

Research report

Personal Independence Payment user-centred design: Strand 1 report

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Department for Work and Pensions

Research Report No 794

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Becky Duncan

A report of research carried out by IFF Research Ltd on behalf of the Department for Work
and Pensions

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First published 2012.

ISBN 978 1 908523 56 3

Views expressed in this report are not necessarily those of the Department for Work and Pensions or any other Government Department.

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Acknowledgements

This research was commissioned by the Department for Work and Pensions (DWP).

We are very grateful to the guidance and support offered throughout by the Insight team at the DWP and particularly to Natalie Rhodes, Ellie Lusty and Lynn Tarpy.

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

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Lorna Adams and **Katie Oldfield**, Directors, are currently heading up the IFF team responsible for conducting research among customers to inform user-centered design for Personal Independence Payment. Both have considerable experience in researching benefit delivery and equality issues particularly among disabled people.

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John Newton and **Becky Duncan**, Research Executives, completed the IFF team responsible for delivering this study.

Abbreviations

DLA	Disability Living Allowance
DWP	Department for Work and Pensions
ESA	Employment and Support Allowance
GP	General Practitioner
IB	Incapacity Benefit
IS	Income Support
JSA	Jobseeker's Allowance
PIP	Personal Independence Payment

Summary

The Department for Work and Pensions (DWP) is in the process of introducing a new benefit called Personal Independence Payment (PIP), to replace Disability Living Allowance (DLA) from 2013, for people of working age (16-64). The DWP is currently undertaking a programme of consultation to influence the design of the new benefit.

As PIP is a new benefit, the process of turning policy into delivery provided DWP with a unique opportunity to design the application process from scratch. Alongside the broader programme of consultation, IFF research was, therefore, commissioned to establish a panel of people in order to carry out a programme of user-centred design research. This is research that seeks to place the user's/potential user's needs and wants at the heart of the design of the claims process.

In practice, this programme of user-centred design will consist of a series of individual research studies, conducted between 2011 and 2012, each of which will concentrate on understanding users'/potential users' views in relation to a specific aspect of the claims process. Participants in each of these research studies will be drawn from the pool of people recruited to join the panel. The panel consisted of:

- DLA recipients with a physical/mental disability or impairment;
- non-DLA recipients with a physical/mental disability or impairment;
- people without any disability or impairment; and
- formal representatives of DLA recipients.

This report presents the findings of Strand 1 of this research, which aimed to explore how the application process for PIP could be designed to meet the needs of both existing DLA claimants as well as potential PIP claimants. This consisted of 21 focus groups and 46 face-to-face in-depth interviews, conducted in September and October 2011.

The context to the introduction of PIP

Several key themes emerged that did not directly relate to the design of the PIP application process but that nonetheless affect how individuals felt about the proposed new benefit¹:

- There is an expectation that claimants will not be treated well by the DWP.
- There is a commonly-held perception that the outcome of the benefits application process is 'a lottery', i.e. strongly subject to an element of chance.
- Misunderstandings about who DLA is intended to help are commonplace.
- Current DLA claimants do not see any logic in having to make a new claim for PIP.

¹ These expectations are strongly influenced by experiences of DLA, as many of the individuals participating in the research were currently receiving DLA or knew family or friends who had made a DLA claim. As a result, the findings in relation to PIP to some extent mirror research conducted about DLA (see Sections 2.2 and 2.3 for further details).

Key considerations for stages of the customer journey

In order to develop a PIP application 'journey' which individuals could be confident in, they were asked to describe an ideal benefit application process. Many of those involved in the research had at least some experience of making a claim for either ESA or DLA (even if they weren't a current claimant) and the views they expressed tended to be based on these experiences.

Deciding whether to apply: For those currently receiving DLA, applying for PIP was perceived as something they would have to do (i.e. because of needing the money), rather than a choice. The majority of DLA claimants did not see PIP as an entirely new benefit (or indeed different at all – but rather just a name change²) and, as a result, saw their receipt of DLA as a sign of eligibility and argued that they should automatically be transferred onto PIP. Current DLA claimants were particularly anxious that there might be a gap in their benefit payments between DLA ceasing and PIP being awarded.

The consensus was that it was key to communicate both the eligibility criteria and the claims process in 'good time' which claimants generally considered to be between 6 and 12 months before their DLA ended. Individuals wanted this information to be made available in a number of different places, such as General Practitioner (GP) surgeries, Jobcentre Plus and local council offices.

Application: Past experiences of benefit application processes tended to be negative. Individuals found current forms overly-long and difficult to complete, and perceived them to be deliberately repetitive (i.e. in an attempt to 'trick' applicants into contradicting themselves). Simpler, shorter, more tailored forms were requested. Individuals also wanted the opportunity to express their support needs and how their condition affects them in their own words at the start of the form. Current benefits claimants also wanted the DWP to recognise existing relationships with claimants by pre-populating forms with information that the DWP already holds.

Previous experiences of medical assessments tended to involve performing tasks that were thought to be irrelevant or humiliating. Individuals wanted transparency about what the assessment would involve and how this would be used to make a judgement on their eligibility for PIP. All wanted a medical professional of their choice to be involved in some capacity, on the basis that they knew the most about the individual's condition. For many this was their GP, although others definitely did not want their GP to be involved and wanted to be able to choose alternatives, such as a psychiatrist, social worker or consultant.

As there was widespread suspicion of the application process, there was a desire for the DWP to reassure claimants by 'playing back' to them the evidence they had provided throughout the claims process, giving them opportunities to check and add evidence.

Awaiting the decision: For many, applying for a benefit was seen as a daunting process with significant financial implications. Individuals therefore wanted the DWP to confirm that the application had been received and to clearly communicate the timescales for their decision. Many also welcomed proactive updates from the DWP about any delays, and there was interest in a range of communication channels for these updates.

Decision: Individuals wanted a hard copy letter as a written record and to show to others (e.g. when consulting intermediaries, claiming other benefits or as evidence if submitting an appeal). Current DLA award letters were seen as cold and generic, and lacking an explanation of the reasons behind decisions in a way that claimants could understand; leaving many feeling that the DWP was not

² This was despite their being shown stimulus material explaining that PIP is an entirely new benefit that would be introduced after DLA ceased.

recognising they had a health condition. This apparent lack of recognition of evidence provided, together with a view that decisions are regularly overturned at appeal, meant that most current DLA claimants viewed an appeal as the next logical step following disallowance. For some, this message had been reinforced by intermediary organisations and occasionally by DWP staff.

Ongoing relationship: The majority of individuals did not feel it was their responsibility to tell the DWP if their circumstances change. Some expressed concern that any improvement in their condition may be short-lived and were fearful of having to go through the application process again as a result of reporting a change to the DWP.

Communication channels

Individuals expressed preferences for making claims through different channels, but channel choice and flexibility was important to most.

Individuals would like to be able to indicate upfront how they would like to contact, and be contacted by, the DWP. They wanted preferences to be remembered and consistently applied. However, they also wanted there to be flexibility throughout the claim, to adopt a different channel when this assists them (for example, the DWP phoning them to clarify a query on their paper application form; or sending a hard copy record of information given by telephone or online, to enable the claimant to review it).

When it comes to claiming online, past positive experiences included occasions where reassurance was provided that information was being saved and had been submitted correctly (and conversely negative experiences included examples of crashing and lost information). The opportunity to use questionnaire routing in an online form (where irrelevant questions are skipped) was attractive for some claimants. Individuals felt that an online claims process should be accompanied by additional support for those who needed it (through 'help' buttons or visual examples within the online claim form, and/or the option of a helpline should someone get stuck).

The skills and attitude of the person on the other end of the phone was crucial in telephone claims. Many DLA claimants described negative past experiences of discussing their claim over the phone and felt that call handlers displayed minimal empathy or compassion. There were concerns about the level of lack of familiarity with claimants' conditions on the part of DWP staff who handle the calls.

Positive telephone claim experiences included features such as being able to request a call-back if the individual became fatigued, being able to call someone back to 'validate' an unsolicited call, call handlers going 'off-script' to ensure the conversation was more personalised, having a named individual or team of individuals handling a case, being spoken to with a sympathetic tone, and being sent hard copy confirmation of what had been discussed by phone.

Key issues for sub-groups

Discussions with small samples of individuals from specific customer sub-groups tended to reflect the views and experiences raised by individuals generally (as described above). However, there were some respects in which specific customer sub-groups shared slightly different views or experiences.

For **transitional claimants (who had recently moved onto adult DLA after turning 16)**, the process of making a claim typically involved making key decisions about who would take control of their adult benefit payments. This was in the wider context of also having to prepare for their adult life with an impairment or health condition – making this transition phase a difficult time for claimants. There was therefore a strong desire for as much information as possible about PIP to arrive well in advance

of the claimant's 16th birthday, and a need for particular sensitivity around how the outcome of a PIP application is communicated.

Interviews with claimants' **organisational representatives** revealed considerable knowledge of the benefits system and a desire to be kept up to date with the details of the benefit reforms. Some representatives (typically those in a healthcare role) wanted greater involvement in the application process and for their account of a claimant's condition to carry greater weight than they felt it does at present. **Personal formal appointees** tended to feel guilty or uncertain about how benefit payments should be used and sought greater clarification or guidance here. There was also demand among this group for further guidance on reporting changes in circumstances.

Individuals who had previously been **disallowed DLA** were negative about the application process, feeling that they had not been able to fully explain their condition and how it affected them. They felt a new benefit application process should have an improved outcome notification stage, involving signposting disallowed claimants to an ombudsman, giving a helpline where you could get personalised feedback on the reasons for the decision and signposting to other organisations that could provide information and support for their condition. Some felt that individuals who had been unsuccessful in their previous DLA claims would be deterred from applying for PIP.

Individuals with **sensory impairments** highlighted the value of telephone calls in informing them that important written information had been sent out and in allowing them to give their claim details over the phone (with written confirmation then being sent of the evidence given over the phone).

Underpinning values

Individuals' views on an ideal benefit application process have been analysed and a set of ideal values that should underpin the development of the claims process for PIP have been identified by the research team. By informing how the claims process is designed, these values have the potential to:

- guide DWP decision-making about the design of every aspect of the PIP claims process, so that it delivers the experience that individuals have told us they would ideally want;
- support delivery of DWP's business objectives for PIP, i.e. designing a claims process that is simple to administer, easy to understand, fair and supports people who face the greatest challenges to remaining independent and leading full and active lives;
- increase individuals' trust in the claims process and confidence in its outcomes, therefore helping to achieve operational benefits (e.g. in terms of minimising unnecessary claims and appeals).

In practice, trade-offs may be needed between these values, the costs of implementing them and the potential operational benefits.

These underpinning values fall into three broad types, according to what they contribute to the claims process.

Firstly, there are values that help to make the claims process **credible**, from the individual's perspective. This involves the process being **professional/expert**; and **consistent**.

Examples of what this might mean in practice included: ensuring DWP staff are experts in the PIP claims process and in 'soft skills' such as listening rather than being specifically medically trained themselves; involving the individual's choice of relevant medical staff at key points; and ensuring decisions are made according to consistent criteria.

Secondly, there are values relating to **transparency**, i.e. that the process should be **simple, clear and easy; open and trustworthy; and reassuring and supportive**.

In practice, this might mean having clear upfront explanations of the purpose of PIP and associated eligibility criteria; avoiding repetition of similar questions within claim forms; allowing the individual to choose the channel by which they communicate with DWP; and clear explanations of how decisions were reached and validated by quality-assurance.

The third set of values is those that help ensure the individual receives **appropriate treatment** within the claims process. To do this, individuals felt that the process needed to be **respectful and empathetic; flexible and personalised; and allow the individual to be recognised and heard**.

In practice, this would ideally mean maintaining an adult-to-adult tone throughout communication with individuals and avoiding sceptical treatment of individuals; allowing individuals to express their situation and support needs in an open-ended way; 'playing back' to individuals what they have already said; and building in opportunities to review, amend and add to evidence.

Other conclusions

The other key conclusions that can be drawn by the research team from this first strand of research conducted with the PIP user-centred design panel are that:

- with expectations at a low level, the introduction of PIP presents an opportunity to signal a break with perceived poor treatment in the past and to develop processes and procedures that deliver a better claimant experience;
- while some of the requests for changes in the PIP application process might have significant delivery implications, there is scope for considerable improvements in the claimant experience to be achieved through change in the tone of interactions throughout the process from written correspondence, staff contacts and approach to assessment. It will be particularly important to reassure claimants that the DWP does not doubt that they are disabled or unwell even if they are not eligible for PIP;
- some of the more structural considerations that could help to ensure a significantly more positive application experience under PIP than claimants feel that they have received under DLA revolve around incorporation of:
 - a better institutional memory of claimants for example, retaining and using reported preferred methods of communication;
 - tailoring of the process to customer needs;
 - building in review phases so claimants can check and accept or amend the details they have provided (and, perhaps, what has been written about them);
 - a clear response to all evidence provided;
- it is likely to be very important to involve intermediary organisations in the delivery of PIP. Historically, organisations have met the need for face-to-face assistance in completing applications that some claimants feel that they will need and this is likely to continue. Encouraging claimants to consider asking a representative from a support organisation to accompany them to a face-to-face assessment may help to ensure that this process records (and is seen to record) claimants' situations more accurately;
- the outcomes of appeals lodged in the first few months following the introduction of PIP will be very important in determining how individuals respond to having their claim to PIP disallowed. It is important, therefore, to ensure that any training on making consistent decisions (for DWP staff as well as staff in the Tribunals Service) is delivered well in advance of the introduction of PIP.

1 Introduction and background

The Department for Work and Pensions (DWP) is in the process of introducing a new benefit called 'Personal Independence Payment' (PIP) to replace Disability Living Allowance (DLA) from April 2013 for working age people (16-64). It aims to help those people with a long-term illness or impairment with the extra costs they may face due to their condition. PIP is being designed to consider an individual's personal circumstances and the support they need.

People currently receiving DLA will be asked to make an application for the new benefit between 2013 and 2016, as DLA for working age claimants (16-64) is ceasing. All DLA recipients between 16 and 64 will be invited to make a new claim to PIP. There are no current plans to replace DLA with PIP for children aged under 16 and people over the age of 65 who are already receiving DLA.

The DWP is undertaking consultation work to feed into the design of the new benefit and is talking to its staff and to people in voluntary and charity organisations who represent disabled people about how best to make the changes.

