categories	Representative quotes
Household	Furniture	<p>“On UC, there is not an awful lot left at the end of the month... I need a new bed at the moment. Hopefully with the extra bit of money, I will be able to buy a new bed and get new clothes.”</p>
	‘Around the house’	
	Carpets fixed	
	Necessities	
Assistance with health condition	Alternative therapies	<p>“I think it would make me more independent. It would allow me to get a bath or a shower without my husband having to help me. I cannot just nip in the shower just now, I have to wait for my husband, which at 44 is ridiculous.”</p>
	Physical aids	
	Uncertainty	
	Formal care	
	Independence	
	Modified utensils	
	Home adaptations	

		<p>"I'm personally hoping this [current health problem] won't become a long term issue. I am hoping PIP can help support my recovery."</p>
Transport	Taxi	<p>"Where I live, from my house in the town centre, it used to take 10 minutes, it now takes 40 minutes. There isn't money for buses all the time. I know it is not a huge amount, but it builds up."</p>
	Mobility	
	Car	
Savings	Save up	<p>"It would give me some extra money. Might help with different outgoings. I need to build up some money to be able to move out of my parents' house."</p>
	Independence	
	Uncertainty	
	'If needed'	
	Health	
Bills	Utilities	<p>"Universal Credit doesn't even cover the basics. I need to borrow money to stay where I am."</p>
	Rent	
	Gas	
	Electric	
	Prepaid	
	Council tax	
Daily living	Clothes	<p>"All my utilities go out like a couple of days after my Universal Credit goes in, so I know what is left. Back in 2017, we were going to food banks, so we have had</p>
	Food	
	Children	
	Survival	

	Leisure	to make sure that I can stretch money and everything gets paid first.”
	Struggle	

5. Participants’ final comments

In closing, we asked: **“Finally, if you had to say one thing to someone in your position who was thinking about applying for PIP, what would it be?”**

Summary

All individuals interviewed would recommend applying for PIP. In their advice, individuals echoed their concerns of deservedness by adopting a reassuring message and emphasising the minimal cost of applying. Nonetheless, in setting expectations, interviewees cited a lengthy application process.

Table 8 Final comments

Core concept	Key categories	Representative quotes
Nothing to lose	Try and see	“It’s worth a try”
	Confidence	“Erm... I’d say to apply for it because you’ve got nothing to lose and it’s a bonus if they decide you are entitled, so that’s good.”
	Appeal	
	A bonus	
	Worth it	“You never know really and if it can make your life easier and give you that support then it’s worth taking that chance to do”. “Apply for PIP. There is no harm in trying. And if you can’t do the form yourself, get a benefits adviser to help you.”
	No harm	

Deserve	Social comparison	<p>“Don’t feel like you don’t deserve it.”</p> <p>“Everybody is entitled to help; don’t feel like you don’t need it just because you’re not as disabled as the person next to you... apply.”</p> <p>“We’ve all got different things wrong with us and no one can tell us that we’re right or wrong for being the way we are.”</p>
	Entitlement	
	No stigma	
	Reassuring	
Lengthy wait	Low expectations	<p>“Don’t expect to get it any time soon.”</p> <p>“Yeah, go for it, you’re not going to lose anything, but expect a long wait (laughs), don’t expect a quick turnaround.”</p> <p>“You just have to grin and bear it. There is a bit of a time lag and a bit of uncertainty.”</p>
	Uncertainty	
	Slow	
	Lag	
	Patience	

Recommendations

1. Continue and expand work by Disability Services Advocacy Team to raise awareness of PIP, with public/third sector services and the general public. This could include:
 - a. Wider publication of distinct travel benefits for disabled people (i.e. separate to PIP and Motability).
 - b. Promote the Access to Work Passports' to facilitate continued employment.
 - c. Promoting the GOV.UK 'Eligibility Checker' for individuals to use prior to applying for PIP.

Suggested future research

- Qualitative investigation of third-party stakeholders (NHS personnel, disability charities, social services) to explore their awareness and perceptions of PIP, with a view to determining what information is being given to service users. This would enable us to explore and clarify channels of communication between DWP, customer, and professional stakeholders.

