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Claimant views on ways to improve PIP and ESA questionnaires

Final report of research findings

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Executive summary

In response to recommendations made by the [Work and Pensions Select Committee](#), the Department for Work and Pensions (DWP) commissioned research to explore claimant experiences of claiming Personal Independence Payment (PIP) and Employment and Support Allowance (ESA) and, more specifically, to obtain their views on how the questionnaires used as part of the respective benefits' assessment processes, could be made more user-friendly and "less distressing" for claimants.

The research involved an initial phase of focus groups and in-depth interviews with PIP and ESA claimants to explore their experiences of completing the questionnaires and their suggestions for making the questionnaires more user-friendly. Following a workshop with DWP colleagues to discuss potential solutions to the issues raised by claimants, a further round of focus groups and in-depth interviews were conducted with PIP claimants, to explore claimant's views on some additional information that might be provided along with the PIP questionnaire. These focused on whether any of this additional information might have helped to address claimants' concerns about the assessment process.

PIP and ESA claimant preferences and suggestions for questionnaires

PIP and ESA claimants commonly described the experience of completing the assessment questionnaires in a negative light. They felt that the questionnaires forced them to focus on their worst experiences and lowest points. Both PIP and ESA claimants felt that they struggled to know what information DWP was looking for, as they felt the basis of how PIP and ESA was awarded was not made clear. This left them feeling anxious about what information to include. PIP claimants felt strongly that there was a lack of transparency from DWP on how the benefit is awarded.

PIP and ESA claimants suggested improvements, including: more routing within the questionnaires or separate questionnaires for different conditions or disabilities, this would provide greater clarity on which questions they need to answer; an option to complete online, which would enable claimants to complete the questionnaire in stages and assist those that struggled with physically writing answers into the open text boxes; and extending the deadline to six weeks, to allow more time for gathering evidence and/or accessing support to fill the questionnaire in.

PIP claimant views on additional information being included with the PIP questionnaire

Additional information was shown to PIP claimants during the final stage of the research. They were shown a seven-page document that provided more information on the assessment process, how points are awarded and what is involved in the face-to-face assessment.

For some claimants the additional information was felt to be of practical value, even when claimants felt uncomfortable that the assessment process involved a points-based system. Therefore, the research suggests that including this information within the PIP application pack could be helpful. Directly addressing concerns regarding the points-based system by adding some further explanation could also, potentially, add value.

There were some claimants that were more positive about and keener to receive this additional information, but they commonly reported having been able to cope quite well with the questionnaire already. This suggests that the additional information may not have as much impact on those that require the most support.

Even once PIP claimants had reviewed this additional information, strong concerns remained around whether the 'How your disability affects you' questionnaire captures the full and complex impacts of certain health conditions and disabilities. It was clear that claimants did not feel that this additional information had addressed this key concern and therefore it would have a limited impact on reducing levels of anxiety amongst claimants.

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We would also like to acknowledge and thank all the research participants for giving up their time to participate in interviews and providing valuable information on their experiences and views.

Authors' credits

Lorna Adams and Angus Tindle, Directors, headed up the IFF team responsible for the research. Both have considerable experience in researching employment support and welfare issues, particularly in relation to vulnerable client groups. Helen Greevy, Senior Research Manager, was responsible for day-to-day management of the study. Sam Stroud, Research Manager, and Oliver Gooding, Senior Research Executive, worked on the fieldwork, analysis and reporting alongside Helen, Angus and Lorna.

Glossary of terms

Disability Living Allowance

Disability Living Allowance (DLA) is a benefit for those under 16 or over 65 on 8 April 2013 that helps people with the extra costs of a long-term health condition or disability. It is being replaced by Personal Independence Payment.

Employment and Support Allowance

Employment and Support Allowance (ESA) is an income-replacement benefit for people who have a health condition or disability that affects their ability to work. ESA offers financial support if you are unable to work, and personalised help so that you can work if you are able to.

Health Care Professional

The Health Professional is a doctor, nurse, paramedic, occupational therapist or physiotherapist who is fully registered with the relevant licensing body. All Health Professionals must go through a formal approval process to ensure they meet the DWP's requirements in relation to experience, skills and competence.

Personal Independence Payment

Personal Independent Payment is a benefit that helps people with the extra costs of a long-term health condition or disability. It replaces DLA for working age claimants (between age 16 and the day before State Pension age).

Abbreviations

DLA	Disability Living Allowance
DWP	Department for Work and Pensions
ESA	Employment and Support Allowance
MSK	Musculoskeletal conditions
PIP	Personal Independence Payment

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Chapter 1: Background and methodology

This chapter outlines the background to the project and provides an overview of the methodology.

1.1 Background to the research

In February 2018, the [Work and Pensions Select Committee](#) made a number of recommendations to improve the application processes for Personal Independence Payment (PIP) and Employment and Support Allowance (ESA). One of the recommendations was that the Department for Work and Pensions (DWP) should conduct research into the impact of the application process on claimants' health and wellbeing. This included a focus on how the questionnaires used as part of the assessment process for the two benefits could be made more user friendly and, in their words, "less distressing" for claimants.¹

In response, DWP commissioned IFF Research to explore what changes could be made to the PIP 'How your disability affects you' questionnaire and the ESA 'Capability for Work' questionnaire, to help minimise distress and improve the claimant experience. The research aimed to:

- Determine which particular aspects of the questionnaires may cause difficulty or distress;
- Explore potential solutions; and
- Test these potential solutions with claimants.

1.2 Methodology

The project was conducted over three phases.

Phase 1 research on the PIP and ESA questionnaires

Thirty ESA claimants and 31 PIP claimants took part in this research. The sample was provided by DWP. All of the participants had been informed in December 2018 or January 2019 whether their claim was or was not successful. This helped to ensure that the application process was still fresh in their minds. More information on the profile of participants in Phase 1 can be found in Annex 1 of the Appendices.

¹ In this report, all research participants are referred to as claimants irrespective of the outcome of their claim. However, those who are not awarded PIP following a review of their application and/or an assessment will not be in receipt of PIP. For ESA, claimants will already have been awarded the benefit before completing the ESA50 form.

Research participants were given the option of either attending a focus group or a face-to-face in-depth interview, at a location of their choice. Before attending, claimants were posted a hard copy of either the ESA 'Capability for Work' questionnaire (ESA claimants) or the PIP 'How your disability affects you' questionnaire (PIP claimants), together with relevant supporting materials, to allow them to refresh their memories of completing their PIP application or ESA assessment form.

Fieldwork took place between late March and early June 2019. Discussions focussed on:

- Claimants' thoughts and feelings about their actual experience of completing the questionnaires;
- Claimants' suggestions for what their 'ideal' experience of completing the questionnaires would be like, by comparison;
- A section-by-section discussion of the questionnaires, to explore in detail what worked well and what caused difficulties; and
- Claimants' views on supporting materials provided with the questionnaires.

Phase 2 workshop

IFF Research presented the findings from Phase 1 research to DWP staff involved in the design and delivery of PIP and ESA. Based on ideas generated at the workshop and input from DWP senior leaders, a further phase of research and testing was agreed – to focus specifically on the PIP questionnaire and whether claimants would be helped by DWP sharing with them more detailed information on how the assessment works, how points are awarded during the assessment and what is involved in a face-to-face assessment.

Phase 3 research on additional information for PIP claimants

DWP provided a new sample of PIP claimants for this next phase of the research. The sample was drawn from those who had applied for PIP and had received their award decision between January and September 2019. More detail on the profile of the participants in Phase 3 of the research can be found in Annex 2 of the Appendices.