As PIP is a new benefit, the process of turning policy into delivery has provided DWP with a unique opportunity to design the application process from scratch. Alongside the broader consultation, DWP is, therefore, undertaking a programme of user-centred design research which seeks to place the user's/potential user's needs and wants at the heart of the design of the claims process.

IFF research was commissioned to establish a panel of people in order to carry out this user-centred design research. In practice, this programme of user-centred design will consist of a series of individual research studies, conducted between 2011 and 2012, each of which will concentrate on understanding users'/potential users' views in relation to a specific aspect of the claims process.

Participants in each of these research studies will be drawn from the pool of people recruited to join the panel. The panel consisted of:

- DLA recipients with a physical/mental disability or impairment;
- non-DLA recipients with a physical/mental disability or impairment;
- people without any disability or impairment; and
- formal representatives for DLA recipients.

This report covers the findings from Strand 1 of the programme of user-centred design research. Strand 1 in effect offered individuals virtually a 'blank sheet of paper' and asked them to describe their ideal application process for the new benefit, drawing on their positive and negative experiences of other applications processes. Strand 1 involved IFF conducting 21 focus groups and 46 face-to-face depth interviews in five locations across the UK. The research was conducted in September and October 2011 and participating individuals included both those who currently claim DLA and those who do not currently claim DLA, but may need to claim PIP in the future. Those individuals who took part had a wide range of impairments and support needs.

1.1 Aims and objectives

The business objectives for DWP for PIP is to design a benefit process that is:

- simple to administer;
- easy to understand;
- fair; and
- supports people who face the greatest challenges to remaining independent and leading full and active lives.

In order to help DWP achieve these business aims, Strand 1 of the research programme consulted customers on the design of the end to end process of a benefit claim.

The overall research objectives of Strand 1 therefore were to:

- explore communication approaches that would ensure those who need PIP make a claim, and therefore find out where people would go to get further information;
- understand the information claimants would need to help decide whether to make a claim to PIP and therefore minimise the number of claims by people who are not eligible;
- understand how to make the claim process transparent and clear and as such build confidence in the assessment and decision process;
- explore the best ways to communicate with claimants, particularly in terms of the award decision; and
- learn about how customers currently claiming DLA feel about the need to apply for PIP, how the migration should work and what communication channels are most appropriate for different customers.

1.2 Methodology

DWP provided a sample from its current database of claimants to IFF for the recruitment of individuals to the panel. The sample of current claimants was organised into different persona groups³ in order to ensure coverage of a wide range of current claimants according to current award level of mobility, care needs and recency of decision. Those claimants who have an appointed formal representative were also included as a separate group, so that the views of those going through the application process on behalf of someone else could also be understood.

In addition, four further groups were recruited on a free-found basis to ensure that views were also heard from people who are not currently claiming DLA. These groups involved people who have an impairment and might claim PIP in the future and also people from the general population who do not currently have any disabilities, but may need to apply for PIP in the future on behalf of a friend or relative, or due to a change in life circumstances themselves.

³ These persona groups were devised by the DWP as a means of using data held by DWP (on type of support needs, recency of receiving DLA decision and age) to identify groups of individuals who may potentially have shared characteristics and who may, therefore, need specific types of support within the PIP claims process (see Table 1.1 for a description of each persona group).

Descriptions of these persona groups are outlined here:

Table 1.1 Overview of personae

Persona	Description
1A	Possible future PIP claimants, non-recipients of DLA, aged 16-45 years
1B	General public (not disabled), aged 16-45 years
2A	Possible future PIP claimants, non-recipients of DLA, aged 46 years+
2B	General public (not disabled), aged 46 years+
3	Formal representatives (personal) of DLA claimants
4	DLA claimants with physical walking difficulty, frequent care needs, no recent decision
5	DLA claimants with physical walking difficulty, limited/no care needs, no recent decision
6	DLA claimants with physical walking difficulty, decision in last three years
7	DLA claimants that need guidance or supervision out of doors, no recent decision
8	DLA claimants that need guidance or supervision out of doors, decision in last three years
9	DLA claimants with no difficulty getting around out of doors but have care needs

Prior to being approached about the research, individuals in the sample provided by the DWP were sent an opt-out letter providing some details about the research programme. Once the opt-out period had passed, individuals were approached by telephone to enquire about their interest in being part of the panel. At this point willingness to participate in different research formats (focus group or interview) was explored and any special requirements were recorded.

For Strand 1, 21 focus groups and 46 face-to-face depth interviews were carried out across five locations; Leeds, London, Edinburgh, Manchester and Cardiff. The mix of group discussions and one-to-one interviews was selected to maximise the chance of individual panellists being able to participate (for instance, those who found it difficult to travel to the central locations in which the discussions were held, or who were not comfortable with discussion in a group, were included in this way).

Focus groups were used to capture the views of the majority of individuals. By interacting with other people in similar circumstances an environment was created which allowed participants to bounce ideas and experiences off each other and so creatively discuss the possible modifications and improvements to the claim process. The number of attendees for each focus group ranged from five people in some to a maximum of nine participants in others. Each group discussion typically lasted 90 minutes.

Table 1.2 summarises the composition and location of the focus groups.

Table 1.2 Overview of fieldwork approach – focus groups

	Leeds	London	Edinburgh	Manchester	Cardiff	Total groups
Persona 1A	X				X	2
Persona 1B		X				1
Persona 2A		X				1
Persona 2B			X			1
Persona 3				X		1
Persona 4	X		X			2
Persona 5		X		X		2
Persona 6	X			X	X	3
Persona 7	X	X			X	3
Persona 8		X	X			2
Persona 9			X	X	X	3
Total	4	5	4	4	4	21

A number of qualitative interviews were also undertaken as part of Strand 1. The interviews explored the same issues as were discussed in the focus groups and lasted around 45 to 60 minutes on average.

Respondents participating in depth interviews included:

- those who felt unable to participate in a group discussion (which included a number of formal appointees with caring responsibilities);
- organisational representatives (such as solicitors, housing departments and local council staff); and
- representatives of specific booster groups identified by the DWP as being of key importance to the project, e.g. individuals with very specific requirements such as people with sensory impairments.

Face-to-face interviews were used to allow a detailed exploration of these individuals' experiences and specific circumstances.

Table 1.3 outlines these depth interviews by respondent type and number of interviews conducted.

Table 1.3 Overview of fieldwork approach – depth interviews

Respondent type	Number of interviews
Unable to participate in group sessions	11
Formal (personal) representatives	5
Organisational representatives	5
Transitional customers	5
Individuals disallowed DLA	5
Individuals with sensory impairments	5
Individuals with chronic fatigue syndrome	3
Individuals with epilepsy	2
Individuals with learning difficulties	3
Individuals with autistic spectrum disorders	2
Total	46

Both the group discussions and the interviews involved an open exploration of the whole process of applying for PIP and the priorities for individuals at each stage. Individuals were asked to draw on their experiences of other application processes and to think beyond these to design a new process 'from scratch'. To structure the discussion, individuals were asked to think about the different stages of an application process, namely:

- Deciding whether to apply.
- Making an application.
- Awaiting the decision.
- The decision; and
- The ongoing relationship.

All interviews and group discussions were recorded on encrypted digital voice recorders. Where permission was given by all respondents, group discussions were also video-recorded. The audio of all groups and interviews were transcribed following the interview. Transcripts were then analysed thematically in order to produce the research findings. Interview transcripts were entered into an analysis framework which allowed analysis both overall by the different stages of the process and across booster subgroups.

All topic guides used in the research can be found in Appendix A-C.

1.3 Report structure

The remainder of the report is structured into four chapters of findings (Chapters 2 to 5), a chapter covering the overarching themes that emerged from the research and a final conclusions and recommendations chapter.

- Chapter 2 discusses the context within which individuals viewed the claim process.
- Chapters 3 and 4 explore the various stages of the claim process and individuals' feelings towards different communication channels.
- Chapter 5 covers some additional findings which came out of the research concerning individuals with particular impairments or in specific situations.
- Chapter 6 outlines some of the themes that underpin the process of claiming for a benefit.
- Chapter 7 presents conclusions and recommendations from the research.

1.4 A note on the reporting approach

Throughout this report, all suggestions made about the ideal design of the PIP application process were explicitly made by individuals participating in the research, except where we have stated otherwise (i.e. suggestions that have been made by the research team, building on individuals' feedback, are clearly described as such, through the use of phrases such as 'in our view', 'our assessment is that...' and 'we believe that...').

2 Context of introduction of Personal Independence Payment

This short chapter summarises some of the key themes that emerged from many of the group discussions and depth interviews and that – while not directly related to the potential design of the Personal Independence Payment (PIP) application – nonetheless coloured the way in which individuals felt about the new benefit. Many of these are issues that have been raised frequently in previous research⁴.

The themes dealt with in this chapter were expressed by most of the current Disability Living Allowance (DLA) claimants that we spoke to. Similar comments also tended to be made – albeit to a lesser extent and with less strength of feeling – by possible new claimants with existing disabilities, many of whom were familiar with the benefits system (either from claiming benefits such as Employment and Support Allowance (ESA) and/or Jobseeker’s Allowance (JSA) themselves, or by hearing about the DLA claims process from friends or family). There was no notable pattern of differences in the views of current DLA claimants and those of possible new claimants with existing disabilities, in relation to the issues discussed in this chapter.

On the other hand, members of the general public without any current disability tended not to raise the issues discussed in this chapter at all (as a result of their lack of experience of benefits claims processes).

The key background themes that emerged from those who had personal experience of the benefit claim system are that:

- individuals do not expect to be treated well by the Department for Work and Pensions (DWP);
- there is a commonly held perception that the outcome of benefit claims is subject to a ‘lottery’ or chance element;
- there is widespread misunderstanding about what DLA is for and who it is intended to help; and
- current claimants do not see any logic in having to make a new claim for PIP.

Each of these is discussed in more detail below.

2.1 Expectation of poor treatment

The majority of current and unsuccessful DLA claimants had negative feelings about the process that they went through when applying for DLA and as a result do not expect to be treated well by the DWP.

‘[DWP] make you feel dirty because you’re saying I need a bit of financial assistance ... I’ve gotten very, very sick, physically and mentally and when you’ve been seeing your own psychiatrist, therapist, psychotherapist, doctors, GP and they’re all on the same page ... I’ve been declined. [It] just put me off the whole process.’

(Female, Persona 1a, Leeds)

⁴ These issues are strongly influenced by experiences of DLA, as many of the individuals participating in the research were currently receiving DLA or knew family or friends who had made a DLA claim. As a result, the findings in relation to PIP to some extent mirror research conducted about DLA (see Sections 2.2 and 2.3 for further details).

More detail about the specific types of negative experiences that claimants had is provided in later chapters of this report but there was a general feeling that the DLA application process was opaque, i.e. that there was a lack of clarity about how the system works. There was also a sentiment expressed that the process was sometimes degrading and often impersonal for example, decision letters did not address to the applicant by name and terminology often left them feeling that the Department doubted their disability/condition was not real.

In our view, these negative experiences mean that customers are likely to approach the new process for claiming PIP with some degree of suspicion and with the expectation that they will not be treated well.

2.2 Belief that the benefit application process is a lottery

Claimants did not generally have confidence that the process of assessing DLA claims was consistent. For some this was reinforced by their own personal experiences of having decisions changed following an appeals process. Others had experiences of award levels changing following re-assessments which they felt were unjustified because their health condition had not changed. Others drew on their knowledge of other people who they considered to be in a similar situation to themselves but who had received different outcomes from their applications; this seems to be borne out of people thinking that a specific rate of DLA is based on condition as opposed to the severity of the condition or on an individual's ability to cope with their situation. The perception that there is an element of luck in the outcome of an application led some individuals to view the application process with distrust. Because many people had experience of a successful appeal themselves or knew someone who had, this meant individuals were less likely to trust DWP or the decision given if it was unfavourable. As a result they tended to see appeals as very much part of the process of securing the benefit and the logical step to be taken on being disallowed⁵.

'I know cases that have been decided based on mistakes that have been made internally ... they hadn't given proper consideration to the information – it depends whose desk it falls on.'

(Male, Persona 9, Manchester)

In our view, this belief means that claimants will need considerable reassurance that the application process for PIP is fair and consistent and that there is not a need to appeal against disallowance simply to counter the possibility that the outcome was the result of luck or chance.

2.3 Misunderstandings about DLA

Claimants were quite commonly unclear about how eligibility for DLA was assessed and the different levels of payments that were made. There was a quite widely held belief that DLA was a benefit only for those not in work (rather than available to those both in and out of work). This led customers to

⁵ As noted, this echoes previous research. A qualitative study conducted with 100 people who had made a claim for DLA which had been initially disallowed found that there was a high number of speculative applications, with some of these applicants expressing 'the strong view that the entire process was essentially one of chance and, like a lottery, you couldn't win if you didn't enter' (from 'Disability Living Allowance: Disallowed claims' by Andrew Thomas: DWP Research Report Number 490, 2008).

believe that in order to be eligible for DLA they had to prove that they were not able to work⁶.

'I was on benefits before that but when you are ill ... normally when you go to something like this you are not working, you don't work, that's what she basically told me. Well, you'd be better off not working ... that is the advice basically she gave me.'

(Female, Persona 7, Leeds)

Issues of limited knowledge about DLA and misunderstandings about the benefit present challenges in terms of communicating the introduction of PIP. During the research, PIP was introduced to claimants as a new benefit that would be introduced after DLA ceased. Despite this, many DLA claimants simply saw PIP as the rebranding of DLA and thought it was 'just a name change'. Some did not see the differences between the two benefits and – in our view – without a reasonable understanding of the eligibility and assessment process for DLA, it will be difficult for claimants to understand how PIP differs.

2.4 Perceived lack of logic in migratory customers making a new claim

Current claimants struggled to understand why they would need to re-apply for PIP. There was a strong feeling among claimants that it was unreasonable for them to have to take part in a re-assessment process. Generally, claimants felt that the information provided for their DLA claim should be used to transfer their claim automatically across to PIP, which we believe highlights the necessity to explain that PIP is a completely new benefit.

'Me personally, I wouldn't like to spend my time sitting there filling in forms. If I filled in a form once telling you about my disability – if it's the case I know my fits are never going to get better, my personality disorder's never going to go away, my bipolar may become a bit better that I'm able to cope and live with it but it's never going to get better – for me to know that next year I have to go and fill in the exact same forms I've already filled in and my condition hasn't changed in any way, that's a waste of time to me.'

