



Department
for Work &
Pensions



Personal Independence Payment Claimant Research – Final Report Summary

Key findings from the three waves of qualitative and quantitative research exploring claimants' experiences of the PIP claim process

Joanna Barry, Margaret Blake, Lauren Bridges,
David Candy, Emma Carragher, Kate Duxbury,
Harriet Fowler, Claire Lambert, Leila Morris

September 2018

Summary

Background

Personal Independence Payment (PIP) is a new benefit which contributes towards the extra costs of long-term ill-health or a disability for people aged 16 to 64 who need help with mobility or daily living costs. PIP is replacing Disability Living Allowance (DLA) but maintains the key principles as a non-means-tested, tax free cash benefit available to people in and out of work. It has been rolled out since 2013 initially for people making new claims, then for DLA claimants whose award ended (reassessment) and then for those who had an indefinite DLA award (full PIP roll-out). In order to claim PIP, claimants first make a call to the PIP claim line and then complete a paper form about how their disability affects them. They may then be invited to a face-to-face assessment consultation or may be assessed on paper before receiving the PIP decision letter informing them of their award. Claimants may be awarded one or both of two elements (mobility and daily living) and may be awarded one of two levels for each element (standard or enhanced). Alternatively they may receive no award. If claimants think the outcome of the assessment is incorrect they can request a mandatory reconsideration (MR), where the DWP re-examine the case. If they think the outcome is still incorrect after the MR they may appeal the decision at a tribunal.

Between the introduction of PIP in April 2013 and April 2018, over 3.4 million claims for PIP had been cleared, resulting in 1.8 million claims in payment. Forty-five per cent of new claims and 72 per cent of reassessment decisions had been awarded PIP, with over a quarter of normal rules claims receiving the highest level of award. Nearly all special rules (terminally ill) claimants were awarded PIP.

By the end of April 2018, there had been 781,000 requests for a mandatory reconsideration (23 per cent of all cleared claims) resulting in 83 per cent of new claims and 77 per cent of reassessment decisions receiving no change to the award¹. As of March 2018, there had been 300,000 PIP appeals lodged (9 per cent of all cleared claims) of these 211,000 PIP appeals were cleared at hearing, resulting in 35 per cent of these cases being upheld and 65 per cent in favour of the appellant².

¹ Official statistics on Personal Independence Payment published by the DWP are available online: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/714950/pip-statistics-to-april-2018.pdf

² Official statistics on Tribunals published by the Ministry of Justice are available online: <https://www.gov.uk/government/statistics/tribunals-and-gender-recognitions-certificates-statistics-quarterly-january-to-march-2018>

Methods

Ipsos MORI carried out three waves of quantitative and qualitative research during 2016 and 2017 to explore PIP claimants' experiences of the whole PIP claims process, from the decision to apply for PIP to the outcome of the appeal (if applicable). At each wave, a survey and qualitative interviews were carried out to explore one stage of the process. At wave one, 1,106 survey interviews and 50 qualitative interviews focussed mainly on the initial phone call and completing the 'How your disability affects you' questionnaire³. At wave two, 1,203 survey interviews and 50 qualitative interviews explored claimant experiences of the assessment and decision stages. During wave three, 1,205 survey interviews and 50 qualitative interviews focused on the MR and appeals processes. Survey interviews were carried out by telephone and qualitative interviews in person and by telephone using quota samples. At waves two and three, some of the survey participants were newly sampled and some were claimants who had taken part in a previous wave.

In this summary, findings presented as percentages come from the surveys and those from the qualitative research are referred to as such.

Motivation for claiming PIP and prior knowledge

Claimants in the survey applied for PIP for a variety of reasons, including covering the extra costs related to their disability or illness (35 per cent) and sometimes to replace lost income and pay for the basic costs of living (18 per cent said they could no longer work, 13 per cent to supplement money from other benefits). Other reasons given related to previously being on DLA and being told to claim or feeling entitled to PIP (12 per cent and eight per cent respectively).

While most claimants (83 per cent) were clear about how to take the first step in claiming PIP (calling the claim line), the survey showed that before they called the claim line, claimants had limited understanding of the process of claiming PIP (46 per cent said they knew nothing) or about why someone might be awarded PIP (36 per cent said they knew nothing). The qualitative research also highlighted that there was limited understanding of PIP as a benefit, in terms of its different components and levels of award.