Focus groups were held with PIP claimants in February 2020 in both London and Newcastle. Alongside this, three in-depth interviews were convened with claimants with sensory impairments. Within each discussion:

- Claimants discussed their actual experience of completing the PIP 'How your disability affects you' questionnaire;
- Time was then given for claimants to review the additional information about the PIP application process (i.e. in addition to what they had received when making their own recent PIP application);
- Claimants then discussed their initial impressions of this additional information, before exploring in detail their views on each section, with a focus on how useful the information would have been during their original application.

1.3 Reporting conventions

Attributions for quotations are provided in the following format:

- PIP claimant quotations - location, health condition, awarded or not awarded the benefit and benefit type.
- ESA claimant quotations - location, health condition, found to have limited capability for work or found not to have limited capability for work and benefit type.

The word 'questionnaire' is used to refer to the ESA 'Capability for Work' questionnaire or the PIP 'How your disability affects you' questionnaire. Both questionnaires are referred to, unless stated otherwise.

Interpretation of findings

In qualitative research it is important to ensure that you speak to a variety of individuals, so you can capture a range of experiences. Qualitative research does not aim to be generalisable to the wider population but aims to generate detailed insight on individual experiences.

Chapter 2: Reported preferences and suggestions for questionnaires

This chapter contains findings from the in-depth interviews and focus groups conducted in Phase 1 of the research, in which Personal Independence Payment (PIP) and Employment and Support Allowance (ESA) claimants discussed their experiences of completing the respective questionnaires. It presents:

- Claimants' actual experiences of completing the questionnaires;
- Claimants' suggestions for an 'ideal' experience; and
- Claimants' suggested solutions for some of the issues raised.

Findings common to both questionnaires are presented first, followed by points that were specific to PIP or ESA.

2.1 Actual experience of completing the questionnaires

During both the in-depth interviews and focus groups, PIP and ESA claimants were first asked to describe the thoughts and feelings about their experience of completing the questionnaires. These thoughts and feelings were then explored in-depth to understand what about the questionnaires made them feel this way.

2.1.1 Common experiences among PIP and ESA claimants

The current experience of completing the questionnaires was often seen as negative and upsetting. Claimants described the process as “stressful”, “worrying”, “daunting”, “overwhelming”, “emotional” and “repetitious”. There were several issues raised in relation to both questionnaires which had contributed to these negative feelings and thoughts. These are described below.

Questionnaires are not a good match for how conditions affect claimants

Claimants felt that the questionnaires were not a good match for how their conditions affected them and impacted their lives. Those with mental health conditions felt that neither questionnaire worked well for them. The questions focus on having difficulty, needing help, or whether or not claimants are able to undertake a task, whereas

claimants explained that with a mental health condition, they may be physically able to undertake a task, but on some days they are unable to bring themselves to carry out certain tasks. Some people with physical health conditions also experienced similar frustrations. They argued that they may be able to undertake a task, but there may be negative after-effects; for example, it may leave them exhausted or in pain.

Claimants also struggled to understand why the questionnaires asked when their health condition or disability had started. They felt that in most cases this would be extremely difficult to answer, as they either could not remember or would be unable to pinpoint the exact beginning. This was especially true for those with mental health conditions.

Lack of clarity and transparency around what DWP is looking for

Both the PIP and, to a slightly lesser degree, the ESA questionnaire, felt repetitious to claimants. Claimants felt that they both contained questions that were similar to questions that had already been asked, which meant they had to remember the previous answers they'd given earlier in the questionnaire. This led many claimants to feel the questionnaire was 'testing them' and trying to 'catch them out', by finding inconsistencies in the information they were providing. This feeling was exacerbated by the perceived lack of transparency within the questionnaires and supporting information about how points are awarded.

Claimants – and particularly those who had fluctuating conditions – felt like they were having to revisit their worst days to score points. Furthermore, claimants were not clear what DWP were looking for, so felt it was necessary to provide as much detail as possible. This focus on their lowest points felt emotionally draining to many claimants. Compounding this, some claimants, especially in relation to PIP, felt that they would be judged as unsuitable for the benefit if they said anything positive or showed any signs of coping, either within the questionnaire or during the assessment.

“After reading through everything, it made me feel down because I can't do much by myself.”

(London, Mental Health, Awarded, PIP)

This feeling of having to 'play to your worst days' and 'run the gauntlet' to secure the benefit was felt by a few to be a symptom of a flawed system; and, in the case of PIP, was felt to run counter to the implied purpose and ethos of the benefit, which claimants had taken to be about providing funding to help you manage and be more independent. This had often come as a shock to claimants, who had expected a more supportive and straightforward process. This sense of 'running the gauntlet' had emerged at different stages and in different ways – sometimes from the experience of filling in the questionnaire, sometimes from the experience of the face-to-face assessment and/or receiving the decision, or sometimes from hearing about their likelihood of success from other claimants or support organisations.

Many claimants also felt that the questionnaires were not actually read, often citing examples from the assessment to support this. Additionally, across both benefits, many claimants were of the view that the appeal process was usually necessary to

be awarded the benefit. These factors meant that completing the questionnaires sometimes felt somewhat futile from the start.

Format of the questionnaires and use of open-text boxes

In both the ESA and PIP questionnaires, the open-text boxes provoked anxiety because there were felt to be too many. Claimants also felt it was unclear what sort of information was relevant and not relevant to include. There was a perceived obligation to complete all of these, and a fear that omitting information might make the difference between being awarded or not. This led to a lot of anxiety about 'getting it right', due to the financial importance of the outcome.

"It's difficult remembering what I've done, making sure I didn't forget anything. It's all important, there's pressure that if you leave anything out it might stop you getting it."

(Cardiff, MSK, Found not to have limited capability for work, ESA)

This was compounded by claimants themselves sometimes struggling to recall or fully understand aspects of their conditions and the associated effects. There was also concern about the ability of the person assessing the response to correctly interpret it. Some claimants also struggled to write at length or feared that their handwriting would be illegible. There was, however, still an appetite for some open text boxes, so claimants could communicate 'in their own words'. The key issue was with the number and extent of these in both questionnaires.

Deadline for completion is too short

Beyond issues with the structure and content of the form, many claimants felt that the deadlines for completion given with both questionnaires were too short, especially considering the time it takes to collect medical evidence. Many claimants also felt that access to support with completing the questionnaires was often difficult to come by, within these deadlines.

"I can't even finish a chapter in a book because I can't focus, and you've given me all this to fill in."

(London, Mental Health, Not Awarded, PIP)

Positive aspects of the questionnaires

Despite these common negative perceptions, some claimants felt that the questionnaires seemed very thorough, which was reassuring, to some extent. The tick boxes in both the ESA and PIP questionnaires were also felt to be an efficient way of giving information and providing a structure to the open-ended questions, making it a little clearer what information DWP was looking for. There were also a handful of claimants from both benefits who found the questionnaires straightforward to complete, with some pointing out that the key information was laid out simply in

bullet points. These claimants were generally those who had experience of completing paperwork in their jobs.

2.1.2 Specific to experiences of PIP claimants

Length of the questionnaire

The length of the PIP questionnaire was more of an issue for claimants than the length of the ESA questionnaire. Claimants felt that the questionnaire was “daunting” due to its length and took many hours and occasions to complete.

Questionnaire was not a good match for how conditions affect claimants

PIP claimants noted that a number of sections did not seem relevant to their health condition or disability, but they were concerned about what would happen if they did not fill these sections in.

PIP claimants particularly felt that mental health conditions were not sufficiently covered in the questionnaire. They felt that mental health was covered late in the questionnaire, and in inadequate depth, unlike the ESA questionnaire where there is a clearly signposted mental health section. Claimants perceived it to be unfair that such a small section of the daily activities was explicitly linked to mental health, when various aspects of daily life could be severely affected by mental health conditions. Some called for separate application questionnaires for mental and physical conditions. Even a few claimants who had both mental health and physical health conditions, felt that two questionnaires would be more suitable.