(Female, Persona 8, London)

Hence, claimants tended to view the introduction of PIP with suspicion. Many assumed that the key reason for the change was a need to save public money through reducing the size of the claimant population or the level of awards. Customers anticipated that savings would be made through lowering payments for certain conditions, excluding those who are employed that receive DLA or excluding from PIP some customers who are currently on 'lower' awards of DLA.

⁶ As noted, this mirrors previous research on DLA. For instance, Carol Goldstone Associates found 'some evidence that many people who apply for DLA are unaware that it is a non means tested benefit and can be claimed whether or not they are in work'; while Andrew Thomas reported that 'the most evident misunderstanding about DLA was its confusion with out-of-work benefits', with 'a great many of the disallowed claimants ... under the impression that, like Incapacity Benefit (IB)...being out of work was a sufficient condition for receiving it'. Evidence cited is from 'Knowing and understanding Disability and Carers Service customers' by Dr. Janine Hawkins, Dr. Carol Goldstone and Meena Bhagat (DWP Research Report Number 439, 2007); and 'Disability Living Allowance: Disallowed claims' by Andrew Thomas: (DWP Research Report Number 490, 2008) respectively.

'My concern is because I work and I can, when I am well I can live a normal life. I think when I reapply for that, they would view me that I can actually work some of the time, and I don't think I'll get it, I think it'll be taken away from us.'

(Female, Persona 7, Leeds)

While a few felt that making savings on DLA payments was justified in the context of the current economic climate, for the most part claimants felt that making cuts in the benefits available to disabled people was unfair.

We believe that the key recommendations arising from this chapter are that:

- There will be a need to build trust in, and understanding of, the PIP claims process, by providing clear eligibility criteria and creating an assessment process that is easy to comprehend.
- In order to successfully communicate both the eligibility criteria and how the claims process works, it will be essential to communicate that PIP is an entirely new benefit and combat misconceptions that PIP is merely a 'change of name'. This represents an opportunity to dispel myths associated with DLA by explaining that PIP is a universal benefit, awarded on the basis of someone's care and mobility needs, not on their medical condition or working status. This will also be key in order to explain to current DLA claimants why they need to make a new application for PIP.
- An assessment system which gives multiple opportunities for people to check information provided, and which asks for additional evidence where needed, will be required in order to overcome the perception that benefit claim decisions are subject to a 'lottery' or chance element.

3 Key considerations for stages of the customer journey

On the whole, individuals tended to be nervous and concerned about Disability Living Allowance (DLA) coming to an end and PIP being introduced. The views and experiences raised about the application process tended to be based on past experience of DLA and Employment and Support Allowance (ESA) applications.

Deciding whether to apply: The majority of individuals did not see PIP as new benefit. Current DLA claimants felt that their receipt of DLA should be treated as an indication of their eligibility for PIP. Hence there is a need to persuade claimants of the rationale for the introduction of PIP and how it differs in principle from DLA. All would expect Department for Work and Pensions (DWP) to produce communication materials about PIP that would be made available in a number of different places, such as General Practitioner (GP) surgeries, Jobcentre Plus and local council offices.

Application: Past experiences of benefit application processes tended to be negative. Individuals found current forms difficult to complete, seeing them as purposefully complicated, repetitive (in order to catch people out) and long. Simpler, shorter more tailored forms were requested. Claimants also felt that forms should be pre-populated with information that the DWP already holds.

Individuals tended to view medical assessments as degrading and humiliating. There was a strong request by some that the assessment be administered by their own GP who had full knowledge of their medical history. Some, however, did not want their GP involved in either the assessment or provision of evidence and instead wanted to choose alternative professionals to give evidence, such as a psychiatrist, social worker or consultant.

Individuals tended to be quite suspicious of the DLA application process and many felt that it was deliberately designed to trick people. Most had little faith in the consistency of the decision process. Therefore, 'playing back' what people said and giving them options to add evidence throughout the process may help.

Awaiting the decision: For many applying for a benefit was seen as a daunting process, with important financial implications, so individuals want to be given set timeframes for processing of their claim and said they would contact DWP if there was a delay. An option to request updates on the progress of their claim would provide reassurance for some.

Decision: Current DLA award letters were seen as cold and generic, some mentioned not being addressed by their names and did not feel letters acknowledged they were ill. Some current claimants felt that lodging an appeal was an automatic response to receiving a disallowance decision.

Ongoing relationship: The majority of individuals did not see it as their responsibility to inform the DWP of any changes in their condition. Some expressed concern that any change may just be short-term and were fearful of triggering a new application process.

In order to develop a PIP journey which individuals were confident in, they were asked to describe an ideal benefits application process, which would be easy to use and that would suit them. To help develop this ideal application process the customer journey was split into five chronological steps:

- Deciding whether to claim;
- The application process;
- Awaiting the decision;
- Receiving the decision itself; and
- The ongoing relationship with the DWP.

Each stage was discussed in turn, with individuals being prompted to describe and explore what was important to them. This included factors such as: type and level of contact with DWP staff, the timings of contact, and level of support/information needed from DWP and/or other intermediaries. Individuals were encouraged to consider what they would ideally like from each stage of the journey, as well as commenting on what they had not liked about any previous claims processes.

The majority of those taking part in the research were claiming DLA although a small number of people were not. Many of these (as well as some of those who were not claiming DLA) were also claiming ESA or had made a claim due to illness or disability in the past. Therefore, although some other application processes were mentioned, many of the comments made and topics that were raised in the research drew on individuals' past experiences of DLA and – in some instances – the ESA application process. Some current claimants were confused about the distinction between DLA and ESA, often referring to the application processes for these two benefits interchangeably.

3.1 Deciding whether to claim

When asked to consider what information individuals would like to be available to aid their decision on whether to claim PIP or not, a wide range of types of communication were mentioned, such as leaflets, booklets, posters, advertisements and information online. The GP surgery was suggested by many individuals as somewhere they felt the information should be available. GPs in particular were mentioned as playing a key role in setting their expectations as to whether or not they would be eligible for PIP.

'If your doctor knows that you've got an illness, your doctor should be able to tell you, go and speak to so and so, they'll give you advice on [the] benefit.'

Maybe the medical profession needs to be brought in to say, well, look, this is [a new benefit] – and give [people] more awareness.'

(Discussion in Persona 9, Cardiff)

There were a number of other places where individuals suggested they should be able to find out information about PIP. This included from intermediaries such as the Citizen's Advice Bureau, Jobcentre Plus, social or mental health support workers, council offices and charity organisations, such as Age UK. Therefore we believe that early engagement by DWP with these sources of support to explain PIP eligibility may help to minimise inappropriate referrals. Similarly signposting people to intermediaries who may be able to offer services – such as counselling or support groups, social services or charity groups – could be more relevant for an individual than claiming PIP and so may be beneficial. In our assessment, where PIP is unlikely to be awarded and when alternative help may be more applicable, having details of other support agencies may reduce the number of nugatory claims (i.e. by suggesting to some potential claimants an alternative avenue to pursue, rather than making a claim for PIP that is unlikely to succeed).

In addition, previous DWP research suggests that the perception that DLA claims are a 'lottery' encourages nugatory claims, i.e. even if there is little likelihood of being awarded DLA, the perceived 'element of chance' means that it is worth making an application, as there is a slight possibility that the effort of making an application may result in payments being made as a result of an application 'falling through the chinks' in the system⁷.

Individuals felt any promotional materials developed by the DWP would need to be in a variety of formats, such as Easyread, Braille, or large print for example, so that they would be accessible for anyone with special requirements such as sensory impairments, or learning difficulties. Most wanted these materials to explain what PIP is and the reason for the change from DLA to PIP.

They expressed a desire to know upfront how the application process would work and more specifically the eligibility criteria on which PIP would be awarded. In order to understand how PIP would affect their finances individuals also felt they would need to receive information regarding how much money they would be able to get, what the money should be used for, such as whether the money can be used for food or transport or living costs in general. Individuals also wanted information about any potential effects that receiving PIP could have on other benefits or sources of income they were currently receiving, before applying for PIP.

Many current DLA claimants felt they would need a lot of information from the DWP and that this would be better delivered as a pack of information, rather than just a letter. Current DLA claimants thought the following information should be included in the pack:

- An explanation of the reasons behind the decision to stop DLA.
- What the differences were between DLA and PIP and specifically why the new benefit was being introduced.
- Details of the application process (in comparison to DLA).
- What evidence would be needed.
- The specific eligibility criteria.
- The levels of award that could be received.

Generally, current DLA claimants expected DWP to send information about PIP through the post. However, a few individuals (particularly those with mental health issues) expressed concern that they might ignore communication in the post and felt that they might need additional contact to ensure they read, understood and acted on the information enclosed.

'[When receiving unexpected post] as soon as the brown envelope lands on your doorstep you go 'God, what now?'

(Male, Persona 4, Leeds)

Two common likely misconceptions that were highlighted by the research were that PIP would be:

- an out of work benefit only;
- assessed and awarded purely on a condition basis (and that therefore medication levels were also assessed).

These misconceptions were based on current misconceptions of DLA. We believe that there is, therefore, an opportunity for the communication around the introduction of PIP to counter these

⁷ *Disability Living Allowance: Disallowed claims'* by Andrew Thomas: (DWP Research Report Number 490, 2008).

ideas by positioning PIP as a universal benefit, and while recognising that all those applying are unwell, explaining that PIP is awarded on the basis of care and support needs and not medical condition.

A few current DLA claimants had researched PIP before attending the research groups. In our view, this identified a risk that these individuals may seek out misinformation before official guidance has reached them, as not all the information shared by individuals that had done this background research was factually correct.

Most current DLA claimants said that they would want to be told about the changes and the application process in ‘good time’. The average suggestion was between six months to a year before their DLA ended.

Another point commonly raised was that they would require reassurance that their DLA would continue and that there would not be a gap between DLA and PIP payments. Some automatically assumed that there would be a date on which DLA would be stopped and that they would need to apply in good time to ensure there was not a gap in payment. We believe that this would need to be carefully managed as, if not, it could attract a significant amount of nugatory contact.

‘You should have the option to apply for it in enough time so you’re getting [it] before your previous benefit stops.’

(Male, Persona 6, Cardiff)

Generally, the majority of current DLA claimants perceived their receipt of DLA as a sign of eligibility for PIP. Many expressed anger and suspicion at the idea of having to apply for PIP and most thought they should simply get transferred over to PIP automatically – i.e. yet more evidence in our view that communications should highlight that PIP is a totally new benefit. Even when told that they would definitely have to apply for the new benefit, most still referred to the process as ‘re-applying’. Whilst nearly all acknowledged a need to fast-track terminally ill claims, there were also suggestions from some that those with progressive illnesses should also be fast-tracked because their conditions are only going to get worse. In these cases individuals felt that the DWP should be able to get the information they needed from their own records and from checking with GPs.

There were particularly high levels of confusion among current DLA claimants on indefinite awards as to what the changes would mean for them. Even once the proposed changes had been explained as part of the research, many of those on an indefinite award initially assumed the changes would not apply to them and that they would not need to apply for PIP and go through an assessment process again. When it was explained that it would apply to them as well, there were high levels of disbelief and anger. Our assessment is that tailored communications for those on indefinite awards to explain how the changes apply to them and what is required of them might therefore be necessary.

‘Will the people who have got it ... [they] said about having it for life, my husband’s is for life, will they have to reapply for this or will they get it automatically?’

(Female, Persona 1b, London)

Many current DLA claimants suggested that the introduction of PIP was simply a way for the government to ‘cut costs’ and reduce the number of people currently claiming. There was an acknowledgement from some individuals that there was a need to ensure that only those who deserve PIP should receive it, and some understood that there were claimants in receipt of DLA that were not entitled to it. These individuals cited anecdotal evidence of individuals perceived to be unfairly receiving DLA. However there were also fears that the cuts would not be targeted and

so would affect everyone, including the most deserving. If a key reason for the introduction of PIP is to reduce spending, some expressed that DWP should acknowledge this and communicate this upfront.

‘[I want] the truth to be honest and have them put down on that card this is why we are doing these changes, to squeeze people out.

Which is exactly what they are doing, they are putting a new name on it. We know they need to make cuts, we know they need to weed out the people that are doing it and don’t need it.’

(Discussion in Persona 7, Leeds)

‘If it’s valid where they cut back on people who shouldn’t be on benefit, that is a totally different argument, but if they’re just cutting back on people with disabilities, I think that’s totally unfair.’

(Female, Persona 2a, London)

Some current DLA claimants expressed a desire for a shift in the wider media narrative surrounding benefits, from stories which propagate the image of ‘scroungers’ to one which promotes how PIP has enabled recipients to live a full and independent life. Although this particular suggestion was only made by a few, in our view communication of the positive impact of PIP would go some way to counteract the negative effects of the stereotype of the ‘undeserving’ claimant.

‘We don’t really want to be on the sick, we don’t want to be claiming these benefits ... they don’t take these things into account; they just think that you’re there trying to get something for nothing.’

(Male, Persona 5, Manchester)

In our view, the key recommendations from this section are:

- It will be important to make available at an early stage information that (for example) explains what PIP is (including that it is an entirely new benefit), why it is being introduced, who it is for and how to apply, in order to minimise the risk of misinformation being sought elsewhere.
- Early engagement of GPs and other intermediaries, to explain PIP eligibility to them, will be important to help minimise inappropriate referrals.
- There is an opportunity to use the introduction of PIP to counter current misconceptions of DLA by positioning PIP as a universal benefit that is awarded on the basis of support needs (not medical condition).
- In order to avoid nugatory contact, there will be a need to reassure current DLA claimants that there will be no ‘payment gap’ between DLA ceasing and (if awarded) PIP being paid.
- There is likely to be a need for tailored communications for those on indefinite awards to explain how the changes apply to them and the steps they need to take, to combat the assumption that the changes will not apply to them.
- The introduction of PIP also provides an opportunity to achieve a shift in the media narrative away from the stereotype of the ‘undeserving’ claimant. This will be important to give individuals a claims process that feels respectful and empathetic. By reducing the stigma attached to being disallowed PIP, it may also help make claimants more accepting of an unsuccessful outcome to their application.

3.2 The application process

Individuals were asked how they would like to make an application and a range of channels were mentioned. For example, while some individuals expressed a preference for particular communication channels, others were actively opposed to using them and suggested another way. Therefore, a variety of channel choices in the PIP application process would be needed. Some expressed a preference for an online application, while others claimed they would be most comfortable over the phone. Many of the claimants also felt that they would ideally like to speak to someone about the application face to face. However, some did recognise that although they would prefer face-to-face it may not be possible because of the cost implications.