³ The 'How your disability affects you' questionnaire is the questionnaire that claimants are sent after their initial phone call. During the interviews we referred to this as an application form, so in question wording that term is used.

Making the PIP application

Call to the claim line

Most survey claimants reported that calling the claim line was as easy as or easier than expected (52 per cent and 27 per cent respectively). However, 15 per cent found it more difficult than expected and the qualitative research showed that some claimants needed help from someone else to make the call, especially where they had a speech or hearing impairment, learning disabilities, anxiety or memory problems.

Completing the form

When it came to completing the 'How your disability affects you' questionnaire, over half of survey claimants sought help (59 per cent). The most common source of help was a friend or relative (33 per cent) followed by help from a charity or support group, a social care professional or from Citizens Advice. Help from DWP with completing the form was sought by two per cent of survey claimants. The qualitative research showed that not requesting help from DWP related to a lack of trust or previous poor experience of calling government departments, desire for face-to-face contact (including the need to find someone who could write down their responses and complete the form on their behalf), and a lack of awareness that DWP could help with this.

Most claimants agreed that the form allowed them to explain how their condition affects them (69 per cent) and 92 per cent were able to complete all sections of the form. Although most found completing the form as easy or easier than they expected (63 per cent), around one-third (34 per cent) found it more difficult than expected. The qualitative research showed that difficulties with completing the form related to the questions not being deemed suitable for conditions which fluctuated or which were not physical. In other cases, difficulties with completing the form resulted from the claimant's disability or literacy or English language skills making it difficult for them to read or understand the form and the guidance document sent with the form. The form was also felt by some to be repetitive and designed to 'catch out' claimants.

Evidence

Evidence is an important element in applying for PIP and completing the application form. About half of survey claimants sought help in relation to the information or evidence they should provide to support their claim, with the most common source (mentioned by 34 per cent) being a health or social care professional. Claimants varied in their understanding of evidence and their ability to provide it. Over three-quarters (78 per cent) were clear about how to submit evidence but fewer, just under two-thirds (65 per cent), were clear about how much evidence to provide. When deciding what to provide, nearly one-third (30 per cent) said they provided everything they could whether or not it was requested.

Most claimants did provide evidence with the PIP claim (84 per cent). However, claimants were not always able to provide all the evidence they wanted, with almost one-third (31 per cent) saying there was evidence they wanted to submit but did not. The main reasons for this were that they could not get hold of the evidence in time,

that they would be charged for it or that they thought DWP would contact their doctors if they needed more evidence. There was a widespread misconception (shown in the survey and the qualitative research) that DWP would gather medical evidence as part of the assessment process, partly because claimants were asked to provide contact details for their doctor on the 'How your disability affects you' questionnaire.

The PIP assessment process

Knowledge and expectations

In the wave one survey (before claimants had reached the assessment stage), less than half of claimants (46 per cent) said they expected a face-to-face assessment. Qualitative interviews (wave one and wave two) showed that claimants who had been on DLA were most likely to be surprised about being invited to an assessment.

When asked about whether information from DWP was clear about specific aspects of the process, 89 per cent agreed DWP made it clear they might need to have a face-to-face assessment. However, claimants were less likely to agree that DWP made it clear why they might need a face-to-face assessment (53 per cent) or what happens at a face-to-face assessment (57 per cent). The survey showed that about half (48 per cent) thought the assessment would involve assessing how their condition affects their day-to-day life, which is the aim of the assessment. The qualitative interviews also showed that claimants made misplaced assumptions about the assessment, particularly that it would involve a medical assessment by a doctor familiar with their condition.

Evidence

Over half of the survey claimants agreed DWP made it clear that they could take additional supporting evidence to their assessment (58 per cent). About half of claimants (48 per cent) did not take any supporting evidence to their assessment, and just under one-third (30 per cent) took reports from health professionals. The main reasons for bringing evidence at this stage were that they thought it would be helpful to bring everything (33 per cent) or that they did not have it in time to submit with their original application (29 per cent). Around a fifth of claimants (21 per cent) had evidence they wanted to bring to the assessment but did not have it at this stage. Other reasons for not bringing evidence to the assessment raised by claimants in the qualitative research included: having already provided everything they had, a belief that their verbal evidence and physical presence at the assessment would be enough, not being aware they could provide evidence at that stage, and an assumption that DWP would gather the evidence themselves anyway.