“How could someone who’s struggling with their mental health sit there and go, ‘I can tell you all the things that are going on for me,’ when I can’t even get out of bed for the day?”

(London, Mental Health, Awarded, PIP)

Those with fluctuating health conditions (often an overlapping group with those with mental health conditions) felt that the PIP questionnaire was not well suited to capturing the difficulties they experienced. It was generally agreed that claimants had to focus on the ‘worst days’ of their condition, in order to be awarded. This made filling in the questionnaire more stressful, and for some also triggered feelings of guilt about having to ‘play to’ these ‘worst days’ when completing the questionnaire.

“Like, can you lift pans and stuff like that? Of course, you can lift pans. But the two or three days where I’m not able to, I can’t. Do you know what I mean? It’s hard to explain to somebody who-, they don’t know what you’re talking about.”

(Newcastle, MSK, Not Awarded, PIP)

Other elements of the assessment process

While the discussions focused on the experience of completing the PIP questionnaire, for many claimants, the whole experience was overshadowed by other

elements of the PIP application process, which they felt were more important. There was a strong consensus that the face-to-face assessment posed several issues for claimants and was a key reason for their lack of trust in DWP.

Many felt that the PIP assessment was degrading, and that they were 'made to feel like liars'. PIP claimants highlighted that the questions from the questionnaire were often repeated in the assessment, making the assessment feel like a 'lie detector test', and convincing many that the questionnaires were not read. PIP claimants also felt that the medical evidence that they provided was often disregarded or they were unsure how it was used.

"When I went to assessment, the first question she asked was, do you drive? If she had seen the form, she would know immediately that there is no way I could ever drive."

(London, Sensory Impairment, Not Awarded, PIP)

For many there was an overall sense of distrust in DWP. This was a result of a combination of the above points, but also the general impression that PIP was an exercise in removing benefits or reducing the amount received. Many had previously been on Disability Living Allowance (DLA) and had seen a reduction in their payments. Some had also been through other benefit application processes and had had bad experiences.

"I've got no trust in it at all. I think they're just trying to get you back out, to get you to work."

(London, Learning and Other, Not Awarded, PIP)

2.1.3 Specific to experiences of ESA claimants

Format of the questionnaires and use of open-text boxes

Some of the text boxes in the ESA questionnaire caused particular difficulty. For example, the first large open text box at the start of the ESA questionnaire, which asked for an explanation of why the form is late, was particularly problematic. For many, this immediately set an intimidating tone to the questionnaire, and caused anxiety even when they did not expect to be submitting the questionnaire late.

Many ESA claimants also felt that the large text box asking them to describe their condition was intimidating. ESA claimants described how the act of having to write about their condition in detail made them feel worse. The length of the box provoked anxiety, as it was felt that they were being asked to write an 'essay' on their condition. However, some were more positive about having an opportunity to provide details of their condition in their own words.

The preference for filling out the questionnaire online was more pronounced among ESA claimants. This was often related to the issues around text boxes. Claimants were often worried about spelling and the legibility of their handwriting, especially with respect to the smaller text boxes where they might need to provide a lot of

information. For many, filling the questionnaire out online would solve the issues of handwriting, spelling and the size of text boxes. The suggestion of an online questionnaire often came from claimants who had conditions which made filling in forms difficult, such as those with a visual impairment or certain physical conditions.

Questionnaire was not a good match for how conditions affect claimants

ESA claimants also had difficulty using the questionnaire to express how their conditions fluctuate. While claimants felt that the “it varies” tick box acknowledged that their condition was changeable, most felt that there was not enough space to explain exactly how their condition varied. Similarly, at other questions, especially those on mental health, claimants felt that the text boxes where they were asked to explain their answers were far too small to convey their situation in sufficient detail.

Another issue more commonly raised by ESA claimants was the apparently contradictory or excessively repetitive nature of questions, which they felt could have been avoided. There were several examples given of one activity seemingly relating to another, making some questions feel redundant for some claimants. The details around raising your arms, standing, walking and cooking were all queried in this respect.

"They ask how long you can stand for. I can't. They then ask if you can cook. Well you need to stand up to cook, so if I can't stand then I can't cook. Silly questions really."

(Cardiff, MSK, Found not to have limited capability for work, ESA)

2.2 Ideal experience of completing the questionnaires

Following a discussion of claimants' actual experiences of completing the PIP and ESA questionnaires, claimants were asked to consider the thoughts and feelings they would associate with a hypothetical 'ideal experience' of completing the questionnaires. Claimants were then encouraged to consider what would need to be different about the questionnaires to create this ideal experience.

When discussing their ideal experience of completing the PIP and ESA questionnaires, claimants often tended to provide words that were opposite in meaning to those describing their actual experience. The most commonly suggested words included “easier”, “simpler”, “shorter” and “clearer”. In practice, this meant that claimants would prefer a questionnaire which contained fewer questions, and questions which were easier to answer. Alternatively, they would prefer to not fill out a questionnaire at all, and for the benefit to be awarded on the basis of medical evidence or a medical assessment.

Claimants made suggestions about how the questionnaires could be simplified:

Questionnaire more tailored to specific conditions

PIP and ESA claimants often wanted the questionnaires to be more tailored to specific conditions, meaning that all questions would be relevant to them. This would entail separate questionnaires for different condition types. As an alternative to different questionnaires for specific conditions, claimants suggested making it clearer that whole sections could be skipped if they do not relate to the claimant's condition.

Multiple choice questions

PIP and ESA claimants also frequently expressed a preference for the bulk of questions to be multiple-choice, as this would require less writing. However, claimants across both benefits also wanted the opportunity to explain the impacts of their condition in their own words at some stage, requiring at least one open text box within the questionnaires.

More consistent access to support

PIP and ESA claimants consistently wanted the process to feel more supportive. As the benefits are for those with health conditions, they often wanted the process to feel more sympathetic to the difficulties they faced. This included making support with completing the questionnaire more consistently and easily available to claimants who would otherwise struggle to complete the form.

PIP and ESA claimants also cited instances of interactions at the face-to-face assessment and in phone calls associated with completing the questionnaire which they felt were not supportive. For example, some claimants felt that assessors implied that the fact that they had managed to communicate in an articulate manner or successfully arrive at the assessment had in some way counted against them by proving that they were 'not ill enough'.

For many of the ESA claimants, the involvement of a medical professional or their own GP would have made them feel more supported in the application process. Several also suggested that, ideally, a medical professional would come to their home to carry out the assessment.

More accessible options

Among both PIP and ESA claimants, there was a strong appetite for completing the questionnaire online. They felt that this would provide a variety of benefits, such as being able to save the questionnaire and come back to it, being able to easily amend any of their answers, cut and paste answers from previous sections where relevant, upload documents, and save a soft copy of the questionnaire for future reference in the assessment. It would, they felt, also allay their concerns about the legibility of their handwriting.

Claimants across both benefits also suggested that if you had claimed before there could be some pre-population of the form if it were provided online. Some also felt that an online interactive questionnaire would allow all the information currently included in the questionnaire and information booklet to be in one place. Clarification boxes or pop-ups could be embedded within the questionnaire to provide further detail that is currently included in the information booklet. Claimants believed that this

move online would help to reduce some of the stress and difficulties associated with physically completing the questionnaire.

ESA claimants also suggested that they would prefer to talk about their difficulties, rather than writing them down. Some mentioned that this could be in the form of a telephone interview, or a dedicated telephone helpline, as they found “talking it through is easier”. ESA claimants commonly felt that it was difficult to obtain the help they needed to complete the questionnaire and would have appreciated more signposting to organisations who could provide this help.

More transparency on eligibility and assessment

Finally, with both questionnaires, PIP and ESA claimants struggled to understand exactly what DWP were looking for and would have preferred more transparency around how the benefits were awarded. However, this did come out more strongly in the discussions with PIP claimants.