'That [face-to-face contact] would mean they would have to employ more staff and that's just not going to happen ... they saved a fortune, didn't they, taking it out of the offices to the call centres.'

(Male, Persona 7, London)

Individuals' specific views about channel choice and their needs and wants if completing an application over the phone or online will be covered in Chapter 4.

In terms of the structure of the application process, perhaps due to their past experiences of DLA and ESA, most expected the application to include a questionnaire-based form and a face-to-face assessment of some kind. Some felt that there should be a 'full' version of the process for new claimants and a 'stripped down', or simplified, version of the application process for those who had received DLA previously. This was particularly mentioned in correlation to those on an indefinite award and some felt this would also be beneficial for those with progressive illnesses.

'[DWP] could fast-track the simple or the simpler cases.'

(Male, Persona 2b, Edinburgh)

'Also, if the case is that genuine, they should try to fish you out as if to say, "well, that's a dead cert".'

(Male, Persona 9, Cardiff)

3.2.1 The pre-claim eligibility check

The idea of a pre-claim check where a few questions would be asked to applicants upfront to clarify eligibility was tested among individuals⁸. The details of these pre-claim check questions were not available at the time of fieldwork so claimants were told they would include details like age and residence information that would be used to check whether they were eligible to claim. Most current non DLA claimants were broadly neutral about the idea of answering a short list of simple eligibility questions. However, current DLA claimants tended to react more negatively, and were sceptical about the need for this stage. Some questioned DWP's 'motive' in introducing it.

Current DLA claimants tended to view the pre-claim process as an unnecessary step and wanted to know what the value of this stage would be. There was some recognition that for completely new claimants this stage might be useful, however a number of current DLA claimants felt strongly that

⁸ The concept of a pre-claim check was informed by previous qualitative research with 100 disallowed claimants, which found that 'the opportunity to help filter out claims almost certain to fail was being missed' and 'at points of telephone contact ... There did not appear to be routine attempts even to verify that claimants met basic eligibility requirements' (from *Disability Living Allowance: Disallowed claims* by Andrew Thomas: DWP Research Report Number 490, 2008).

they should not need to fill in this pre-claim form and the most common reaction from these to the suggestion that they would need to do so, was that it was a waste of time and money.

'I just think it's an unnecessary administrative step that's going to cost money.'

(Male, Persona 9, Manchester)

Another suggestion from a significant number of current DLA claimants was that as DWP is seen to already hold this eligibility information about them, being re-asked the information that DWP already holds evokes feelings of distrust, suspicion and frustration. One way in which this frustration could be alleviated would be for DWP to pre-populate any questions with information that they already hold and then ask for these details to be verified. This was viewed positively by many – most felt this would improve the application process and would suggest that DWP was trying to make the process as easy as possible for current DLA claimants.

'To receive a partially filled in form, to me, it's a sign that things were moving in the right direction. If I requested one of these forms and they just asked for my name and address and I received the form that had my National Insurance number already filled in, age already filled in, I would think ... you know, that [the DWP] do actually know what they're doing this time.'

(Male, Persona 6, Manchester)

There were concerns expressed by some about the extent of information being asked at this stage. Some speculated that they might be required to give details of their conditions at this point. The idea of giving details of medical conditions was not supported by all. In addition, some were confused as to whether this would be the only chance they would have to give medical information and, if so, did not feel this would be sufficient for someone to make a decision about their care needs. We believe that it was evident from all the discussions that a great deal more clarity would be required so that people could differentiate between the various stages of the process and why different information was needed at each point.

'But if there are certain keywords and you don't give them and that's it – you've already [hit] a brick wall.'

(Female, Persona 9, Cardiff)

'It's almost like they're under interrogation already ... it would be quite unfair to the person who was making the application because when they're making a written application, there are more points that are considered, whether they're eligible or not, because [if] it's just a phone-call that is totally brief and that's just trying to restrict the applicants.'

(Female, Persona 2a, London)

Individuals were confused as to whether DWP would make a decision about whether they could or could not apply for PIP on the basis of answers given at the pre-claim stage and if they would be 'judged' at this stage. This led to a strong fear from some current DLA claimants that the pre-claim was simply there to help reduce the number of people making a claim to PIP.

'Maybe I am a bit suspicious, but to me that's the first thing to weed people out.'

(Female, Persona 6, Leeds)

If there is to be a pre-claim eligibility check, individuals stressed this should be simple and short. Positive experiences of other application processes (some outside the benefits system) were often driven by the use of a straightforward 'yes/no' tick box format. It was also quite important to some individuals to be able to answer positively, i.e. ticking 'yes' at each question to confirm eligibility was a more positive experience than having to give a mixture of 'yes' and 'no' responses. The latter approach was more likely to lead to individuals not understanding what the questions were 'trying to get at'.

In summary, our key recommendations for the pre-eligibility check are that:

- Using information already held to pre-populate forms wherever possible, and asking claimants to verify this information, will help to minimise feelings of suspicion or frustration that can arise from being asked to submit the same information again.
- Any pre-claim check should be kept as short and straight-forward as possible. In particular, the use of questions that are phrased so claimants are able to answer positively (ticking 'yes' to confirm eligibility) is linked to a more positive application experience and a clearer understanding of what these questions are 'trying to get at'.
- There is a need for clear communication of the role of the pre-eligibility check within the claims process overall – i.e. whether this represents the only chance to give medical information; whether the individual will be allowed to continue with the claim, on the basis of the information submitted at this stage; whether answers given are used in the assessment; and what further information will be collected and considered.

3.2.2 Attitudes towards having an application form

When thinking about the application process nearly all individuals – across both current DLA claimants and potential claimants – envisaged the PIP process involving a form of some sort. Some were positive about getting their thoughts down on paper as they felt they could take their time to think about their answers and complete the application in several sittings if needed.

'For me, the way the forms are done ... I'd rather sort of have a think about [it], certainly the initial part, I think it's something that needs a bit of care and thought and maybe can't be, you know, done in one sitting.'

(Male, Persona 6, Manchester)

Based on past experiences of benefit claim forms, individuals described being daunted by the size, language and complexity of forms. Many felt that they would want some assistance and help in completing the form. Therefore, the concept of a phone claim or helpline for assistance for those who wanted to have further help with the form was welcomed by most individuals.

'They should have options for people on the phone, if you have difficulties with filling forms, and would you like to speak to someone on the phone.'

(Male, Persona 8, London)

People had varying attitudes towards whether they would want to call the DWP themselves for help. Some cited bad experiences in the past – for example, staff not being adequately trained – and others did not feel comfortable talking on the phone. Details of feelings about the use of telephone as a channel will be explored in detail in Chapter 4.

Some – and particularly individuals with mental health problems or learning difficulties⁹ – were very nervous of the application form and strongly felt they would need the option of a face-to-face appointment with DWP staff and/or need to contact a support agency for help.

⁹ These were individuals in Personae 7 and 8, i.e. current DLA claimants needing guidance or supervision out of doors.

'Face-to-face with someone, they can see the distress you are in, they try to put you at a bit of ease, they try to understand.'

(Male, Persona 7, London)

Many of these individuals with mental health problems would ideally like to by-pass the form stage altogether, because they find the filling in of the form (and forms in general) so stressful.

'Yes, I think don't make an application [form] at all, when they are switching over [to PIP], go for a medical straight away and [then you] bring a report from your doctor.'

They [could] see 15 people a day, half an hour, each person ... instead of waiting and chewing your nails and days of anxiety thinking this letter is going to arrive.'

(Discussion, Persona 7, Leeds)

3.2.3 Opinions of current benefit claim forms

Individuals offered some suggestions for how current benefit application forms could be improved. One suggestion included having bullet points at the start of the form to give an indication of the information people would need in order to complete it so that they could have everything to hand at the outset and therefore avoid having to get up and down to fetch additional information.

In the past, individuals had struggled to understand the relevance of all the questions asked. In the future, many would welcome more information about what is meant by the questions and the rationale behind them (i.e. why the information is needed).

When considering the forms or questions that would be asked by DWP at this stage, there was strong demand for questions to be simple and clear. Keeping the language simple and easy to understand and including clear instructions would help many. Some also suggested including examples of how to complete questions or pictures next to the questions for extra help about what is needed.

In general, most individuals' past experiences of benefit claim forms (mainly drawing on DLA and ESA experiences) tended to be negative. Current benefit claim forms were generally seen by most as too long, confusing and repetitive.

'You may get four [similar] questions throughout but there's just that little bit of twist on it and sometimes that twist throws you...but it is basically, it's the same question.'

(Male, Persona 5, Manchester)

This repetition was a cause of much concern among current DLA claimants and for a sizeable number led to mistrust of the DWP (based on the assumption that the repetitive questioning was intended to 'catch them out').

'[It's asked] a different way round but still the same question. About 4 or 5 pages along and you get another one saying the same thing don't you?

Yes, they are trying to catch you out aren't they?

Any excuse not to give you the benefit.'

(Discussion in Persona 6, Manchester)

Some felt that the way current forms were structured, the way the questions were worded and particularly legal disclaimers, all gave the impression of scepticism from the DWP about the genuine nature of their claims.

'Like they are saying 'and if this is false, this will happen', you know and you think 'well, there's nothing that I'm putting on this form that's false' ... the way they make you feel, they make you feel like rubbish, even for attempting to apply in the first place.'

(Female, Persona 1a, Leeds)

This left many individuals feeling that the DWP's 'starting point' was to doubt their application until they could 'prove otherwise'. Many individuals felt that the application process was therefore about them providing proof of the existence of their illnesses or conditions, rather than communicating any support or care needs they may have as a result of those conditions.

3.2.4 The type of questions that should be asked on a form

There was a strong request by all for an application process which recognised that each individual was different and that the way in which conditions affect people's day to day lives also varies widely. Questions asked on DLA/ESA benefit claims forms were cited as being too specific; i.e. asking if an individual can perform a certain task, for example walk a certain distance. Instead, individuals expressed a desire to be asked more questions about how that particular task affects them personally, for instance how a task makes them feel, how long it takes them and whether it varies on a day to day basis; whether they need help to carry out the task; and whether they could repeat the task more than once.

'They have the DWP handbook which has loads of illnesses listed in it, and ... how ... you are meant to be suffering, but it doesn't work like that. They don't know what I am going through, the pain that I suffer constantly.'

(Male, Persona 7, London)

In conjunction with the need to be treated as an individual, nearly all wanted the opportunity to be able to explain how their condition affects them in an open-ended, unstructured way at this application stage. Individuals often felt the questions and answer codes were too narrow to allow them to fully explain their situation.

'You tick 'no' or 'yes', but then, under the box, you [should] get your chance to explain: 'well, yes, I can – but it is ... only under certain circumstances or it's only certain days or only certain times' [that I can do it].'

(Female, Persona 8, Edinburgh)

For most individuals, the ability to explain their conditions and their support needs in their own words was important; however it was particularly important for those who had fluctuating conditions. Individuals with fluctuating conditions felt that being able to fully express themselves on the form would require them answering questions on the basis of both good and bad days. By being able to describe both the good and the bad, individuals felt they would be able to give a more rounded picture of how their condition affects them. Therefore, we believe that a clear instruction as to whether individuals are being asked to complete the form from the angle of their 'best' or 'worst' days would be essential.

'And I think, sometimes, when you're filling in forms, and if you're having a good day, you fill it in differently from how you would if you were having a bad day.'

(Female, Persona 9, Edinburgh)

One popular suggestion was to include a 'personal statement' at the beginning of the form to allow individuals to explain how their condition affects them and their particular support needs. Others suggested that this information could be collected in a diary format so that the DWP would be

able to judge their level of need based on the how their condition really affects them day to day (although our assessment is that there were indications that this would be seen as too burdensome by others).

In fact, some individuals strongly felt that the benefit claim form should be tailored to different conditions and that only questions directly related and relevant to their condition should be asked. There was also a request by a few people that not only should the form be condition-specific, but that DWP staff should also be specially trained in different medical conditions and therefore be able to understand what extra support may be needed.

3.2.5 Practical requests for the application form

Individuals also requested that claim forms should clearly highlight what questions could be skipped. The Census was mentioned as a positive example of a long paper form that had clear routing instructions and so helped people only answer the relevant questions and skip those that were not needed. Similarly, the online census was again praised for skipping questions that were irrelevant.

Individuals expressed the view that they would like the opportunity to re-visit and review their answers and possibly add new or overlooked information throughout the application process. One popular suggestion was to have a hard copy of any telephone conversations posted back to them. This was thought to be beneficial in helping people to spot any areas where information had been partially recorded, incorrectly noted or missed out. Therefore, this was seen as a chance for individuals to check that DWP had all the correct information needed and as such we believe that this would build trust between the individual and the DWP.

'If DWP was as open as they possibly could be and [I] could return to it as many times as I wanted to find out as much information as I needed, it would make me feel they had done all they could.'

(Female, Autism booster depth, Manchester)

In summary, our key recommendations for the application form are that:

- There is a need to recognise that many individuals find the size and complexity of benefit application forms daunting. DWP can help with this through the use of accessible language within the form itself; by offering a phone helpline (as per page 1 of the current DLA form); by giving the option of completing the form via telephone or online; and/or through proactive signposting to intermediaries who can assist with its completion (i.e. expanding on the reference to Citizens Advice on page 1 of the current DLA form).
- The application of clear routing instructions to maximise the extent to which individuals can skip irrelevant and/or repetitious questions will help make the forms less daunting while also reducing suspicion that DWP is using repetitious questioning to try to ‘catch people out’.
- An explanation of what is being asked and why, with examples, pictures or extra instructions next to questions will help individuals to understand the purpose and relevance of the questions, therefore helping to reduce distrust and building confidence among individuals that they have answered the questions appropriately.
- Consideration should be given to including a ‘personal statement’ that allows individuals to express in their own words how their condition affects them and their support needs; and to giving increased guidance on how to convey both ‘good and bad days’. Both of these measures will help to build confidence among individuals that they have expressed their needs in full.
- Currently, many saw the form as a place where they needed to ‘prove’ their medical condition. Instead this should be explained as a way to communicate any support or care needs, with the medical evidence being supplied elsewhere by professionals.
- Individuals would welcome the opportunity to revisit and review their answers and add new information throughout the application process – by, for example, sending individuals a written confirmation of any telephone conversations for them to review. Again, this would help to build confidence among individuals that their claim is being assessed on the basis of a full and accurate expression of their situation and needs.