Attending the face-to-face assessment

Surveyed claimants were presented with several positive statements about attending the face-to-face assessment. While over 80 per cent agreed with each of the statements about the convenience of the appointment time, notice given and the accessibility of the venue for the face-to-face assessment, fewer (65 per cent) agreed that it was in a place they could get to easily.

In the survey, 60 per cent of claimants indicated they did not make any preparations for the assessment (for example, doing research on the internet, or speaking to a health professional, someone who had a face-to-face assessment before, social worker or support group). However, some of these claimants said they had gathered together evidence to take, despite saying they did not make any preparation. A general theme in the qualitative interviews was that claimants did not know what or how they should prepare.

Two-thirds (67 per cent) of claimants who attended a face-to-face assessment took someone with them and the most common person to take was a relative (70 per cent). The main reasons for taking someone with them was to support them with needs related to their disability (62 per cent) or for moral support (42 per cent). The qualitative research showed that having someone to support them at the assessment was invaluable, particularly in answering questions.

While most claimants understood what was being asked of them at their assessment (80 per cent) and that they had enough time to explain how their condition affects them (74 per cent), fewer agreed that the measurements and functional tests were relevant and appropriate (60 per cent). The qualitative research also highlighted that claimants felt the assessment repeated the same questions as the 'How your disability affects you' questionnaire so difficulties experienced with completing the form were also experienced at the face-to-face assessment. On the whole, claimants were happy with the role of the assessor. However, while 89 per cent agreed that assessor treated them with dignity and respect, a lower proportion (71 per cent) agreed the assessor understood their form and supporting evidence.

Among the quarter of claimants (26 per cent) who found the assessment more difficult than they expected, the main reasons were that the assessment was stressful (42 per cent) or the assessor was seen as unhelpful and/or unfriendly (24 per cent).

The PIP decision

Although 82 per cent of claimants understood what their award was, understanding was lower when it came to how DWP had reached their decision (66 per cent) and how the form, evidence and assessment had been taken into account in reaching the decision (68 per cent). The qualitative research showed that lack of understanding of the decision was related to skimming the letter, having a condition or disability which made reading, understanding or remembering information difficult, or disagreeing with the outcome of the application.

Claimants sought help with understanding the decision letter from friends or family (42 per cent), DWP (23 per cent), a social care professional (15 per cent) or a charity or support group (12 per cent). Among those who sought help from DWP, half (51 per cent) said they did not have a clearer understanding after contacting them.

Personal Independence Payment Claimant Research – Final Report Summary

Those who had been awarded PIP were asked how they would use the money. Just under half (48 per cent) said they would use it to cover basic living expenses, 40 per cent for costs of travel associated with disability, and 33 per cent for additional costs of daily living associated with their disability. Claimants also felt that the award would improve their quality of life (48 per cent), increase their independence (26 per cent) or allow them to live more independently (22 per cent).

Mandatory Reconsideration

After receiving their PIP decision letter, claimants who are unhappy with the outcome can request a mandatory reconsideration (MR), before going to appeal. Wave three focused on MR and appeal, so the sample was designed to include sufficient numbers of claimants who had been through these.

Knowledge and expectations

Broadly speaking, understanding of MR was lower than understanding of previous stages of the PIP claim process.

After receiving their decision letter about half of survey claimants (53 per cent) reported that the information about MR in the letter was clear and about one-quarter said they knew why a person might request MR (25 per cent) or how to request MR (23 per cent). Despite this, about half of claimants (51 per cent) did not proactively request any information from DWP about MR. Among the claimants who did seek information from DWP, the main sources of information were the decision letter (35 per cent of all claimants reported this) and the 'How your disability affects you' questionnaire (30 per cent).

The qualitative research revealed that claimants were sometimes reluctant to contact the DWP for advice or further information after receiving their decision letter, due to concerns that it would not be impartial.

There was also some confusion among participants in the qualitative research about the difference between MR and appeal, and why it was necessary to go through MR before being able to appeal.