Conclusions

Regarding *which* conditions PIP claimants declare, most people cite multiple health conditions, often a combination of mental and physical conditions. Regarding *where* claimants heard about PIP, people were recently made aware of PIP through contact with formal services (including JCP) friends and family. Few participants mentioned media or social media. Regarding *what* circumstances trigger a claim, health deterioration, financial hardship and employment concerns were the main triggers for PIP application. Finally, regarding *how* claimants think PIP will be helpful, individuals cite daily living, utilities and household costs as primary targets for their potential PIP award.

Key messages

- Claimants are continuing to present with a wide range of conditions.
- Poor mental health was prevalent, and most people relied on multiple carers.
- People were recently made aware of PIP through their contact with formal services including JCP.
- Main triggers for PIP application were health deterioration, financial hardship and employment concerns. Individuals may have been previously eligible, however their claim was triggered by a recent decay in circumstances.

- Individuals were keen to receive validation of their disabled status and saw PIP as a means to achieve this.
- Most individuals cited financial support as the driving 'purpose' of PIP.
- People cited daily living, utilities, household costs and transport as their intended uses for PIP.
- The process of form filling, health assessment, and corresponding wait times provoked anxiety.

Key words

Personal Independence Payment, Disability, Job Centre Plus, Quantitative, Qualitative, Trends, Interviews, Health, Universal Credit

Appendices

Appendix 1: Advance letter to claimants

Please share your experience with us

Research into Personal Independence Payment (PIP)

Dear Customer,

We are conducting some research with a small sample of people who have started a claim for Personal Independence Payment (PIP) in the last three months, to understand your experience of applying for PIP.

If you choose to take part it will involve a 30 minute telephone interview with one of our researchers, between 22nd November and 3rd December. You do not need to prepare anything in advance for this, although you may like to arrange a friend or carer to be present.

You don't have to take part if you don't want to, if you wish to opt out please email us, if possible before 22nd November.

Please note that if we call you, our call will show as "number withheld". The rest of this letter explains how we will protect your data. We'll also cover this at the start of the interview, and we'll ask you to confirm your agreement to participate then too. You can ask us any questions about the research or decide not to take part. If we call at an inconvenient time, you'll be able to re-arrange the interview to another time.

If you do not wish to take part in the research, please email us at: XXX.XXX@dwp.gov.uk

Please note that we cannot discuss your PIP claim with you. If you have any questions about your claim, please call the DWP PIP enquiry line on:

Telephone: 0800 121 4433

Textphone: 0800 121 4493

Relay UK (if you cannot hear or speak on the phone):
18001 then 0800 121 4433

If you call us, please have the answers to your security questions ready.

Thank you for your help.

Yours sincerely,

Department for Work and Pensions In-House Research
Unit

Personal Independence Payment (PIP) Research Information Sheet

The research will help us to find out about people's experiences of claiming Personal Independence Payment (PIP), including how you found out about PIP and how and why you decided to apply.

The research is being undertaken by the Department for Work and Pensions' In-House Research Unit. We will share the findings with senior officials, but we do not intend to publish them. All findings will be presented anonymously. This means that it won't be possible to identify you or anyone you mention.

What does participation involve?

Taking part will involve a 30 minute telephone interview. There are no right or wrong answers, we are just interested in hearing about your own experiences and views. You do not have to take part and your decision to do so is completely voluntary. Whether you

take part or not will not affect your PIP claim, or any of your dealings with the DWP, Job-centre Plus, or any other government agencies. The benefits you may be claiming will not be affected in any way.

The researcher will ask whether they can take notes of the conversation they have with you. We will store the notes safely and will not share them with anyone else. We may want to include something you say during your interview in our report, but we will not mention your name or anything that could identify you. If you do not want us to include anything you say, then that's ok too.

What happens to information collected about me?

We will remove all the details which could be used to identify you as soon as we practically can. This is usually within three months.

Responses from all individuals taking part in the research will be reported anonymously, meaning you will not be identifiable in any way. If you change your mind about participating in this research, please let us know as soon as you can by emailing xxx.xxx@dwp.gov.uk and where possible, we will not process this data.

How We Protect Your Data

This information sheet tells you more about how your data will be used and stored.

Data protection legislation and personal data

Data protection legislation determines how, when and why any organisation can process personal data. 'Personal data' means any information which can identify someone. 'Processing' means any actions performed on personal data, including collection, storage, alteration or deletion. These laws exist to ensure that your data are managed safely and used responsibly. They also provide you with certain rights in respect of your data and create a responsibility on the Department for Work and Pensions to provide you with certain information.