3.2.6 The assessment

As mentioned earlier in this chapter, a common misconception held by individuals was that DWP was focused on obtaining evidence and proof of the existence of applicants’ medical illnesses or conditions, rather than assessing the extent of any support or care needs they may have as a result of them. As such, many felt that the purpose of a face to face medical assessment was to identify whether or not someone was ill.

As a result of this, many individuals felt it was right that medical professionals should be involved in the application process. However, rather than independent assessments, a large number expressed a preference for medical evidence to be sought from their own GPs and/or other medical professionals they were treated by.

‘[DWP] should accept the documentation from the qualified person – which is the consultant or the doctor – as part of the evidence and not question it. They are not qualified to question it.’

(Female, Persona 6, Leeds)

Some customers wanted a simple tick box on the form where they could indicate their permission for DWP to contact a medical professional on their behalf¹⁰.

However, a proportion of individuals did not want their GP to be automatically approached to give evidence. The reasons given for this varied, from those who rarely visited their GP, those who felt the GPs were too busy to give thorough recommendations and others who did not feel they had any real relationship with their GP.

'A doctor doesn't know how much pain you're in everyday and how you feel inside.'

(Female, Persona 6, Leeds)

'But because I don't go down to see the GP every five minutes there's nothing so much on record, so from my own personal point of view that would look not very good.'

(Female, Persona 6, Leeds)

'[You might have] moved out of that catchment area and gone into another catchment area, so this doctor doesn't know you ... all they know [about] you is what's written down.'

(Female, Persona 8, London)

Quite a lot of individuals felt there were other medical professionals who would be better placed to provide evidence. Therefore, some wanted the opportunity to give the details of a number of different people to be contacted for evidence, such as their psychiatrist, consultant and/or support worker.

'In my form you have to put down your GP, [but there are] these other specialist consultants and that that you see ... the cardiologist, such and such worker, blah, blah, then I wrote in the thing specifically 'Do not ask my GP for a report' because they just give them the same report every time.'

(Male, Persona 7, London)

Many people had either had negative experiences of medical assessments for benefit claims themselves or knew people who had. In particular, the negative experiences described tended to relate to individuals being asked to perform tasks that they did not see as being related to their condition or that some found humiliating.

'She said I can't bend down, it's hurting my neck. They said do what we say ... as far as you can, that is it. And she got knocked back. She could touch her toes even though she were crying with pain.'

(Female, Persona 6, Leeds)

Assessments were perceived as tests, and therefore something where everything that a person said and did would be judged and lead to a pass or fail. As such, they were regarded as a stressful and daunting part of the process.

'I think a lot of people would be quite nervous, having somebody assessing them, [and] that may affect what they say and how they act and how can that be a true assessment, if somebody is very nervous and only gives the answer they want to hear, or making themselves look better because they don't want to disappoint the person?'

(Female, Persona 1a, Cardiff)

¹⁰ Page 7 of the current DLA form allows the individual to give permission to contact their GP, or the people or organisations involved with them, but does not allow the individual to stipulate which specific individual/organisation they would prefer DWP to contact.

From their own past experiences, in cases where the benefit had not been awarded, individuals tended to feel that their condition and honesty had been doubted and medical evidence ignored at the face-to-face assessment stage.

'It wasn't even a doctor who assessed me; it was a nurse. And her word overruled what my doctor was saying.'

(Female, Persona 9, Edinburgh)

A suggestion for improving this part of the claims process was to create more of a two-way dialogue in these assessments, and to move away from a 'test' like situation. Individuals felt if they were encouraged to start by explaining how their impairment affected them in their own words, a truer account of their support needs may be achieved. The ideal 'assessment' described was closer to a 'consultation', and – in our view – this might be useful terminology to consider.

'Well I don't think I've ever been asked "what's wrong with you?" It's as simple as that ... [the doctor should say] "you tell me, you tell me what is wrong with you in your own words".'

(Male, Persona 5, Manchester)

In addition, travelling to and from the venues was reported as problematic for some, particularly those who suffered from mobility impairments. However all individuals felt that the assessment venues needed to be accessible and on a public transport route¹¹.

'And where they send us for a medical ... Way, way off the bus route so you're forced to get a taxi. They'll pay your bus fare but they won't pay your taxi fare.'

(Male, Persona 6, Cardiff)

A few individuals found the assessments so stressful that the fact that they attended the assessment in the first place was a sign that they were having a good day. Some felt that on other occasions if they had been feeling ill they would have had to cancel the assessment and that this would be viewed negatively by DWP.

'[In regards to the] medical, if that person is poorly you ring in and say you are sick, sometimes they get funny about it. They say 'right if you don't go for this medical we stop your benefit'. ... Which I think is wrong because it is not your fault ... you can't predict when you are going to be ill.'

(Male, Persona 7, Leeds)

As a result of these issues many individuals would welcome the possibility of a home assessment as they felt this would negate the travel problems and stress of a test environment and as such provide a better view of how people live and cope with their impairment in a real life environment.

'The idea of being assessed in your own home would be less stressful.'

(Female, Persona 3, Manchester)

We believe that one way in which the assessments could be made less nerve-racking for individuals could be to allow someone else to attend the assessment with the claimant. Some felt the need to impress the assessors or the need to try their best in the assessments and so may not always make clear the extent of the impact of their impairment. Individuals may be put at

¹¹ The location of assessment venues was raised spontaneously by respondents and was not systematically explored in the research. Comments made related to the logistics of travel to the venues, including proximity to public transport links, rather than distance per se.

ease by having a familiar face with them in the assessment and additionally, these people may be able to add background context to the individuals' situation and encourage them to provide a more balanced view of what they can and can't do for themselves. This would also give individuals someone to discuss the assessment with afterwards and another person to remember what had been said.

In some cases, official intermediaries might provide this support. Currently most individuals only seek the advice of intermediaries at the appeal stage and we suggest that, by including intermediaries at the assessment stage, this might help the claimant feel they were fully supported throughout the process and confident that all relevant evidence had been presented and considered at this stage.

In summary, our key recommendations for the assessment are that:

- Face-to-face assessments were seen by many as clinical, often humiliating, 'tests' to 'prove' an individual's medical condition. There is an opportunity to reassure individuals that the best-placed medical professional will provide evidence of their condition, as a separate exercise; and to reposition the assessment as a two-way 'consultation' to discuss their support needs.
- Individuals should be able to use the assessment as an opportunity to give a personal account of how their condition affects them (therefore helping to build confidence that the claims process has accurately captured individuals' support needs).
- Assessment centres should be easily accessible for all and have good public transport links. Where it is too difficult or distressing for the individual to attend the assessment centre on a particular day, consideration should be given to allowing appointments to be rearranged; and, in selected cases, to offering a home assessment.
- Encouraging someone else (either a friend, relative or intermediary representative) to accompany the individual to the assessment may help to put the individual at ease; provide valuable background context to the case (e.g. by constructively challenging what the individual is saying – for instance, where they are under-reporting how their condition affects them); and provide someone for the individual to discuss things with after the event. This would help to instil confidence that all the relevant evidence was communicated within the assessment, by giving the individual someone to discuss the assessment with afterwards.

3.3 Awaiting the decision

When discussing their ideal process when awaiting their decision, individuals often assumed that, at this point, they would have submitted an application form and undergone an assessment. However, some were adamant that there should not be an assessment stage at all. These individuals, therefore discussed what they would like to happen when awaiting the decision with the expectation that the decision would follow on directly from submission of the form.

Nearly all individuals agreed that they would like reassurance that their application had been received and was being processed. The communication methods via which people would like to receive these updates will be covered in Chapter 4.

‘[DWP should tell you] “it’s been processed. We have got it” ... letting you know that they have got all the details and they are looking into it and ‘when we have [an] issue, we will tell you straightaway.’

(Female, Persona 6 Manchester)

Some people described past experiences of applications where forms had been incorrectly completed or a piece of information had been missing, and as a result their application had been delayed, rejected or sent back in the post. Ideally, individuals would like DWP to proactively contact them (by telephone or email, depending on channel preference) to try and resolve these issues without it impacting too significantly on the progress of the claim.

Similarly if there had been a delay in processing the claim for some other reason, individuals were in agreement that they would welcome proactive contact from the DWP to notify them of the delay and explain where the blockage had occurred. There was the suggestion that if a GP was holding things up the individuals could play a part in prompting them to return the required information.

For the most part individuals felt that being informed accurately about how long the decision process would take was more important than the process being completed quickly. Being able to sign up for SMS text and email updates and/or being able to track the progress of claims online was also popular with some.

‘If you send an application off and you are awaiting the decision and it is taking a long while, you phone up to try and chase that application – that is quite difficult. So maybe each form should have a unique number so you’ve got a reference number, a tracking number ... tracking should be easier.’

(Male, Persona 1b, London)

Some current DLA claimants were concerned about whether existing payment arrangements would be mapped across to the new benefit automatically. They were anxious to avoid any downtime in which no payments would be made if DLA stopped before they had received a decision from applying for PIP.

In summary, our key recommendations in relation to individuals awaiting their decision are that:

- There is a need to reassure individuals that their application has been received, and to inform individuals of a realistic timescale for DWP making a decision. Consideration should also be given to allowing individuals to opt in to receiving regular reassurance or update communications, via SMS or email and/or allowing them to track their application progress online. Doing so will help to minimise unnecessary inbound telephone contact.
- DWP proactively contacting individuals to deal with missing or incorrectly submitted information, and working with the individual to resolve these issues (i.e. without halting the claim or sending their application back to them) would contribute to a positive claims experience.
- DWP proactively contacting individuals to inform them about any delay, and the reasons for the delay, will help to build trust in the claims process (and may also empower individuals to prompt any parties – e.g. GPs – who may be holding up the decision).

3.4 The decision

There was strong demand for the final decision to be provided in a formal hard copy letter. This could then be kept as a written record of the decision to show to intermediaries, feed into the appeal process or to claim other benefits.

Most wanted the option of a free phone helpline number clearly highlighted on the decision letter in the event they wanted to check something. This was more popular than receiving an unexpected follow up phone call from the DWP as some found the idea of unsolicited calls very daunting (reasons for this will be covered in Chapter 4).

If a claim was successful then individuals would need details of how much they had been awarded, when the payments would start and (in some cases) whether there were any limitations on what the money should be used for (the concept of indirect spend was not understood for example, using the money for an every day expense because they had used other money for disability reasons). The length of the award and any future renewal dates were also requested by some. There was some confusion as to whether PIP would impact on other benefits people may be receiving or may be eligible for and so clarification about these issues would also be welcomed at this stage as well as at the outset of the process.

Individuals mentioned that decision letters they had received in the past from the DWP often used difficult or confusing language. Some also stressed how communicating an outcome in terms of numbers of points awarded (as in the case in ESA for example) was hard to understand and accept. Where individuals had been told they had received 'no points' in a past claim they tended to take this as meaning that the assessor or decision-maker had concluded that there was nothing at all wrong with them. This led to an instant decision to appeal.

'You could be at home half-dying, but because you've not scored enough points, that's it – you get nothing. Do you know what I mean? And that is all through a decision-maker sitting in a room with no medical qualifications whatsoever deciding on somebody who is not medically fit.'

(Male, Persona 9, Manchester)

Some individuals suspected that DWP or medical assessors had 'disallowance targets' which sometimes influenced how they weighed up the evidence on a particular case (with the implication being that there was inconsistency in how claims were processed depending on progress against target). Many also suspected that not all the evidence supplied was read or taken into account. Similarly, some individuals felt that the current decision-making process was too subjective and that decisions could vary dependent on which member of staff in DWP dealt with their case.

'It is a really imperfect process, it's very much dependent on whose desk your paperwork lands on ... I'm quite clued up on the process, and, in my experience, it's very much hit and miss.'

(Male, Persona 9, Manchester)

These fears and suspicions (typically held by current DLA claimants, but not exclusively) meant that individuals wanted an outcome letter which laid out the reasons behind the decision in plain English, with clear reference to the eligibility criteria. It was also important for some that the evidence considered was listed so they were reassured that nothing had been overlooked or forgotten.

'When they send you the decision ... the department [should send] you every bit of information that they've used to come to that decision.'

(Male, Persona 9, Manchester)

A few individuals suggested that decisions should be audited by independent ‘experts’ in the claims process, to ensure consistency. This was thought to be particularly relevant when PIP was first introduced as the process would be new for everyone. Some felt that if the DWP published details about the quality assurance or auditing process it might go some way to convincing them that a consistent approach was being taken to decision making.

Other negative past experiences of decision letters related to the letters not being addressed to people by name or having been written in ‘cold’ language. Therefore individuals requested that the PIP decision letter convey more empathy for their individual situation, be more tailored to their individual situation and generally be more human and personalised.

This empathy was seen as particularly important for those who receive a disallowed decision. Individuals wanted DWP to communicate that they understood that this would not be good news for people. They also ideally wanted DWP to communicate that they did not doubt their medical condition, but that at present, their level of care or mobility needs were not high enough to warrant PIP. Generally, adopting a tone for communications which was adult-to-adult and sympathetic (i.e. recognises that an individual is unwell) was considered very important across the board.

‘[They should address you] by your name, say “hello Mrs xxx” or “Dear Mrs xxx or so and so, I am sorry but you don’t qualify”, you know, “I am very sorry” ... be really nice and warming.’

(Female, Persona 6, Leeds)

In addition, it was suggested by some that having details of other relevant avenues for support, whether financial or emotional or disability-specific, would be beneficial here. For example, signposts could be included to relevant support organisations at the end of the decision letter; such as their local benefits office, charities, support groups and others. These signposts were suggested as beneficial to all, but particularly for those who receive a disallowed decision as this would give the individual a feeling that there were options, rather than seeing the decision as the end of the line.

‘You might get some help from another source, not even from the government, but there might be a charity or someone else that might be able to help you and it would just be nice to have something back instead of doors shut in your face.’

(Female, Persona 1a, Leeds)

Almost all current DLA claimants mentioned the need for details of how to appeal to be included on the decision letter, and most saw this as an integral next step in the process if they were disallowed. High numbers of those taking part in the research had either been through the DLA appeal process, or knew someone who had. There were strong indications that current DLA claimants are likely to appeal a disallowed PIP decision while they suspect that there is a reasonably good chance of a decision being over-turned. For many DLA claimants appealing was perceived as part of a standard claim journey.

‘So the thing is now I have to appeal. I then got knocked with the first appeal, that was another downer – that was another two months out for me. I then picked myself up again to do it again. The reason why I kept fighting was because I was mad and angry because they didn’t show any signs of understanding my condition.’