PIP claimants were particularly keen for the process to be more transparent, so they could better understand how they were being assessed. For example, many claimants wanted more clarity about how the questionnaire would be used in relation to the face-to-face assessment, and how the information and medical evidence they provided would be taken into account.

2.3 Suggested improvements

This section describes a range of potential improvements and solutions suggested by claimants. Their ideas were spontaneous, i.e. they were not prompted with any possible solutions by the researcher. A table summarising these suggestions is provided at the end of this section.

2.3.1 Improvements common to PIP and ESA questionnaires

One of the most consistently raised sets of issues with both questionnaires was their length and complexity, and how difficult they were to answer. Some claimants suggested ways of trying to resolve these issues.

More routing or separate questionnaires

PIP and ESA claimants felt overwhelmed by the length of the questionnaires and the number of questions that they had to answer. This was also not helped by the impression that they had to provide an answer to every question, as they feared being penalised if they missed anything.

Solution: more routing throughout or separate mental health and physical condition questionnaires.

The cancer treatment section (page 5 of the ESA questionnaire) was noted as a good example of how routing could be used within the questionnaire.

More transparency on eligibility and assessment

Many PIP and ESA claimants found it difficult to know what DWP were 'looking for' and had concerns about providing the 'right' information. Most were unsure how their free text responses would be used and what types of information would be sought from medical professionals, creating anxiety about writing 'the wrong thing' or leaving out crucial information.

Some PIP claimants felt that in an ideal process you would have the 'marks' or 'points' shown against each question while filling the questionnaire in, to help you understand at a later date how your questionnaire has been 'scored' and why you have been awarded or not awarded the benefit. Claimants often struggled to know with certainty what information would be relevant to the assessment and felt that a clarification of the points-system might address this.

"You're just looking through it and not really taking it in. But say they had big red writing saying 'this is a point-based system to award the benefit' then you would take it more seriously... I assumed from the form that I'd get to see someone, and they would see what condition I was in, and it would be quite straightforward. I got the letter back and it said I had no points, which shocked us."

(North Shields, Sensory Impairment, Not Awarded, PIP)

Solution: more transparency on eligibility and how award levels are assessed.

Including a detailed explanation of the following, would help to reassure claimants on the level and type of information needed:

- What points are awarded for;
- Which questions are used to award points;
- Whether health professionals will be contacted;
- What information health professionals will be asked to provide;
- How medical evidence will be used; and
- How the questionnaire interacts with the information gathered at the assessment.

Separate questions for 'good' and 'bad' days

The lack of clarity on what information to include also caused issues around handling 'good days and bad days'. Many claimants across both benefits had the impression that they should focus on their worst experiences in order to have a chance of being awarded the benefit. This felt distressing or reminiscent of "begging".

Solution: include separate questions for 'good' days and 'bad' days.

Claimants felt that this would be more empowering and make it easier to record the 'bad days' without feeling like this was disingenuous.

More information captured by assessors only

Related to the frustration of not knowing what information to provide, some PIP and ESA claimants felt that the face-to-face assessments repeated much of what was

asked in the questionnaires. Not only was this frustrating, it also meant that claimants were unsure whether their open text responses were read at all and they felt like they were being 'tested', by being asked the same questions at two stages of the process.

Solution: some of the information in the open text boxes is captured by an assessor instead.

This would help reduce the sense of repetition and claimants felt that some of the more sensitive, challenging information may be more easily gathered via a conversation face-to-face.

More consistent access to support

Compounding the issue of not knowing what DWP were looking for, some PIP and ESA claimants felt they would struggle to adequately articulate their health conditions and all of their effects in any case. This added to the stress of what was already considered a 'high-stakes' application.

Solution: provide more consistent access to support with filling in the questionnaire.

Claimants typically said they needed help with the questionnaire, even when their education and line of work meant they were familiar with completing application forms.

More accessible options

As well as needing assistance to assess their own condition and its impacts, some PIP and ESA claimants also had difficulty writing and were concerned that their handwriting would not be legible and understood by the reader. Others felt that writing down personal information was a more emotional and difficult experience than typing answers or explaining in person.

Solution: More completion options.

An online questionnaire was suggested when claimants were asked to describe their ideal experience. As noted earlier, claimants suggested this could be completed in stages and that they could correct or adjust answers more easily. Others noted that discussing the questions in person would be easier for them.

Extend or remove the deadline

Beyond the contents and structure of the form, claimants were concerned about the length of time they had to complete it. They mentioned that accessing support with filling in the questionnaire typically took three to four weeks and collecting evidence could also take considerable time. By the time the questionnaire arrived, some only had two to three weeks left, which did not leave long enough to access support or gather evidence.

Solution: consider extending or removing the deadline.

This might entail changing the deadline from four weeks to six weeks, which would give claimants around four weeks in practice to complete the questionnaire.

2.3.2 Improvements specific to PIP questionnaire

Ensure prompts map to question responses

PIP claimants felt that the tick-box questions did not allow them to accurately convey the impacts of their conditions. They felt that focusing on what the claimant can or cannot do, or what they need support with can often miss the detail of what causes challenges for people. For example, individuals may not do something due to depression, however they do not see themselves as being unable to do it. Conversely, someone with a physical condition may struggle to complete a task, and yet not see themselves as needing support to do that task.

Solution: change question wording so that the prompts map to question responses.

Consider asking individuals how difficult they find a specific activity. Currently these ideas are included as prompts at the start of the section but do not map to the actual question and response wordings, leaving it up to the claimant to add this in the open text.

Include mental health questions and prompts earlier in the questionnaire

PIP claimants with mental health conditions also had particular concerns about the structure of the questionnaire. The questions that they perceived to be more overtly mental health-relevant come near the end of the form and, in earlier questions, mental health-relevant prompts also appear last in each list. Some saw this as a signal that their condition would not be seen as relevant to the benefit application.

Solution: place the mental health relevant questions earlier in the form and prompts earlier in each section.

This would reassure claimants that mental health issues are not seen as 'an afterthought'.

2.3.3 Improvements specific to ESA questionnaire

Reduce size of initial text box and move it to later in the questionnaire

An issue raised by many ESA claimants, which caused much anxiety, was the large text box at the beginning where claimants are requested to provide a justification if the questionnaire is going to be returned late. It was felt that this started the questionnaire on an unnecessarily negative point.

Solution: reduce the size of this text box and move it towards the back of the questionnaire.

Integrate prompts into questions and clarify ambiguous terms

Most ESA claimants did not read the additional prompts to do things "safely, to an acceptable standard, in a reasonable time and as often as needed," or felt these did not provide greater clarity.

Solution: integrate information into the questions and clarify ambiguous terms.

It was felt that it may help to integrate these prompts into the questions, to ensure the information is read. It would also be beneficial to clarify what is meant by "acceptable standard" and "a reasonable length of time".

2.3.4 Summary of suggestions

The below table outlines a summary of the suggested improvements by ESA and PIP claimants.

Table 1: Summary of improvements

Suggested improvement	ESA claimants	PIP claimants
More routing throughout or separate mental health and physical condition questionnaires	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
More transparency on eligibility and how award levels are assessed	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Include separate questions for 'good' days and 'bad' days	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Some information in the open text boxes is captured by an assessor instead	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
More consistent access to support with filling in the questionnaire	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
More completion options (e.g. online and in person)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Extending or removing the deadline	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Change question wordings so that the prompts map to question responses		<input checked="" type="checkbox"/>
Place the mental health relevant questions earlier in the form and prompts earlier in each section.		<input checked="" type="checkbox"/>
Reduce the size of the 'returning the questionnaire late' text box and move it towards the back of the questionnaire	<input checked="" type="checkbox"/>	
Integrate supporting information into the questions and clarify ambiguous terms	<input checked="" type="checkbox"/>	

2.4 Workshop discussion of findings among DWP colleagues

2.4.1 What did the discussion involve?

The workshop involved IFF Research presenting findings from Phase 1 of the research to DWP colleagues. This then informed a workshop discussion of what the implications of the findings might be, including what solutions might be developed in response to claimant feedback. Once the issues raised by claimants had been discussed, DWP colleagues worked-up a range of possible solutions to these issues.