The legal basis for processing personal data

The legal basis under which DWP processes personal data and 'special category data', such as information about your health and well-being, racial or ethnic origin, is public task. DWP can rely on this lawful basis when processing personal data to fulfil DWP's public authority duty and for research that is in the public interest.

Your personal data collected in this research project will only be used for research. DWP will treat the data they hold with respect, keeping it secure and confidential.

The period for which personal data will be stored

Data protection law requires that personal data are kept for no longer than is necessary. We only continue to hold personal data when it is still being used to carry out research in the public interest. In addition, we will remove all the details which could be used to identify you as soon as we practically can – by 31 March 2022 at the latest.

Notes will be kept by DWP for up to three months from the research ending and will then be destroyed by 31 March 2022.

Your rights

You have rights under data protection law to make the following requests about the personal data held about you, including:

- to request access to this data
- to amend any incorrect or inaccurate information
- to restrict or object to your data being processed
- to destroy this data
- to move, copy or transfer your data.

If you wish to discuss these rights, have any concerns, or want to make any requests about your personal data please contact the research team at: xxx.xxx@dwp.gov.uk

Further information on the rights available to you is also available from the Information Commissioner's Office - the independent body responsible for regulating data protection within the UK. They can also deal with any complaints you may have regarding our use of your data. You can contact the Information Commissioner's Office at:

- Telephone: 0303 123 1113
- Email: icocasework@ico.org.uk
- Post: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF
-

Further information

For more information on how and why DWP use your personal information and your rights and responsibilities, DWP's personal information charter is available to view at:

[Personal information charter - Department for Work and Pensions - GOV.UK](https://www.gov.uk/government/publications/personal-information-charter-department-for-work-and-pensions)
(www.gov.uk)

Appendix 2: Topic guide

INTERVIEWER NOTE:

The questions are here as a guide to ensure all the desired information is gathered, but they may not naturally come up in this order. Feel free to adjust the order and wording as feels natural to you, but please aim to include all the questions where relevant.

You may be interviewing participants on their own, or participants accompanied by a friend or carer. Phrasing may need to be tweaked according to the situation.

Points marked 'LISTEN FOR' are not to be prompted on.

I'd now like to get an idea of the long-term health condition or disability that your PIP application is related to if you feel comfortable talking about this. Could you tell me a bit about this?

Reassurance: this is so that we can understand your situation better. Please be assured that your response is confidential.

- What is your health condition/disability?
- Approximately when did this start?
- How do you manage your health condition/disability at the moment?
- Do you receive help from another person in managing this?

IF PARTICIPANT MENTIONS MULTIPLE CONDITIONS:

Is your application for PIP in relation to all of these?

- If not, why not?

How are you affected by this condition/disability in your day to day life?

LISTEN FOR:

- Practically (mobility, employment etc.)
- Financially
- Emotionally
- Socially

What do you think the purpose of PIP is?

- What does it mean for you?

<ul style="list-style-type: none"> • What do you think the Department for Work and Pensions is trying to do by providing PIP?
<p>How did you come to know about PIP?</p> <ul style="list-style-type: none"> • Who/where from? • When was this? • What did they/it tell you about PIP? • Have you seen anything in the media/TV/social media about PIP? • What and when?
<p>Have you ever sought information about PIP?</p> <ul style="list-style-type: none"> • What information were you looking for? • Who/where from? • What encouraged you to find out more information about PIP? • Did you find the information you were looking for? Would anything else have been helpful? •
<p>Have you considered applying for PIP previously?</p> <p>IF YES, why did you decide not to apply for PIP before now?</p> <ul style="list-style-type: none"> • LISTEN FOR: <ul style="list-style-type: none"> ○ Hadn't thought about it ○ Had been aware but thought they weren't eligible (explore why) ○ Didn't want to apply (explore why)
<p>Has anything changed in your life, that made you decide to apply now?</p> <ul style="list-style-type: none"> • Can you talk me through this? • How did this affect your decision to apply? <p>ASK ALL TO WHAT EXTENT THE FOLLOWING HAVE CHANGED, AND WHETHER THEY HAVE HAD AN INFLUENCE:</p> <ul style="list-style-type: none"> • Change in health • Any recent changes in your household income? <ul style="list-style-type: none"> ○ Removal of the UC £20 uplift <ul style="list-style-type: none"> ▪ Do you receive Universal Credit? ▪ Has there been changes to the amount of UC you receive? ▪ To what extent have these changes affected your decision to apply for PIP? ○ Ending of the furlough scheme <ul style="list-style-type: none"> ▪ Were you previously being supported by the government's furlough scheme? ▪ If so, to what extent, if at all, did the furlough scheme ending affect your decision to apply for PIP? • Change in personal circumstances
<p>What are your main reasons for applying for PIP?</p> <ul style="list-style-type: none"> • LISTEN FOR: <ul style="list-style-type: none"> ○ Help with extra costs (which ones?) ○ Unable to work