The most common reasons for requesting a MR were that they did not get an award (40 per cent), that the assessor was seen to be unfair (22 per cent) or that DWP was not thought to have taken into account all the evidence provided (18 per cent). Claimants also requested a MR because they did not get an element or a level of award they expected.

Evidence

At MR, 65 per cent of claimants submitted additional supporting evidence, although of these, 35 per cent said they submitted evidence they had already provided. The main reasons for submitting additional evidence at MR, rather than earlier in the process, were that they did not have it in time for the original application (29 per cent) or that they did not know it would be useful when they submitted their application (27 per cent). Among the 29 per cent of claimants who did not submit any additional supporting evidence, the main reason was not knowing that they could.

Decision

Some claimants who requested MR also reported on their initial and post-MR award outcome in this survey. Half of these claimants reported they did not receive an award at either stage (52 per cent). One-quarter had an award which was not changed after MR (25 per cent) and 15 per cent received a new or improved award as a result of MR. These outcomes broadly reflect the outcomes of MR applicants as a whole.⁴

About half of claimants agreed that DWP made it clear how they had reached their decision (53 per cent) and one-quarter felt the decision was based on all the information available to DWP (25 per cent). This is lower than the 68 per cent who felt their form, assessment and evidence had been taken into account in reaching the original decision.

Appeals

Knowledge and expectations

Most (61 per cent) claimants agreed that information in the MR notice about appeals was clear but one-third (33 per cent) did not. Over three-quarters (77 per cent) did not seek any information or advice from DWP about the appeals process before making an appeal. Where information was sought from DWP, over half (58 per cent) said the information was clear, while 35 per cent said the information was not very or not at all clear.

The main reasons for appealing the MR decision among those who had no change to their award at MR were that they did not get an award (42 per cent), that DWP did not take their evidence into account (26 per cent) or that the assessor was unfair at the face-to-face assessment interview (25 per cent). The qualitative research also showed that some claimants doubted their application had been properly reconsidered at the MR stage, as the initial decision letter and MR notice were so similar. Of those who did not appeal their decision after having no change to their award at MR, the main reason was that the process would be too stressful (37 per cent), while one-fifth mentioned that they did not expect the award to change (20 per cent) or that they were too unwell (20 per cent). The reasons identified in the qualitative research included not being able to get help to navigate the appeals process, the view that the stress and anxiety that an appeal would cause would be detrimental to their condition, and not having the physical and emotional energy that the appeals process was deemed to require.

Attending the tribunal

The qualitative research highlighted the importance of support in enabling claimants to go to appeal. Indeed among the surveyed claimants who appealed and attended the tribunal in person, 86 per cent took someone with them. The main reasons cited

⁴ Official statistics on Personal Independence Payment published by the DWP are available online: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/714950/pip-statistics-to-april-2018.pdf

in the survey for taking someone to the tribunal were to support them with needs related to their disability (68 per cent), for moral support or company (38 per cent), to help with information or answer questions (20 per cent) or to speak on behalf of the claimant (16 per cent). The qualitative research also showed the importance of emotional support at this stage.

Among those who attended the tribunal in person, the majority agreed that they were asked relevant and appropriate questions (73 per cent) and that the questions allowed them to fully explain the impact of their condition on their day-to-day life (71 per cent).

Evidence

The survey showed that 62 per cent of claimants who went to appeal submitted additional evidence as part of this process, whether or not they attended the tribunal in person. The main reason for not submitting this evidence earlier in the process was that they did not have it in time for their application (33 per cent).

Decision

For those survey participants who appealed and also reported on their post-MR and appeal award outcome, over half went from having no award at MR to having an award, or having an increase in their award (34 per cent and 22 per cent respectively)⁵.

Participants were asked what they considered to be the reason for their award changing at appeal. The main reason given for the outcome among those who received a new or improved award after appeal was a belief that the original assessment understated their condition (23 per cent). The qualitative research showed that claimants felt the tribunal panel were independent and impartial and valued the expertise of the doctor on the panel.

After the appeal outcome, the majority said they understood the decision (83 per cent), how the judge reached their decision (73 per cent) and the reasons for the decision (74 per cent) which shows a higher level of understanding than after MR.