2.4.2 Conclusions

After the session DWP colleagues reviewed the potential solutions that had been discussed. Upon reflection it was decided that the best use of the next phase of research among claimants would be to test the potential impact on the experience of PIP claimants of additional information being provided with the PIP questionnaire – including whether this information would have an effect on perceptions of transparency and trust in both DWP, and in the PIP application process.

Chapter 3: PIP claimant views on additional information being included with the PIP questionnaire

This chapter contains findings from a further round of in-depth interviews and focus groups in which Personal Independence Payment (PIP) claimants were shown some additional information related to the PIP application. The chapter describes claimants' views on how this additional information might have changed their own experiences of completing the PIP questionnaire.

3.1 Summary of additional information tested

The additional information relating to the PIP application was presented for discussion in the interviews and groups as a seven-page booklet. (Annex 3) It was divided into four sections which covered the following:

- An overview of the basis of PIP entitlement, including an explanation that it is not based on health condition or disability, but is instead awarded using a points-based system related to the effects of conditions rather than the conditions themselves.
- An explanation of the 12 daily activities and their association with the points system. This section also explained what is considered when assessing how many points to award for each activity.
- A breakdown of the points required, for a claimant to be awarded the daily living and mobility components of PIP, at the standard and enhanced rates. This was followed by a table across three pages, detailing all the descriptors within the 12 daily activities, and the points associated with each.
- A summary of what the health professional will do during a face-to-face assessment. This included information about how they may judge claimants' abilities and limitations against the daily activities. It also included details of how informal observations might be carried out, and not carried out. This was followed by links to two sections of the GOV.UK website: firstly, further information on informal observations and, secondly, the full guidance for health professionals to use when assessing a PIP application.

3.2 Initial impressions of the additional information

PIP claimants were given time to read through the additional information. The initial overall impressions were then discussed before moving through the information to discuss each section in more detail.

3.2.1 Positive initial impressions

PIP claimants were immediately drawn to the section of the information containing the table which breaks down the points associated with each descriptor. While not everything said about this was positive, many asserted that the table and explanation text made it clearer 'what DWP were looking for', which would have been useful when filling out the questionnaire.

"It's a little bit more thorough. It gives you an overview of what to expect. So, it is slightly less scary, and you can see the points as well. You know what they're looking for, you know what to say. It would have been useful, less scary."

(Newcastle, Learning and Other, Not Awarded, PIP)

Some claimants felt that the information presented in this section was easier to understand than the information included in the questionnaire, and several commented that they might have provided different answers had they seen this information. Others felt that this breakdown would have been useful to cross-reference when completing the form, or even to take with them to the face-to-face assessment. In some instances, this directly addressed one of the negative aspects cited about the experience of filling in the questionnaire (i.e. perceived to be irrelevant or confusing questions or being unsure of what DWP was looking for).

It is worth noting, however, that a few claimants speculated that the additional information might be a replacement for the form, until it was clarified that this was not the case.

3.2.2 Less positive initial impressions

While the points table added clarity for many, there were also concerns raised about it almost immediately.

One of the key issues PIP claimants recalled from filling out the questionnaire was feeling daunted by the size and length of it. Some claimants, especially those who had required more support to fill out the initial questionnaire, immediately reacted negatively to the idea of receiving 'even more information'. They felt that this was not what was needed to make the application less stressful. Some claimants who had required support to fill in the initial application similarly struggled to understand this new information.

"I think it's too much...How are you meant to read all that?"

(Newcastle, Mental Health, Not Awarded, PIP)

One of the original concerns about the PIP questionnaire had been a lack of clarity and transparency around how the benefit was awarded. However, once claimants had understood the significance of the points table, many raised concerns about the principle of awarding a disability benefit on a points-based system. Many felt that scoring people's conditions like this was problematic and lacked empathy. There was a feeling that it was not humane, and not based on a sufficiently holistic understanding of individuals' circumstances.

"Yes, but there again, we're not robots. So, why should they have to put it on the points system?"

(London, Learning and Other, Not Awarded, PIP)

Most of the PIP claimants also raised concerns about people using the points table to apply for PIP fraudulently. Claimants felt that the points breakdown would make it easier to provide false information in a way which would guarantee being awarded the benefit.

"Say you were claiming, and you weren't meant to be claiming, I think that you could literally just go round and tick the ones with the highest scores or something."

(Newcastle, Mental Health, Not Awarded, PIP)

Looking more closely at some of the descriptors associated with points, some PIP claimants found that their initial concerns about the questionnaire not allowing you to accurately record your situation in relation to some health conditions, persisted and were reinforced. Those with mental health conditions particularly felt that the descriptors did not allow them to express what was challenging about completing the activities (although this same point was raised in relation to some physical conditions, such as being in pain).

"The ones at the beginning. 'Can you prepare and cook a meal unaided?' I mean, if you've got a mental illness, sometimes you won't eat for days, and then you stuff yourself."

(London, Mental Health, Not Awarded, PIP)

3.3 Opinions following a more detailed review of the additional information

As mentioned previously, after an initial overview of the information, PIP claimants were guided through a discussion of each section, probing for their views on specific aspects that they felt would have been helpful or unhelpful when completing their own PIP application.

3.3.1 Section one: An overview of the basis of PIP entitlement

The first section of the additional information explained that PIP is awarded based on the impact of conditions, rather than the condition itself. This explanation received a mixed reaction from PIP claimants. For some it added clarity regarding what PIP was awarded for, and they felt that it would have been useful when filling out the application for the first time.

“I think the first part that’s in bold ... That’s it. That’s what you need. That’s what you need the first time you pick up the letter.”

(Newcastle, Learning and Other, Awarded, PIP)

However, for others, this clearer understanding led to a stronger disagreement with the principles of how the benefit was awarded. Those holding this view felt that it was not right to separate the impact of the condition from the condition in this way. For many this related to their original view that PIP award should be based on medical evidence.

Others found it harder to understand this point and seemed to struggle to disentangle the effects of their condition with the condition itself. This was in part due to the requirement to submit medical evidence with their application.

“You want to know I’ve got a disability, but you’re not basing it on that. So, I’m, kind of, puzzled... You’re not basing it on my condition, but you want to know that I’ve got a condition.”

(London, Learning and Other, Not Awarded, PIP)

One PIP claimant had an issue with the start of the first section of this additional information, which informed claimants that this information was not essential to making an application. They felt that this raised the question of why it needed to be read in the first place.

3.3.2 Section two: How the assessment works

The next section of the additional information provided an explanation of the terms “safely”, “repeatedly”, “within a reasonable time period” and “to an acceptable standard”. Again, there were mixed reactions to this from PIP claimants. Some were positive that there was more clarity around what these terms meant in practice, and how they might apply to their condition. Some of those with fluctuating conditions felt

it was relevant to them and were pleased with this clarification. Others, however, felt that the explanation did not fully clarify the terms and felt that it did not address their concern that it was difficult to apply these criteria to their experience of their condition.

“You know when it uses words like ‘to an acceptable standard,’ I think that’s quite insulting. Because what’s an acceptable standard for you, might be a totally different acceptable standard for me.”