- Aware of other people with similar conditions receiving PIP
- Encouraged to by a friend/relative/carer/doctor/charity or support group

FOR EACH REASON MENTIONED EXPLORE:

- How important was this compared to the other reasons you mentioned?

Did you have any concerns about applying?

- What were these concerns?
- How concerned were you about these?
- What would have helped to put you at ease about these?

If you're awarded PIP, how do you intend to use it?

- What kind of support do you hope/expect to receive?
- What changes are you hoping for? Why?
- What, if any difference, would the award make for you? For your household?

(Prompts if not forthcoming: to help start work, to work more hours in the week, to find more suitable work, to study, to socialise, to carry out daily tasks at home, to help get around, for daily living e.g. paying rent, paying utility bills, buying food).

IF RESPONDENT MENTIONS MOBILITY/TO HELP GET AROUND, EXPLORE:

- What type of mobility support? E.g. bus pass, to pay friends/family for transport, to maintain a car etc.

Finally, if you had to say one thing to someone in your position who was thinking about applying for PIP, what would it be?

We've come to the end of my questions now, but before we finish, is there anything else about you, or your experience of applying for PIP that you'd like to share?

I really appreciate your time today, thank you for being so open with me. To confirm, this research has no bearing on your claim, and we do not have access to your claim file. Before we close the interview, do you have any questions for me?

Appendix 3: Links to other evidence

Relevant evidence:

Personal Independence Payment: claimant experiences of the claim process

(Ipsos, 2018): The DWP commissioned Ipsos MORI to undertake three waves of quantitative and qualitative research with Personal Independence Payment (PIP) claimants, designed to give an in-depth understanding of claimants' experiences of the various stages of the PIP process. This mixed method research explores claimants' experiences of the whole Personal Independence Payment (PIP) claim process, including disputes. At each wave a survey and qualitative interviews were carried out to explore different stages of the process. The interview-based research included exploring motivations for claiming and the initial call to the claim line. Key themes identified were health, migration from DLA, and feeling entitled.

The Work Aspirations and Support Needs of Claimants in the ESA Support Group

(DWP, 2017/18): Fifty in-depth interviews and six focus groups to develop a deep understanding of the lives of vulnerable individuals in the ESA support group. Interviews encompassed a fully-representative range of severe health conditions, coverage by geography and age, and often involving advocates/carers. Interviews explored support needs and the extent to which these were met, and how PIP and DLA were used alongside ESA to meet specific needs. Adaptations were made to make depths/groups accessible. The study covered some very sensitive ground around individuals' health conditions and their overall wellbeing and we had to have in place processes for escalating concerns over respondents both internally and to the DWP. Peer interviewing was used to involve disabled people in co-creating the findings.

Impact of PIP on People Affected by Cancer (Macmillan, 2014): Macmillan commissioned IFF Research to conduct a mixed-methodology study which explored the impact of Personal Independence Payment on the financial status, standard of living and wellbeing of people affected by cancer. This study consisted in-depth interviews and a survey, both among individuals affected by cancer who had started to make a claim for Personal Independence Payment. The analytical report was used by Macmillan to determine how they can best provide support for the PIP claim process.

Appendix 4: Relevant policy considerations

- COVID-19.
- March 2021 amendments to Regulations: medical assessments to be conducted primarily by telephone.
- Health and Disability Green Paper (consultation 12 July 2021 - 11 October 2021).
- The National Disability Strategy and the Health is Everyone's Business consultation.
- Changes to PIP law from 6 April 2016, then again in 9 March 2017 (strengthening entitlement for mental health conditions).

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Department for Work and Pensions 2017 Safety and supervision: changes to PIP law from 9 March 2017. URL=<https://www.gov.uk/government/publications/personal-independence-payment-changes/safety-and-supervision-changes-to-pip-law-from-9-march-2017>

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