(Female, Persona 8, London)

In the event of a disallowed decision being received, there is little evidence to suggest that current claimants would ‘accept’ that the right decision had been reached and decide not to appeal. Our assessment is that providing a thorough explanation of how the decision has been reached and showing that DWP understand and recognise their illness may go some way to creating more trust in the process, but ultimately seem unlikely to impact considerably on appeal behaviour while appeal success rates remain high.

In summary, the key recommendations in relation to the decision are that:

- Individuals would like the decision to be sent via a formal hard-copy letter, but with the inclusion of a free-phone number for them to contact DWP if any queries arise.
- The letter should use accessible language to give a full explanation of the decision made; the reasons behind it; and what evidence has been considered. The 'points system' currently used is difficult to understand, is often perceived to imply that someone is 'not ill enough' and encourages individuals to try again (i.e. to see whether they can score enough points next time).
- If PIP is awarded the details of the award need to be clearly outlined, including how much money will be received and when, if there are any limitations on what the money should be spent on, what the length of the award is etc.
- The letter should be written in a personal and empathetic (rather than 'cold') style. If PIP is not awarded, there is a need to acknowledge that this is not the desired outcome; recognise that the individual does have a condition; and explain that currently their support needs are not at a level where PIP can be awarded.
- Signposting unsuccessful claimants to support groups, charities or other local services may give these claimants an alternative avenue, rather than feeling that appeal is the only option.
- Incorporating, and publicising, a quality assurance procedure and an auditing process for PIP decisions may improve people's trust in the consistency and transparency of decisions, especially in the early days following the benefits' introduction.
- Appeal behaviour is unlikely to significantly change while appeal success rates remain high. How the initial appeals against PIP decisions are handled is likely to be critical in determining how appeals are perceived (and how reliable the original decisions are perceived to be).

3.5 Ongoing relationship

Generally, the idea of having an ongoing relationship involving actively volunteering information to DWP about any changes in their health condition was alien to most. The expectation was that DWP would contact them to find out if anything had changed, rather than the responsibility lying with the individual.

There was considerable anxiety about proactively letting the DWP know about changes in circumstances. Many, and particularly those with fluctuating conditions, were concerned that if they were to let the DWP know that their condition had showed signs of improvement, there would be no way of knowing if they would be able to see a return to previous levels of support if the condition then worsened again (and/or how long this would take). Some would welcome an indication of how long an improvement must be seen for, before the individual must tell DWP.

Similarly, in the event of support needs increasing, most described being fearful of getting in touch with DWP to report any changes in case they triggered a whole new claim process which might result in their award being reduced or taken away altogether.

'If you are on DLA now, say for argument's sake you are on the lower rate and your condition has worsened and you [have to] reapply ... if for argument's sake you lose that decision, you stand the chance of losing the low rate ... you stand a chance of losing it altogether.'

(Male, Persona 7, Leeds)

Individuals tended to feel that renewals or reviews should take the form of phone calls from the DWP which just replayed previous information, verified that the level of care and mobility currently being received was still valid and request any updates to be supplied. Ideally, these should not involve the individual having to fill out all the forms again if nothing has changed.

In summary, our key recommendations regarding any ongoing relationship are that:

- There is an expectation that the DWP should be the proactive party in contacting individuals about changes in circumstances. The perceived onerous nature of the application processes for existing disability benefits, and the perceived element of chance in their outcomes, creates anxiety around letting DWP know about any change in condition in case it triggers an arduous new claim and/or results in the reduction or removal of benefits.
- In this context, individuals are unlikely to report changes of circumstances. However, individuals may be encouraged to do so to a degree, if the review/reassessment process that ensues is relatively low involvement (e.g. a telephone call to check information that the DWP already holds, rather than an entirely new claim). Similarly, giving guidelines regarding the amount of time that an improvement in condition must be seen for, before the individual needs to tell DWP, may encourage some to inform DWP of these changes.

4 Communication channels

Different people preferred to make a claim through different channels and as such **channel choice and flexibility** was important to most.

Individuals wanted to be able to indicate upfront how they would like to contact, and be contacted by, the Department for Work and Pensions (DWP). They wanted preferences to be remembered and consistently applied. They also wanted there to be flexibility throughout the claim, for example being called in connection with a query on a paper form, or for a written record of a telephone or online claim to be posted out.

When it comes to **claiming online**, positive experiences tended to relate to either reassurance that information was being saved and had been submitted correctly (and conversely negative experiences were concerned with the possibility of crashing and lost information).

There was some suggestion that the opportunity to use questionnaire routing in an online form (where irrelevant questions are skipped) would be attractive for some claimants. Individuals were keen to stress that an online claim process would need to be supported by the provision of additional help and explanation, whether through ‘help’ buttons or visual examples within the online claim form, and/or with the option of a helpline should someone get stuck.

The skills and attitude of the person on the other end of the phone was crucial in **telephone claims**. Many Disability Living Allowance (DLA) claimants described negative past experiences of discussing their claim over the phone and felt that call handlers displayed minimal empathy or compassion. There were concerns about the level of medical knowledge held by staff who would handle the calls.

Positive telephone claim experiences included features such as being able to request a call-back, being able to call back someone to validate an unsolicited call, call handlers going ‘off-script’ to ensure the conversation was more personalised, having a named individual or team handling a case, being spoken to with a sympathetic tone, and being sent a hard copy confirmation of what had been discussed.

This chapter considers individuals’ communication preferences. It starts with a general discussion of which channels are preferred and the extent to which channel control is important. The second part of the chapter outlines some key ‘do’s and don’ts’ with respect to online and telephone claims, as raised by individuals.

4.1 Channel choice and control

Overall, opinions on the preferred channel of communication varied, with some individuals feeling more comfortable than others with certain channels.

For example, many individuals felt that the internet was a quick and efficient means of applying for things, while others felt it often crashed and therefore was too unreliable. For some the internet was not easily accessible, and for others the internet was too alien to use comfortably.

Because of the perceived complexity of information needed for a DLA application, current DLA claimants were more apprehensive than those not currently claiming DLA about the possibility of an element of the Personal Independence Payment (PIP) application being online.

Face-to-face was the preferred form of communication for many as it was personal and provided more in-depth support at the required pace. On the other hand some felt that arranging such an appointment was too much hassle and slowed the entire process down. As mentioned in Chapter 3, there was a general awareness from some individuals that it would be logistically impossible or too expensive to arrange face-to-face visits for all claimants.

'I think the person, the applicant, should have the right, if they feel uncomfortable in any way about putting it on paper, they want to put something strongly across they should be able to request an interview as well. They might feel better talking to somebody face-to-face.'

(Female, Persona 1b, London)

Views on claiming by telephone also differed. Some individuals preferred the phone to paper forms as they reported often finding it hard to find the right words to explain their condition properly on paper. In terms of resolving queries, some generally felt more comfortable chatting through their issue with someone on the phone rather than searching for the answer online.

'... another reason why I think doing the application on the phone [is better], because sometimes it's not easy to put words onto paper and explain what's wrong.'

(Female, Persona 1a, Leeds)

However, a number of people were more uneasy about receiving phone calls they were not expecting as they were worried that there was no way of validating who they were talking to.

Because of the above point, some people would prefer to make at least the initial call to DWP, although it was noted that this can often be expensive especially for those who don't have a landline.

'I was just saying in general you don't know whom you're speaking to at the other end. They might say they are from the DWP, but they're not. You don't know.'

(Female, Persona 2a, London)

For some others simply having to speak to someone over the telephone led to considerable anxiety and the more anonymous channels of paper or online applications were preferred.

'I sit there sweating and my mouth getting dry and start panicking just because I am on the telephone.'

(Male, Persona 7, London)

Our assessment is that there is clearly no 'one size fits all' in terms of preferred channel for claiming. As well as variation across individuals, one individual may also have varying preferences depending on how they are feeling on a given day or in a particular context. Most people want to have a range of channels open to them so that they can select the one most suitable for them.

Most agreed that it would be very helpful if they were asked what their needs and preferences were in terms of communication channel at the start of the claim process. They wanted their channel choices to be remembered and applied once they have been chosen.

Some individuals also mentioned that they would welcome channel flexibility within a claim process, as well as being able to specify channel preference upfront. For example, while an individual may prefer to submit an application online, they may wish to receive updates from the DWP through other means (perhaps because they did not consistently have access to a computer). Similarly, some claimants were happy to proactively call the DWP to submit or confirm claim information but did not necessarily want unexpected calls back.

Some anticipated that they might want to change their mind about the method of claiming they had chosen. For example, some individuals reported getting stuck during an online claim or application in the past. In these instances they wanted to place a request for a call back and to continue by phone. Generally, the option of helpline support for a paper or online application forms was popular.

'If you've got a problem with these forms, if you've got someone that you can talk to, a person that can understand you and know what you are dealing with then it would be easier for people to use these forms. But there isn't anyone really that you can talk to.'

(Female, Persona 1b, London)

Receiving written confirmation of the content of online or telephone communication was also important for people. Many noted that receiving written confirmation of information submitted online or over the phone reassures the claimant that their application has been received and/or that their telephone call or website was valid and 'on record'.

It was important to individuals that the DWP would be flexible about communication channels in order to keep an application progressing. Some spoke of annoyance in the past where claims were held up where information had been filled in incorrectly on a paper form and they then had to wait for it to be sent back to them. In this situation, many would have preferred to be contacted by telephone and for the information to be corrected by the call handler (with a hard copy record then sent out to them for their information). Ideally, claimants would have indicated at the start of the process that they were happy to be contacted by telephone should there be queries about their application.

'Even if you do miss one question, why can't the person ring you up and say "you've missed this question can you just tell me..."', then they'd put it on, they stamp and sign it saying "rung [the claimant], she's said this..." and then your claim just carries on, not put back on the bottom of the pile until they hear back from you.'

(Female, Persona 1a, Leeds)

'They should actually check that all the information is included [when they receive the application] and then if there's anything else needed they contact you immediately so that you could go in and it doesn't delay any further.'

(Female, Persona 1b, London)

Channel preferences (and reactions to these preferences not being remembered or reflected by the DWP) were particularly acute among some individuals with mental health conditions. While anxiety about the perceived pitfalls of different communication channels were by no means unique to this group of claimants, views on areas such as unsolicited calls or the pros/cons of online claiming were particularly strongly held by those with mental health conditions.

The next section of this chapter looks at the specific features of online and telephone claim processes that individuals highlighted as important.

4.2 Online processes

Individuals were asked to discuss both positive and negative aspects of online claim or application forms that they had experienced, in order to inform the design of the PIP online claim route. It should be noted that detailed testing of the PIP online claim process will be carried out separately

in Strand 2 of the DWP user centred design research programme. The following findings are based on what individuals mentioned as important to them when given a 'blank sheet of paper'.

The following features were spontaneously mentioned as delivering a positive experience:

- Automatic questionnaire routing within an online form enabling individuals to skip the sections that are not relevant to them.
- Ability to change font size and be accessible by screen readers.
- Progress bars to show how far through the form you are.
- The ability to save answers with a view to returning later, so that the form can be completed in several sittings if needed.

Current claimants often stressed that many of the questions asked as part of the DLA process were irrelevant to them. By contrast, some mentioned how the routing embedded in the online Census questionnaire had made the form filling much quicker and easier. Being able to skip irrelevant questions through routing not only made the process quicker but also helped individuals feel that the process was tailored and personalised. There was some indication that promotion of tailored routing through the online questionnaire would make claiming online attractive to some, over a paper-based route.

'With the paper forms, especially with DWP or any Government form you get to a question and you answer yes, go to question 43, if you answer no go to the next question. I took part in a dummy run of the 2011 census, we did a dummy run of that, and when it came out I actually filled mine out online and according to your answer it jumped to the right question for you, it was easier and quicker to fill it out online.'

(Male, Persona 1b, London)

'I absolutely appreciate the experience you have got with this very long form, but of course there are bits in that form which are irrelevant to everybody and ... if we could create a form that was, you know, specific to the individual that would be the ideal.'

(Male, Persona 6, London)

Accessibility concerns were commonly mentioned. Several individuals mentioned how helpful it was to be able to change the font size on online forms. Others mentioned the need to ensure screen reader accessibility.

Some noted that a downside to an online form compared to a paper form was that it is hard to see how far through you are. Online forms that had progress bars, showing the reader how much of the form they had completed, were typically highly regarded. A progress bar was felt to reassure the applicant that they are making their way towards the finish line of what some described as a 'mammoth task'.

Filling in a form (whether online or on paper) was seen as a very daunting task for some. A positive feature of some online applications or forms was the ability to save progress in order to take a break and return to it later at a more suitable time.

'You can save your progress on certain applications, it's not hard to be done, you just save your progress, log back in, and complete it.'

(Female, Persona 1, Cardiff)

Many of those who had experience of completing an application or claim online had wanted or needed additional reassurance or help at some point during the claim. Having help available when completing an online application was thought to make the process quicker and less stressful. Typically, individuals wanted help in the form of:

- Buttons to click for more information about the questions, such as why they were being asked or what information should be included in the response.
- Examples or case studies showing how to answer each question, or visual guidance on correct completion.
- The opportunity to speak to someone over the phone or engage in 'live chat' online to resolve queries.
- Any missed questions being highlighted.
- Being offered a chance to review answers and change any incorrect responses.
- An opportunity to print or request a hard copy of the submitted form in the post.

As mentioned in Chapter 3, many individuals, often when thinking about past DLA claim experiences, commented on how confusing they found certain questions; they often did not know what the question was 'getting at' or why it was being asked. This led to claimants feeling that the DWP was trying to trick them or catch them out, which in turn created a lot of anxiety about how to answer each question. Some felt that having information buttons located close to the question which a claimant could click on to find out more about what was being asked and why, could mitigate against this to some extent.

'What would be nice is if there was like a little box with a question mark or something in it relating to that question where you can click on that box and then it pulls down an explanation of that question.'

(Female, Persona 1a, Leeds)

Some thought that visual guidance on how to correctly complete the form would be beneficial for them.

'It would be great if there was a pictorial reference or a DVD ... anything that makes it simple ... It's a mammoth task to complete a form.'

(Female, Organisational appointee, Depth)

However, some felt that additional information within the online claim process itself would not be enough to reassure them fully about why certain questions were being asked. Ideally these individuals would like the facility to be able to leave questions blank and request a call back, so that they could talk through the questions they found confusing in more detail with someone knowledgeable over the phone. A few suggested having an online live chat option (or spoke positively about having this facility within other online application processes they had experienced). This was seen as a potentially useful feature for keeping the claim process moving and was also considered easier for those without access to a phone or those who were anxious about talking on the phone.