(Newcastle, Mental Health, Not Awarded, PIP)

PIP claimants also raised an issue over the language used in this second section. Some felt that the language was overly complex, and others felt that it was judgemental rather than reassuring. One of the original issues with completing the PIP questionnaire was that some claimants required support to complete it and struggled to access this support. The language used in the additional information meant that it was not useful to these claimants. The following words and phrases were found to be too challenging or confusing: “entitlement”, “descriptors”, “associated”, and “functional assessment”.

“Descriptor, this is the person claiming, isn’t it, from what I would understand? ... So, does that mean the person or the question?”

(London, Mental Health, Not Awarded, PIP)

The phrase “the PIP decision maker” also raised concerns for some. Claimants wanted more information on who the PIP decision maker was.

3.3.3 Section three: PIP entitlement by points

The third section of the additional information was focused on the points-based system. This drew a lot of interest and comments, especially with regards to the table of descriptors. The key positive that claimants took away from this section was the clarity and transparency it provided around how the points-based system works.

Almost all of the PIP claimants were positive to some degree about the information which broke down how the points correspond to the different award levels for daily living and mobility. For many this clarified the distinction between the two components further than they had previously understood.

“I think it’s good because, obviously it helps you understand the severity of it, on a scaling. I think it is good to have something like that.”

(Newcastle, Mental Health, Not Awarded, PIP)

Furthermore, many PIP claimants thought that having access to the points associated with each descriptor could help them to provide the most appropriate information to DWP. For this group, the additional information went some way to addressing the concern of not knowing what DWP were ‘looking for’. It also gave claimants a better idea of what PIP is awarded for overall, and what they might be entitled to.

Some identified that this would have been helpful for them while filling out the questionnaire, specifically by enabling them to provide more succinct answers.

“When I’ve looked at what they’ve asked for compared to what they sent, I got exactly the same score. Yes, that would have been a great help as far as I’m concerned, rather than going into so much detail.”

(Newcastle, Learning and Other, Awarded, PIP)

There were also PIP claimants who viewed the information in this section more negatively. In discussing this section, many PIP claimants reiterated that they felt that the points table could be used for fraudulent applications. Some were concerned that if this greatly increased the overall volume of PIP applications, this could negatively impact on legitimate applications.

Another concern shared by many was the fundamental disagreement with a points-based system being used to award a benefit based on health conditions. The points-based system was felt to be robotic and lacking empathy, treating claimants as numbers rather than people.

“I think the points system is wrong, in general, anyway, because I think you should just be graded on your situation and your circumstances, rather than points.”

(Newcastle, Mental Health, Not Awarded, PIP)

The table of descriptors also confirmed for many their concern that the PIP questionnaire did not effectively capture the challenges they faced day-to-day. Some pointed out that it was not clear if they would get points for things that caused them difficulty, such as being in pain.

Issues were raised by PIP claimants about descriptors across all types of health condition. For example, the activity ‘preparing and cooking a simple meal’ drew many comments, as it could cause difficulty for people with different condition types in different ways. Those with mental health conditions again pointed out that the descriptors did not allow for those with depression to express that they were not completing tasks despite seeing themselves as ‘able’ to do them. It was also highlighted a number of times that the “needs prompting” descriptor relied upon having someone there to do the prompting, leaving those who lived alone unsure of how it would apply to them.

“There’s another thing here, as well, that keeps recurring on all of the different questions. Needs prompting. Needs prompting. What happens if there’s nobody there to prompt you?”

(Newcastle, Mental Health, Not Awarded, PIP)

In addition to raising concerns with the content of the descriptors and how they corresponded to the points awarded, several PIP claimants also had trouble with the phrasing used. The phrasing of some descriptors was seen as either too complex or too ambiguous.

“Cannot convey food’? Just say ‘cannot feed yourself’. Let’s keep this simple. Do you know what I mean? My memory isn’t good and my speech isn’t good, and obviously I get confused with stuff.”

(London, Learning and Other, Awarded, PIP)

3.3.4 Section four: What to expect if you are invited to a face-to-face assessment

The reaction to the final section about the face-to-face assessment was mostly negative, as the information appeared to unintentionally evoke and reinforce existing concerns about the face-to-face assessment experience.

Many PIP claimants took issue with the term “health professional” and wanted to know more about who the person assessing them was. Most wanted to know what qualifications or medical training the assessor had, as they felt that this was crucial to ensure that they could understand the difficulties posed by specific health conditions.

“A health professional, so what is their job title? Who are they? Are they occupational therapists? Are they a nurse? Are they a doctor? It’s, like, am I not entitled to know? I don’t know how safe hands I’m in.”

(Newcastle, MSK, Not Awarded, PIP)

The lack of confidence in the medical expertise involved was compounded for some PIP claimants, who suggested that the list of areas of function which could be assessed was not comprehensive. For example, one claimant with a sensory impairment noted that their condition would not be covered by the list.

The focus on the various ways that the health professional would carry out the assessment made the tone feel “judgemental” and triggered anecdotes about negative experiences at previous assessments attended.

The explanation in this section about ‘good’ and ‘bad’ days drew particular attention. Reactions again were mixed. Some were positive about the inclusion of this, and felt it was important to make this explicit.

“I like the bullet that says there are good days and bad days. You know, on a good day, you might be able to do that, but on a bad day, you can’t even get a foot out of the bed, let alone go to the toilet.”

(London, Mental Health, Awarded, PIP)

Others were very focused on the difficulty of articulating the difference between ‘good’ and ‘bad’ days. A particular concern which had arisen from the discussion of completing the questionnaire and was again raised in light of this section of the additional information, was around being penalised for being presentable on the day of the assessment. The extra information about informal observations only seemed to reinforce concerns about this.

“They go by how you are that day when they see you...If I wasn’t well that day, I wouldn’t be there, because I couldn’t have made it.”

(London, Learning and Other, Awarded, PIP)

3.3.5 Section five: Links to further information

PIP claimants did not express strong feelings about the GOV.UK web-address links at the end of the additional information. The main initial reaction was that it would be difficult and time consuming to type the address links into a computer, if receiving the additional information on paper. Some also mentioned their lack of access to a computer.

There was also a generally negative reaction to the quantity of extra information being signposted to online, with some claimants feeling “overwhelmed” and “exhausted” by what they saw as yet more reading. This did not decrease the stress associated with completing the PIP questionnaire. The issue of high-level and complex language was also raised again in association with these online materials.

Conversely, a handful mentioned that the format of the online material at GOV.UK (specifically, a contents menu and links to specific sections) made the information easy to navigate.

3.4 When would PIP claimants like to receive this information?

As the overall reaction to the information varied considerably, PIP claimants took different views on whether or when it would be best to receive the additional information. Generally, they fell into two main groups:

- They did not wish to receive the information at all.
- They wished to receive the information with the PIP application pack.

Those who did not wish to receive the information had generally felt overwhelmed by the amount of information in the original questionnaire. Many of these claimants had sought support to fill out the information. Although, some who required support did feel that the person supporting them may have found the information useful.

Those who wished to receive the additional information within the PIP questionnaire tended to not have struggled a great deal when filling in the questionnaire. These claimants also noted that it might be useful to take the points table to the face-to-face assessment, or to refer to it once a decision had been made.

In addition, some claimants felt that the information on the face-to-face assessment should only be received by those that were invited to assessment, in the run-up to attending rather than with the PIP questionnaire.

Some PIP claimants also thought that the points table could serve as a replacement to the PIP questionnaire, by removing the points information in the final column and

allowing claimants to tick the relevant descriptors that apply to them. This could then be taken to the assessment and discussed in more detail. Removing the PIP questionnaire completely and relying solely on a face-to-face assessment was also suggested.

3.5 Final position on the additional information for PIP claimants

The additional information on the PIP application process, and specifically the scoring approach, was sometimes of practical value to claimants, even if they objected to or were uncomfortable with the fact that the applications were scored in this manner. For some, it may therefore be worth including this additional information with the PIP application pack.