Overall themes in the research

Evidence

Despite the importance of evidence for DWP in making decisions about PIP, understanding of the role of evidence varied among claimants. There was a widespread misunderstanding that DWP would gather evidence or consult medical professionals themselves which affected the evidence which claimants provided. In addition there was a perception that their condition would speak for itself and would be sufficient evidence (particularly at the face-to-face assessment stage). At later

⁵ Official statistics on Tribunals published by the Ministry of Justice are available online: <https://www.gov.uk/government/statistics/tribunals-and-gender-recognitions-certificates-statistics-quarterly-january-to-march-2018>

stages of the process some of these claimants did submit evidence, having realised or been told by organisations supporting them with their claim that it was important, but some went through the whole process without submitting any evidence. Even among those who understood the value of evidence, difficulties with obtaining it in time or in paying for it meant they did not always submit all the evidence they wanted and only submitted it at MR or appeal.

Communications from DWP and understanding of the process

The majority of survey claimants reported a good understanding of each stage of the process, and when asked to reflect on the process as a whole longitudinal claimants were positive. However, the research highlighted that there is a small group of claimants who struggle to understand the process throughout. The qualitative research uncovered that those with disabilities which affect their ability to read, understand or remember information, or who have limited literacy or English language skills are most affected. Furthermore, a much larger group of claimants found understanding or going through the process at one or more stages of the process difficult.

The research has shown that understanding also varied for different elements of the process. Understanding was less good when it came to how DWP reaches decisions, how evidence is used and why people might be awarded PIP. Understanding of the MR process and outcomes was less good than other stages of the process.

Support throughout the process and contact with DWP

Support with the process was extremely important for claimants. This could be help with the call to the claim line, with completing the form, advice on what evidence to provide, someone to accompany them to the face-to-face assessment or tribunal, and help with understanding the decisions at each stage. The help was needed because of difficulties related to claimants' disabilities or literacy (which might affect their ability to complete the forms or answer questions themselves), for moral and emotional support and for practical matters such as transport. Help was most often given by family and friends, but health and social care professionals, charities, support groups and Citizens Advice also offered support, help and advice throughout the process.

A minority of claimants made contact with DWP or used the DWP website⁶ for help. At early stages of the process not seeking help from DWP was related to not needing help, not being aware DWP could help, or wanting face-to-face support. However, particularly at the MR and appeal stages an additional factor was distrust of DWP since the claimants were going through those stages because they were dissatisfied with their award.

Face-to-face assessment

Although most claimants who had a face-to-face assessment had a positive experience, for example, being treated with dignity and respect and being able to explain themselves, a minority did not. Longitudinal analysis showed that those who

⁶ Although the answer category wording in the survey referred to the DWP website, claimants may have been referring to the GOV.UK website when responding.

had negative experiences at the assessment were more likely to request MR and appeal. Participants themselves cited dissatisfaction with the assessor as a reason for requesting MR and appealing.

Differences between groups

The research has shown that at all stages those who received an award (whether initial award or after MR or appeal) tend to have a better understanding of the process and report a more positive experience (for example, in being able to explain themselves at the assessment or in feeling that the award takes into account all of the evidence). There are two possible explanations. One is that those who have a better understanding and experience of the process are more likely to be successful in their applications. The other explanation is that those who do not receive an award feel more negative about the PIP claims process and therefore give more negative answers in this survey which retrospectively asks about their experience. In practice, it is likely to be a mixture of both these explanations.

The analysis of results from across the waves for those longitudinal claimants who took part in more than one wave of the survey, suggests that there is a small group who find the process more difficult throughout and therefore require additional support to navigate the process effectively and achieve the right outcome.

© Crown copyright 2018.

You may re-use this information (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit <http://www.nationalarchives.gov.uk/doc/open-government-licence/version/3/> or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU, or email: psi@nationalarchives.gsi.gov.uk

The full report of these research findings is published by the Department for Work and Pensions (978-1-5286-0674-5. Research Report 963. September 2018).

You can download the full report free from:

<https://www.gov.uk/government/collections/research-reports>

Other report summaries in the research series are also available from the website above. If you would like to know more about DWP research, please email: Socialresearch@dwp.gsi.gov.uk