There was strong demand for a hard copy record of any online application to be posted out. Individuals felt this would provide confirmation that the application had been correctly submitted and received by the Department. Most people would keep it in their records so that they could refer back to it at a later date if they needed to chase up their application, if they wanted to check

whether they were happy with their answers, and/or to remind themselves what they had written. Having the opportunity to print the form themselves was also very important to most, but this alone would not provide sufficient guarantee the form had been submitted correctly. The idea of receiving a record of the form via email was relatively unpopular as many did not see this channel as sufficiently 'official' and noted that emails could easily be deleted or lost.

Two areas were commonly mentioned as causing people particular problems or distress when making online applications or forms, namely:

- having hard to remember/obscure passwords;
- the system crashing/losing what's been entered.

Many people liked having a password which enabled them to log in to a personalised account from where they could start the application process. Where this also meant some details could be pre-populated with information already held about them it was particularly welcomed. However, many people felt that the passwords they received tended to be obscure and hard to remember. Remembering where they stored the password often caused stress and confusion. Almost all would prefer a password that they could change to something memorable as soon as they received it.

A considerable perceived downside to online applications or claims was the possibility of the computer or system 'crashing' and the resulting loss of time and hard work. Many individuals mentioned this as something that would concern them or has happened in the past. For some, nervousness about 'crashing' was the key reason why they could not envisage themselves wanting to claim online.

'And then if the computer crashes you've lost the whole thing, you might even be at the library using the public computers and something will happen and your time will run out and it'll just switch off or it will crash or it will freeze.'

(Female, Persona 3, Manchester)

Some noted that having a form that automatically saved progress at set time intervals would minimise the risk of losing data, as well as having a function which allowed users to save their work whenever they chose. However, in our view, building in this functionality would not necessarily reassure those who felt too nervous about the potential of crashing and lost information to engage with an online form in the first place.

4.3 Telephone processes

Turning now to consider a telephone claims process (and/or telephone support within a broader claims process), individuals commonly mentioned the following features in association with a positive telephone claim or application experience:

- allowing people to call back and double check unsolicited calls – preferably to get through to the same person where possible;
- the ability to request a call back, but to keep this to a defined period (e.g. an hour); and
- offering to send written confirmation of what said/agreed on phone by e-mail/post.

Many individuals described past negative experiences of ringing up an organisation to chase an application or make a query. In these cases they had been stuck in a long waiting queue and had become very frustrated. Some described positive experiences where the organisation they were calling had let them request a call back when there is a queue, and had been called back within

the hour. Waiting an hour or so for a call back was an acceptable length of time, and the option of having this 'request call back' facility was viewed positively.

'If there are loads of people and you've got to be in a queue, I would prefer them to say "we're inundated with phone-calls, please phone back later". Now, what they do with BT is fabulous. They say, if there's a queue, "we will ring you within an hour".'

(Female, Persona 7, Cardiff)

As with online applications (discussed above), receiving written confirmation following a telephone call was very important to many individuals. This provided reassurance that the telephone call was legitimate and recorded, as well as valuable confirmation of what was said or agreed on the phone.

In relation to the staff handling the telephone calls, some common themes emerged:

- Claimants wanted to talk to someone who understood they were unwell and listened.
- Ideally they would have just one/few named contact(s) throughout (or for each individual they speak with to have an excellent grasp of case notes).
- Claimants wanted to be able to control the pace of conversation and be encouraged to ask for re-explanations if needed.
- Claimants wanted staff to be able to go off-script to help claimants understand the questions or to avoid irrelevant lines of questioning.
- 0845 numbers are expensive, especially as there are often long queues.
- Automated menus are long and complicated.

Where DLA claimants had spoken to someone over the phone in connection with their claim, they often reported feeling like the person on the other end of the phone did not understand they were unwell. They commonly felt that there was little or no compassion or empathy demonstrated and some felt as though they were being spoken to as a scrounger.

'One of these things that you get from the call centres is you can tell by the people's voices that they resent you, the fact that you are getting the benefit, they really resent you getting the benefit, but how dare they? You have paid your taxes for 40 years and you are getting the benefit, and it comes across on the phone, you know they are resenting it.'

(Male, Persona 4, Leeds)

'It doesn't have to be face-to-face, it just has to be somebody ... somebody that has been on the telephone, somebody that has some concern in their voice or concern in the words that they use.'

(Female, Persona 4, Leeds)

Many people would like to have a specific named contact or at least a specific team qualified to understand their disability/condition with whom they can speak to on the phone. A number of claimants said that this would result in them feeling like there was a nice person at the end of a phone – someone who would be pleasant to them. As well as communicating a more friendly and approachable service, individuals felt this would also reduce the amount of times that you would need to explain who you are and reiterate details of the claim, making the process more efficient and – in consequence – helping claimants trust in the process, as it would become more personalised.

'You feel like you're constantly explaining your situation over and over and over again.'

(Female, Persona 9, Edinburgh)

In past telephone claim experiences, DLA claimants often did not feel that they had had sufficient time to think about their answer in detail and so wanted to be able to control the pace of the conversation. Some felt that certain questions had been difficult to understand and had not felt comfortable enough to ask for an explanation. Many felt annoyed when they were asked questions that were irrelevant to their condition and commented on how this impersonal this made the phone call. Linked to this, some also felt they had not been able to explain their condition fully and as a result had not felt listened to and therefore could not be confident that all relevant information about their condition had been taken into account, therefore increasing the potential for claimants to mistrust the process.

'And there's times when I have [called], [they've said] "we haven't got long, they've got someone else waiting on the line", and here I am thinking "I'm trying to rush, because this person's in a hurry; I'm not getting things together", so I end up coming off the phone. So if you had training, and I'm sure they've had training, but they still are not able, not equipped to deal with my needs.'

(Female, Persona 8, London)

Some individuals suggested that if the claimant was able to control the pace of conversation and encouraged to ask for clarification whenever they needed it then that would make for a positive telephone experience. Many also felt that training DWP staff so they were confident and able to go off-script would be likely to result in a more personalised, human call experience.

Some DLA claimants also described upsetting experiences where the person they had spoken to on the phone in connection with their DLA claim had assumed a level of medical knowledge or made an inaccurate assumption about how the claimant's condition might affect them. This undermined many people's trust in the DWP to deliver a fair outcome.

'They are trained to work in the DWP as some grade of administrative assistant, they have no medical background.'

(Male, Persona 1, London)

The use of 0845 numbers was mentioned by many claimants. People complained about the cost of calling this type of number, especially those who have to call on mobiles or payphones as they have no landline. The long queues can then increase the costs much more. People would prefer to ring a free phone number.

'[In the future] not one of these 0845 numbers, your phone bill would just be immense when you are waiting for god knows how many minutes to get through to them. A free phone number they should provide, I think, all the time.'

(Female, Persona 6, Leeds)

A number of people mentioned negative experiences of being transferred directly to an automated menu when making a call. At times, the menu can be too long and make the phone call much more confusing and stressful than anticipated.

'... press this button – this press button, that press button – then you've got engaged, engaged, engaged, [then] two hours later of hanging on it goes "derrr".'

(Male, Persona 3, Manchester)

'Oh my god that is so frustrating. You've now got four options, blah, blah, blah and then it will say "right, now you've got another ten options" and "thanks for ringing, bye" and it's like "hang on!".'

(Female, Persona 3, Manchester)

Long queues generally had been a source of frustration for many. People felt this frustration was exacerbated when there was no indication of the expected waiting period.

In summary, the key recommendations in relation to communication channels are that:

- Acknowledging that different people will have different needs and preferences when it comes to channel choice and flexibility are key considerations for the PIP application process. Claimants should be given the ability to indicate upfront how they wish to be contacted throughout the application process but then also be given flexibility, i.e. to change preferences mid-way through the application.
- Online applications should allow claimants to skip sections according to how they answered previous questions. Accessibility of web pages should also be considered, i.e. including large font size and screen reader compatibility. Having a progress bar for online applications and the ability to save and return to an application can make the process seem less daunting. Highlighting missed questions and being given the chance to review and amend responses would reduce the chances of error and improve trust in the application system. There should also be access to a telephone helpline and the ability to request a hard copy of the completed application. A final consideration for online applications is the need for reassurances over security.
- For communications via telephone staff should be trained, and positioned to the claimant as, 'experts' in the claims process, who are sufficiently confident in the process to 'go off script', i.e. where this makes the experience more personalised for the individual. Staff should display empathy and understanding re: a claimant's situation. If possible, the same individual/set of individuals at DWP would handle an individual's claim from end-to-end. As with online, the ability to request a hard copy of information given will help to reassure individuals that they have fully expressed their situation. Using 0845 telephone numbers and complex automated menus should be avoided, while providing the option to request a call back and the ability to check unsolicited calls would improve trust and demonstrate flexibility.
- There is the opportunity for communication channels to work together to build trust in the claims process. For example, as noted above, individuals wanted the option of a telephone call to verify or correct details submitted via paper form or online; and/or the option of being sent a hard copy of online submissions/details of telephone discussions.

5 Key issues for sub-groups

On the whole, discussions with individuals from specific customer sub-groups tended to reflect the views and experiences raised by individuals generally (as described in Chapters 2-4).

However, there were some areas where specific issues were highlighted:

Transitional claimants (who had recently moved onto adult DLA after turning 16) were typically in the midst of making important decisions about who would take control of their adult benefit payments at the point of making a claim. This transition phase was a difficult time for claimants as they moved towards independence and prepared for their adult life with an impairment or health condition. There was a strong desire for as much information as possible about Personal Independence Payment (PIP) to arrive well in advance of the claimant's 16th birthday. There was a need for particular sensitivity around outcome notifications for this group given the unique anxieties and difficulties facing transitional claimants.

Interviews with **organisational representatives** of claimants highlighted strong awareness of the benefits system and a desire to be kept up to date with the details of the benefit reforms. Some representatives (typically those in a healthcare role) wanted greater involvement in the application process and for their account of a claimant's condition to carry greater weight.

Personal formal appointees tended to feel guilty or uncertain about how benefit payments should be used and sought greater clarification or guidance here. There was also demand among this group for further guidance on reporting changes in circumstances.

Perhaps as expected, individuals who had previously been **disallowed** Disability Living Allowance (DLA) were negative about the application process generally and tended to feel that they had not been able to fully explain their condition and how it affected them. They felt a new benefit application process should focus on the outcome notification stage where signposting to an ombudsman, and a helpline where you could get personalised feedback on your claim, would help them cope with a disallowed claim. There was some suggestion that individuals who had been unsuccessful in their application to DLA in the past would 'not bother' applying for PIP.

Individuals with **sensory impairments** highlighted the value of telephone calls in informing them that important written information had been sent out and in allowing them to give their claim details over the phone (before then receiving written confirmation of the information taken).

As part of the research, booster interviews were conducted with particular customer sub-groups that might have slightly different needs from the claims process. These included:

- Transitional claimants (those who had recently moved onto adult DLA after turning 16);
- Representatives for individuals with care needs (both organisational and formal appointees);
- Individuals that had experienced unsuccessful DLA claims; and
- Claimants with sensory impairments.

This section of the report outlines any instances where the views or experiences of these sub-groups differ from those expressed by individuals generally. As a note, the number of interviews conducted with each sub-group was relatively small (five depth interviews per group), therefore firm conclusions are difficult to establish.

5.1 Transitional claimants

Five interviews were conducted with transitional claimants, these included three interviews with claimants who had recently gone through the transitional stage of moving onto adult DLA, and two interviews with formal appointees of transitional claimants.

The transition for 16 year olds moving onto adult DLA was seen by claimants as a step towards greater independence and becoming an adult. One individual described this process as starting to take responsibility for their condition and becoming self sufficient.

However, individuals did also mention being unaware of the support available for disabled people. Claimants and their appointees can feel isolated and would value signposting to support organisations.

‘There’s a no man’s land between 16 and 18 [in assistance for disabled people].’

(Male, Persona 3, Manchester)

For the transitional claimants the first stage in deciding whether to apply had been receiving a letter informing them of the move onto adult DLA. Individuals were positive about this stage and described how they had been keen to receive as much information as possible, including details of what else they might be entitled to.

‘The letter said what would happen when I reached 16, [I] was told who to speak to and was offered a home visit – job done!’

(Male, Persona 3, Manchester)

The timing for when the letter should arrive was felt to be very important and the general consensus was that between two and six months in advance of the claimant’s 16th birthday was ideal. This timescale allowed them enough time to prepare and make the necessary arrangements, e.g. appointments with healthcare professionals.

Transitional claimants were also positive about the offer of a face-to-face visit at this time, as they felt this was an opportunity to have their needs recognised. Some claimants with formal appointees described difficulties in finding a suitable time for face-to-face appointments because of the multiple responsibilities of the appointee. Flexibility over appointment times and adequate lead times in making arrangements were requested by a number of individuals.

A key stage in the transition to adult DLA was deciding who would take control of the DLA payments. One claimant described a conflict that had arisen where the parent had originally suggested they continue to receive the payments due to concerns over the claimant’s money management. In this situation the claimant over-ruled them as they saw themselves as reaching adulthood (and therefore their condition and DLA payments becoming their own responsibility). For other transitional claimants this decision had been more straightforward, often because the care needs were greater and so payments had to stay with the appointee.

The application stage was often a joint process between claimant and appointee (either formal or informal), and generally transitional claimants had very little experience in filling in forms. Individuals described feeling confused by certain questions on the DLA claim form and had relied on their parents (or appointee) to offer guidance throughout the application process. Other points raised by transitional claimants about claim forms mirrored points raised by other claimants and are noted in Chapter 3.

'I might get stuck on something ... when I have been looking through the application things, there has been stuff I can't fill out because I don't understand it ... I phoned up and asked [the DWP] and they explained to my mum and then my mum told me [what to fill in].'

(Female, Persona 9, Cardiff)

Where transitional claimant appointees were interviewed, they were keen to stress the importance of the money to the individual's life. They expressed concerns that they did not know the system very well and that they were worried that other claimants were getting more than them, demonstrating – in our view – a need for transparency and clarity throughout the process.

There was particular anxiety around the first application for adult DLA as it was felt that the amount awarded would 'set the bar' for future entitlements. Individuals also stressed the importance of preventing any gap in the payments received.