However, there may be a need to try to mitigate objections and concerns about scoring as the basis of PIP assessment. There were strong concerns that the PIP assessment does not fully recognise or capture the impact of certain condition types, and the additional information reinforced this perception for some.

The additional information about the face-to-face assessments was very poorly received. For many, it evoked the negative aspects of the experience and claimants mostly felt that it should probably not be included.

The GOV.UK links and information, while not eliciting strong responses either way, was also thought to add little value.

Chapter 4: Conclusions

4.1 Claimant preferences and suggestions for questionnaires

The research found that PIP and ESA claimants commonly saw the experience of completing the PIP and ESA questionnaires as negative and upsetting and described the process of completing the questionnaires as “stressful”, “worrying”, “daunting”, “overwhelming” and “emotional”. There was a feeling amongst the claimants that the questionnaires encourage you to focus on your worst experiences and the lowest points in your life.

PIP and ESA claimants felt that they struggled to know what information DWP was looking for. They felt the award process lacked transparency and left them feeling anxious about what information to include. They sometimes felt that they included very personal and difficult experiences in their responses to the questionnaire but were unsure if this information was used in assessing whether they were eligible for the benefit. All of this created a feeling of ‘getting through to the next round’ of an arduous process.

Several types of recommendations for improvements were suggested by claimants. PIP and ESA claimants would like both questionnaires to be more tailored to specific health conditions or disabilities. There was a feeling that the current questionnaires were not tailored enough, and claimants were concerned that they may ‘have the wrong questionnaire’. They also suggested, in relation to both benefits, that more accessible options needed to be available, including online completion options, which would enable claimants to complete the questionnaire in stages, while also assisting those that struggle with physically writing and resolving some claimants’ concerns about their writing being illegible. PIP and ESA claimants also suggested an extended deadline, of at least six weeks, to give them sufficient time to gather evidence and/or obtain support with completion.

Although the length of the questionnaires was an issue for some, others felt the level of detail requested was reassuring as it provided a chance to share all the relevant information. The use of tick boxes in both questionnaires was also felt to be useful, as it provided a structure to filling in the questionnaire and, in some instances, it made it clearer what information DWP were looking for.

4.2 Claimant views on additional information being included with the PIP questionnaire

The additional information shown to PIP claimants - especially the outline of the points-based scoring approach - was sometimes of practical value, even when

claimants objected to or were uncomfortable with the way the applications were scored. It may therefore be worth including this information within the PIP application pack. However, it may be advisable for some additional wording to be included to try to mitigate objections to and concerns about PIP applications being assessed on a points-based system.

It is also worth noting that PIP claimants who were more positive about the additional information and stated they would like to receive it, reported having been able to cope reasonably well with the questionnaire anyway. This suggests that the additional information may not have as much impact on claimants that need the most support or assistance.

Strong concerns remain around the PIP questionnaire not fully recognising or capturing the impacts of certain condition types. The additional information also appears to reinforce this perception, rather than dismantle it. The ability of the additional information to reduce anxiety amongst claimants is therefore very limited.

The element of the additional information that focused on the face-to-face assessment received negative reactions. This information appeared to unintentionally bring back previous negative experiences of the assessment and trigger existing anxieties. It is clear from the claimant reactions that this information should not be included in its current format. If the face-to-face assessment information is to be included, it needs an extensive rework, with attention paid to the tone and use of language. If the information is reworded it would be advisable for it to be provided to those that have been invited to an assessment, in the run-up to attending, rather than with the PIP questionnaire.

PIP claimants generally had a neutral reaction to the inclusion of the GOV.UK links. The information contained within the links also did not elicit strong responses but was felt to add little.

Overall, PIP claimants felt DWP was being more transparent by providing the information on the points-based system, but this did not appear to have a positive impact on their trust in the application process or in DWP. Claimants struggled to come to terms with such a personal and individual set of circumstances being judged on a points-based system. They continued to argue that a points-based system was not an appropriate way to judge the impact of a health condition on an individual's life.

Appendices

Annex 1: Profile of claimants in Phase 1

Overall, 61 claimants participated in this phase of the research. The interviews and focus groups were structured as follows:

- ESA claimants: 1 focus group; 23 in-depth face-to-face interviews.
- PIP claimants: 3 focus groups; 18 in-depth face-to-face interviews.

Profiles of the participating claimants have been provided in Tables A1 and A2.

Table A1: Profile of participating ESA claimants

Description		Number of participating ESA claimants
Condition type	Sensory impairment	5
	Learning & other	7
	Mental health	10
	Musculoskeletal conditions	8
Awarded status	Awarded	25
	Not awarded	5
Gender	Female	15
	Male	15
Age	18-24	1
	25-34	4
	35-44	4
	45-54	7
	55-64	14
Total		30

Table A2: Profile of participating PIP claimants

Description		Number of participating PIP claimants
Condition type	Sensory impairment	9
	Learning & other	8
	Mental health	8
	Musculoskeletal conditions	6
Awarded status	Awarded	17
	Not awarded	14
Gender	Female	19
	Male	12
Age	18-24	8
	25-34	7
	35-44	2
	45-54	5
	55-64	9
Total		31

Annex 2: Profile of claimants in Phase 3

Overall, 36 PIP claimants participated in this phase of the research, with 33 of them attending focus group and three attending in-depth interviews.

Table A3: Profile of participating PIP claimants

Description		Number of participating PIP claimants
Condition type	Sensory impairment	4
	Learning & other	11
	Mental health	14
	Musculoskeletal conditions	7
Awarded status	Awarded	17
	Not awarded	19
Gender	Female	15
	Male	21
Age	18-24	1
	25-34	10
	35-44	9
	45-54	8
	55-64	8
Total		36

Annex 3: Additional information relating to the PIP application presented to research participants

This note explains how DWP assesses your claim for PIP. It's for information only, so you do not need to read and understand it in order to apply for or to get PIP.

Overview of the PIP application process

Entitlement to PIP is **not based on your medical condition or disability**. It is based on **how your medical condition or disability affects your ability to undertake certain everyday activities**. The PIP assessment is therefore not a medical assessment to diagnose a condition and its severity, or to recommend treatment options. It is an assessment of your ability to do certain everyday activities. DWP assess this by allocating points depending on the extent to which someone can or cannot do a particular activity. The amount of PIP paid directly depends on the number of points you score.

The PIP questionnaire is a crucial source of information which forms part of the evidence of your ability to do certain daily activities. If more information is needed, you will be asked to attend a face-to-face assessment. This will give you the opportunity to explain how your impairment or health condition affects you.

How the assessment works

DWP wants to understand how your health condition or disability affects you when doing a series of **12 everyday activities**. There are ten daily living activities and two mobility activities. This is because PIP is made up of two separate parts, a **daily living part** and a **mobility part**. People can get either the daily living part, the mobility part, both or they can get neither.

Entitlement to the daily living and mobility part of PIP depends on the extent to which you can undertake these activities. Each activity has a list of descriptors that set out the extent to which someone can undertake the activity. **Each descriptor is associated with a different number of points**. The PIP decision maker considers all the evidence provided and decides for each activity which descriptor is the most appropriate choice for you and awards the relevant points for that activity. DWP refer to this as a **functional assessment**.

For each activity DWP is asking you to tell them whether or not and to what extent you can do the activity. That means telling them things like:

- what assistance or aids you need
- how long it takes you to do the activity
- whether doing the activity means you may have pain, discomfort, breathlessness, fatigue, anxiety or other effects

- whether you can do the activity whenever you need to or whether fluctuations in your condition mean that completing the activity depends on how you are feeling. If so DWP wants you to tell them about your best and worst days and how many good and bad days you have

You must be able to carry out an activity safely, repeatedly, within a reasonable time period and to an acceptable standard. “Safely” means in a manner unlikely to cause harm to anyone during or after completion of the activity. “Repeatedly” means as often as is reasonably required to be completed. “Reasonable time period” means up to twice as long as the maximum period that someone without a physical or mental condition would take to complete the activity. “Acceptable standard” means to carry out the activity to a standard that is good enough.

The 12 everyday activities

Daily living (10 activities):

- preparing and cooking a simple meal
- taking nutrition
- managing therapy or monitoring a health condition
- washing and bathing
- managing toilet needs or incontinence
- dressing and undressing
- communicating verbally
- reading and understanding signs, symbols and words
- engaging with other people face-to-face
- making budgeting decisions

Mobility (2 activities):

- planning and following journeys
- moving around

PIP entitlement by points

If your total point score for the **Daily Living** activities is

- 7 or less you will not be eligible for the Daily Living part of PIP.
- 8 to 11 points you may be eligible for **the standard rate of the Daily Living** part of PIP.
- 12 points or more you may be eligible for the **enhanced rate of the Daily Living** part of PIP.

If your total point score for the **Mobility** activities is

- 7 or less you will not be eligible for the Mobility part of PIP.
- 8 to 11 points you may be eligible for the **standard rate of the Mobility** part of PIP.

- 12 points or more you may be eligible for the **enhanced rate of the Mobility** part of PIP.

The full breakdown of how points are awarded is shown in the table below.

ACTIVITY	DESCRIPTORS	POINTS
1. Preparing food	a. Can prepare and cook a simple meal unaided.	0
	b. Needs to use an aid or appliance to either prepare or cook a simple meal.	2
	c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave.	2
	d. Needs prompting to either prepare or cook a simple meal.	2
	e. Needs supervision or assistance to either prepare or cook a simple meal.	4
	f. Cannot prepare and cook food.	8
2. Taking nutrition	a. Can take nutrition unaided.	0
	b. Needs (i) to use an aid or appliance to be able to take nutrition; or (ii) supervision to be able to take nutrition; or (iii) assistance to be able to cut up food.	2
	c. Needs a therapeutic source to be able to take nutrition.	2
	d. Needs prompting to take nutrition.	4
	e. Needs assistance to manage a therapeutic source to take nutrition.	6
	f. Cannot convey food and drink to their mouth and needs another person to do so	10
3. Managing therapy or monitoring a health condition	a. Either – (i) Does not receive medication, therapy or need to monitor a health condition; or (ii) can manage medication, therapy or monitor a health condition unaided.	0
	b. Needs any one or more of the following – (i) to use an aid or appliance to be able to manage medication; (ii) supervision, prompting or assistance to be able to manage medication; (iii) supervision, prompting or assistance to be able to monitor a health condition	1

	c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week.	2
	d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week.	4
	e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week.	6
	f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week.	8
4. Washing and bathing	a. Can wash and bathe unaided.	0
	b. Needs to use an aid or appliance to be able to wash or bathe.	2
	c. Needs supervision or prompting to be able to wash or bathe.	2
	d. Needs assistance to be able to wash either their hair or body below the waist.	2
	e. Needs assistance to be able to get in or out of a bath or shower.	3
	f. Needs assistance to be able to wash their body between the shoulders and waist.	4
	g. Cannot wash and bathe at all and needs another person to wash their entire body.	8
5. Managing toilet needs or incontinence	a. Can manage toilet needs or incontinence unaided.	0
	b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence.	2
	c. Needs supervision or prompting to be able to manage toilet needs.	2
	d. Needs assistance to be able to manage toilet needs.	4
	e. Needs assistance to be able to manage incontinence of either bladder or bowel.	6
	f. Needs assistance to be able to manage incontinence of both bladder and bowel.	8
	a. Can dress and undress unaided.	0

6. Dressing and undressing	b. Needs to use an aid or appliance to be able to dress or undress.	2
	c. Needs either – (i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or (ii) prompting or assistance to be able to select appropriate clothing.	2
	d. Needs assistance to be able to dress or undress their lower body.	2
	e. Needs assistance to be able to dress or undress their upper body.	4
	f. Cannot dress or undress at all.	8
7. Communicating verbally	a. Can express and understand verbal information unaided.	0
	b. Needs to use an aid or appliance to be able to speak or hear.	2
	c. Needs communication support to be able to express or understand complex verbal information.	4
	d. Needs communication support to be able to express or understand basic verbal information.	8
	e. Cannot express or understand verbal information at all even with communication support.	12
8. Reading and understanding signs, symbols and words	a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses.	0
	b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information.	2
	c. Needs prompting to be able to read or understand complex written information.	2
	d. Needs prompting to be able to read or understand basic written information.	4
	e. Cannot read or understand signs, symbols or words at all.	8
9. Engaging with other	a. Can engage with other people unaided.	0
	b. Needs prompting to be able to engage with other people.	2

people face to face	c. Needs social support to be able to engage with other people.	4
	d. Cannot engage with other people due to such engagement causing either – (i) overwhelming psychological distress to the claimant; or (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person.	8
10. Making budgeting decisions	a. Can manage complex budgeting decisions unaided.	0
	b. Needs prompting or assistance to be able to make complex budgeting decisions.	2
	c. Needs prompting or assistance to be able to make simple budgeting decisions.	4
	d. Cannot make any budgeting decisions at all.	6
11. Planning and following journeys	a. Can plan and follow the route of a journey unaided.	0
	b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant.	4
	c. Cannot plan the route of a journey.	8
	d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid.	10
	e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant.	10
	f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid.	12
12. Moving around	a. Can stand and then move more than 200 metres, either aided or unaided.	0
	b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided.	4
	c. Can stand and then move unaided more than 20 metres but no more than 50 metres.	8
	d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres.	10

	e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided.	12
	f. Cannot, either aided or unaided – (i) stand; or (ii) move more than 1 metre.	12

What to expect if you are invited to a face-to-face assessment

A Health Professional will carry out the assessment for DWP and will:

- gather and record relevant information about all the health conditions or impairments that affect you
- record a brief summary of treatments or interventions, and how effective they have been, and whether any further intervention, such as physiotherapy or a surgical procedure, is planned
- record a concise and relevant social and occupational history
- invite you to talk through all the activities you carry out on most days, from when you get up to when you go to bed
- explore any variability or fluctuation in your condition and functional ability by asking you what you can do on ‘good’ days and what you can do on ‘bad’ days and how many ‘good’ and ‘bad’ days you have over a period of time
- make informal observations of abilities and limitations not mentioned in the claimant questionnaire, supporting evidence or during the information-gathering part of the face-to-face consultation
- examine areas of function relevant to your health condition or impairment, tailoring these to the nature of the health conditions present to cover one or more of:
 - mental functioning
 - vision
 - cardiorespiratory system
 - musculoskeletal system

Informal observations form part of the PIP assessment because they can add to the information that is available to the Health Professional. They may, for example, indicate that a person has problems not referred to elsewhere (i.e. in the claimant questionnaire, supporting evidence or during the history taking for the face-to-face consultation), or give a clearer indication of how people are affected by certain aspects of their health condition or disability.

Observations will only be made during a face-to-face consultation. They won’t be made through things such as CCTV or observation of the car park through a window. They also won’t be done by anyone other than the Health Professional, such as a receptionist. And although informal observations are always considered in the context of fluctuations in someone’s health condition, sometimes the observations are inconsistent with what has been claimed.

There is further information about the informal observations in section 1.6.31 to 1.6.35 of the PIP Assessment Guide:

<https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-1-the-assessment-process#face-to-face-consultation>

The functional examination will be different from the clinical examination you might get at your GP's surgery because the Health Professional is not trying to make a diagnosis of your condition.

A fuller description of the process, if you need it, can be found at:

www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-1-the-assessment-process