The transition phase was seen by some as an anxious and potentially difficult time in terms of individuals reflecting on their impairment. Some individuals felt that if transitional claimants were disallowed adult DLA, there was a sense that – having grown up coming to terms with being different to others as a result of their disability – there was a real danger that being told that they were 'not disabled enough to claim disability benefits' would leave individuals feeling confused and frustrated. Therefore, it was seen as particularly important that any communication of the decision should avoid any language that could be construed as suggesting their impairment was not considered serious enough and instead acknowledge their impairment but concentrate on the levels of support and care needed.

Where transitional claimants had been awarded an amount less than they were expecting, this was very hard for individuals to understand. Without anyone to compare against there were examples of claimants assuming others would be getting more than them even though these notional other people had what they considered less severe impairments. Our conclusion is, therefore, that information provided with the award would ideally need to clearly explain the eligibility criteria, and specific reasons for the level of the award.

They would turn around and say [my disability] is not good enough ... yes [I did think that at the time] ... because they have said it before and it is getting pointless now. It is just upsetting, the fact that they are saying you are not disabled enough ... they have been saying that since I was ten.

(Female, Persona 9, Cardiff)

5.2 Representatives

Interviews were conducted with five organisational representatives for existing DLA claimants. These organisations were typically health and social care organisations or solicitors. Five interviews were also conducted with formal representatives for DLA claimants. These were most often parents or guardians of the claimant. These ten interviews covered views and preferences regarding the application procedures for those who would be completing the forms on behalf of someone else or assisting them with the application process. The claimants involved were likely to have high care needs.

5.2.1 Organisational representatives

Organisational representatives considered themselves to have a strong awareness of how the DLA system currently worked. They expressed frustration over having to re-apply for DLA for claimants they knew required the support.

'That is ludicrous for someone who is permanently disabled and is completely punitive to hassle them every two years with a questionnaire.'

(Male, Persona 3, Manchester)

Organisational appointees wanted to be kept informed of the forthcoming changes and made aware of the details of the new benefit from the Department for Work and Pensions (DWP). Individuals expressed frustration at not knowing all the details of benefit entitlements (including an example of an organisation with a legal duty to apply for everything the service user was eligible for). It was common for potential claimants to seek their advice, and organisations wanted to be prepared. The information they expected to need included the change in rates, when the change was taking place, the eligibility criteria, and why the benefit was changing. Information channels mentioned included letters, leaflets, seminars, or disability publications.

'Good if [there were] local seminars for organisations who represent individuals or someone coming out and speaking to service users one to one.'

(Female, Persona 3, Edinburgh)

Bad experiences of applications (not exclusive to DLA) included instances where DWP staff turnover resulted in a lack of continuity or sense of trust in the outcome of the application. Organisational appointees also highlighted frustrations with applications where DWP staff lacked the knowledge to deal with their specific and often detailed enquiries.

Individuals stressed that it was important to get the timing right in terms of when the initial information about the new benefit for DLA claimants was sent out. Sufficient time was needed to allow the organisation to gather evidence and arrange appointments with healthcare professionals (which may result in waiting lists). Six to twelve months was felt to be an appropriate timescale.

Training for organisational appointees on the completion of application forms was seen as something that may ultimately reduce processing costs.

An online application process was welcomed, but only in instances where the organisational appointee has sole responsibility for filling in the forms. On the occasions where the claimant would be expected to fill in some or all of the form online, appointees expressed a concern that it may be too difficult for many of their service users. There were also some concerns over the security of online applications and one organisation worked within a protocol that stated that they should not use online applications. One individual also mentioned that security questions based on details of the claimant can be problematic when an organisation does not hold personal details.

'Online is always better for record keeping, for simplicity, and if they are not happy it bounces [back] and it's quicker ... I have a record and they have it.'

(Male, Persona 3, Edinburgh)

'Initially [we] have done online [applications] but it's too confusing for the service user, [it's] easier to have a form so [the] person can see.'

(Female, Persona 3, Edinburgh)

Organisational appointees were also keen to stress the importance of ensuring that communications go to the correct person, i.e. the appointee, their deputy or the individual when necessary. There was mention of instances in the past where the wrong person had been contacted and this had led to delays in the application process and anxiety for the claimant. Perhaps linked to this point, there was also a strong desire for acknowledgement of receipt and progress updates as appropriate.

Organisational appointees also discussed whether in the future there could be more scope for them to be included in providing information, records and case notes as evidence in support of the claim. There were concerns that the current assessment procedures worked as a ‘conveyor belt’ with thirty minutes or less allocated to each appointment and that medical information provided by organisational appointees was not given meaningful consideration. If assessors were willing to read or take away the medical evidence they provided, it could curtail the need for a face-to-face assessment.

One individual explained how this could be taken a step further with healthcare professionals (such as themselves) providing consultancy on specific disabilities – in their view, independent assessors should give due regard to their input. They felt that all assessors should be knowledgeable about a range of conditions but there should also be champions for those with a specific disability (i.e. a mental health champion) and that would make the process more meaningful. Another individual felt that appointees for those with mental health conditions should be able to provide the Care Plan Approach so that the DWP can get a better picture of how individuals are able to look after themselves and what level of support they need on a daily basis.

One organisational appointee for individuals with mental health conditions stressed the importance of involving the appointee throughout the claims process as it can be difficult for the claimant to explain their condition or self-report key information.

‘It is important that those with mental disablement are not susceptible to a half hour assessment with someone who is not a specialist and knows nothing about their medical history and is reliant on the person themselves for answers.’

(Male, Persona 3, Manchester)

5.2.2 Personal formal appointees

Of key importance for personal formal appointees was being able to accompany and support claimants throughout the application process. Individuals felt that they knew the claimant’s condition in great detail and in some cases where claimants had high care needs, felt they knew the condition better than the claimant themselves. They needed to be able to accompany them to the assessments in order to reassure them and reduce anxieties for the claimant.

For those looking after individuals with mental or cognitive conditions there was a desire for communications in a format that they could share with the claimant. They felt that ultimately it was the claimant’s money and so they should be involved as much as possible.

Personal formal appointees commonly expressed a feeling of guilt about claiming DLA and a desire for clarity over how the money should be used as they often felt guilty about using the money for day to day expenses and struggled with the concept of indirect spend. However, along with this there were also concerns that some other appointees or claimants were using the money inappropriately which in turn implied to others that they themselves did not really need it.

‘Possibly the government would find it useful to provide some clarification on just what DLA is paid for and how it’s used; exactly what people are using it for and if they can show that it is being used to support that person, and it’s not being used so they can afford to buy caviar instead of a tin of peas.’

(Female, Persona 3, Manchester)

Individuals acting as appointees also mentioned a need for clarity around reporting a change of circumstances. There was concern that if there was an improvement in the claimant’s condition

then the appointee would be unsure whether or not to inform the DWP because the improvement might only be temporary (and therefore they risked being awarded a lower amount only for the support needs to return to previous levels, leaving them unable to cope financially). If the appointee waits too long to inform the DWP of an improvement in circumstances, however, then they were concerned that it could appear fraudulent.

'You don't know whether to tell them or not tell them, you don't want to drop yourself in it.'

(Female, Persona 3, Manchester)

5.3 Disallowed claimants

Five interviews were conducted with individuals who had been previously disallowed DLA. This status was established during recruitment to the research panel when individuals were asked whether they had made an unsuccessful application for DLA in the past. Some of these individuals were in the process of appealing the decision of being disallowed DLA but none were in receipt of DLA at the time of the interview.

Having been unsuccessful in their claim for DLA, individuals generally focused on the negative aspects of the claim process. There was a sense that they considered themselves eligible for the payments but had been assessed incorrectly or that the application process had not allowed them to explain their condition fully.

Perhaps unsurprisingly they would want more information on the eligibility criteria for PIP before deciding whether to apply. However, they typically tended to focus on which conditions would or would not be eligible for the benefit rather than assuming that eligibility would be assessed in terms of support needs. These individuals also mentioned how being informed of what else they might be eligible for could help in the event of a claim to PIP being unsuccessful.

'It would be really useful to have guidance on eligibility, especially if – when you weren't eligible – you were diverted to other benefit options. Otherwise you have to research yourself and ring back. Friends etc say 'try this ...' but you don't know what benefits are available because no-one lets you know officially.'

(Female, Persona 1a, Cardiff)

The previously disallowed claimants also ideally wanted tailored introductory information about PIP which acknowledged them as having been unsuccessful in their previous DLA applications and made it clear to them how PIP would be different (and therefore worth them applying for).

'I'd probably think that I didn't get it [DLA] last time so I won't get it this time. I probably wouldn't bother. There are people worse than me that need it and I know that for a fact.'

(Female, Persona 1a Cardiff)

It was common for disallowed claimants to compare their situation to other people who had been awarded DLA but were thought to be undeserving or 'less disabled'. There was some suggestion that past experience of an unsuccessful DLA application might put individuals off claiming PIP (although note that only five previously disallowed individuals were interviewed). However, as most of the disallowed claimants were in the process of appealing their initial unsuccessful claim, our assessment is that future behaviour is clearly hard to predict.

'At the moment I don't know [about claiming for PIP] because I feel kicked in the teeth because they turned me down. I asked them to help me and I feel let down when I see other people getting it.'

(Female, Persona 1a, Cardiff)

Typically, views and experiences of the application process were similar to those raised by other DLA claimant personae. However, disallowed claimants expressed a number of strong opinions about the decision notification stage of the process. One individual mentioned that they would prefer to be informed via an independent third party benefits adviser as their experience of being disallowed in the past had been extremely upsetting. Another disallowed claimant described how they would like there to be an ombudsman that they could contact to find out if there was anything else they could do. There was also an emphasis on the desire for a helpline that could be phoned if they had questions about the decision they had received and why that decision had been made. This helpline would need to be professional, official and expert but also welcoming and personalised.

‘Where you could phone somebody up and say, ‘what is this decision?’, and the person on the end of the line could explain ... it would have to be somebody from the DWP I think but not some call centre in a tower block.’

(Female, Persona 1a, Cardiff)

5.4 Individuals with sensory impairments

Four depth interviews were conducted with individuals with sensory impairments, covering a range of different conditions (it is worth noting that most of the individuals interviewed were affected by a number of different health conditions and care needs were complicated). On the whole, the issues raised by individuals with sensory impairments tended to align with those raised by individuals generally. However, there were some concerns raised which were specific to those with sensory impairments.

One point mentioned by an individual with a visual impairment was that any introductory letters or literature sent out to them should be followed up with a phone call to communicate that important information had been sent out to them. Another individual described how, due to their visual impairment, online forms or information provided online could make a claims process very time consuming and difficult for them. Instead, they were very positive about having the option to give their details over the phone then have paperwork sent out to confirm the details they had given.

‘I’d have to go online and do a bit at a time and it would take ages ... It is literally because of my eyes and I can’t type like I used to. [On the phone] they would ask me questions and I’d answer them basically. They can always send your paperwork out then you sign it ... You just sign [the forms] to say they are right and send them back.’

(Female, Persona 4, Cardiff)

Some individuals with sensory impairments also highlighted particular issues associated with having a condition that they felt was perhaps poorly understood and/or difficult to convey in application forms (although, in our view, this point clearly is not only applicable to those with sensory impairments). Linked to this, some individuals with sensory impairments would prefer to give details of how their condition affects them rather than the name of the condition because they felt that the way a condition affects a person will vary.

‘It is not designed to go into your problems in enough depth ... they say, ‘can you read?’ I can read, but I couldn’t read the paper – it would take all day.’

(Female, Persona 4, Cardiff)

In summary the key recommendations in relation to these sub-groups are that:

- Transitional claimants should be provided with as much information and support as possible, including details of the PIP claims process and potential other entitlements, well in advance of a claimant's 16th birthday. This is particularly important in view of the lack of familiarity with benefits claims forms and low awareness of sources of support, among many in this sub-group; and the high levels of anxiety surrounding the first application for adult disability benefit, i.e. as being a decision that will 'set the bar' for future levels of awards.
- Organisational representatives should be kept informed of the forthcoming changes to disability benefits – including detailed information on eligibility, rates, when the changes are taking place and why the changes are happening – in order to enable them to advise individuals on the changes. Detailed information on the PIP claims process will be needed 6-12 months in advance of the first applications to enable them to gather evidence and make appointments with healthcare professionals. It will be important to recognise that multiple parties are often involved in claims handled by organisational representatives and, therefore, channel flexibility and keeping everyone involved updated is crucial. Consideration should be given to allowing organisational representatives to play a greater role in the application process, particularly when they are healthcare professionals or expert in specific conditions.
- Personal formal appointees should be able to accompany claimants to assessments and be able to provide input throughout the application process, in recognition of their high level of knowledge of the individual's condition. There is also a need for clarification regarding how disability benefit payments should be used; and at what point a change of circumstances should be reported to DWP.
- Disallowed claimants highlighted the need for greater support at the decision stage, including: the option of being informed of the PIP claim decision via an independent third party; a helpline to contact for clarification of the reasons for the decision; details of alternative sources of support; and access to an independent ombudsman. Previously disallowed DLA claimants may be deterred from applying for PIP: if this is to be mitigated there may be a need for tailored introductory information about PIP which acknowledges them as unsuccessful in previous DLA applications and makes it clear how PIP will be different (and therefore worth them applying for).
- Individuals with sensory impairments should be offered the options of receiving telephone calls to confirm that important written information has been sent; and of being able to submit details of their support needs over the phone, with a written confirmation of the details given then being sent out for them to review.

6 Underpinning values

When asked to describe an ideal benefits application process, individuals' views were informed by positive and negative experiences of other applications processes (as detailed in Chapter 3). It is worth recognising that these are values that have emerged from the description of the ideal benefit application process and in practice there would undoubtedly be trade-offs needed between practicalities of cost, time, and efficiency compared with the outcomes achieved.

However, these comments can be interpreted so as to arrive at a set of key values that should underpin and form the basis of the development of the claims process for the Personal Independence Payment (PIP) in order to make the process as efficient and effective as possible for individuals. These underpinning values can be grouped into three broad types, according to what they bring to the claims process.

Firstly, there are values that help to make the claims process **credible**, from the individual's perspective. To ensure this, the process should be seen to be **professional/expert**; and **consistent**.

Examples of what this might mean in practice included: ensuring Department for Work and Pensions (DWP) staff are expert in the PIP claims process and in 'soft skills' such as listening; involving the individual's choice of relevant medical staff at key points; and ensuring decisions are made according to consistent criteria.

Secondly, there are values relating to **transparency**, i.e. that the process should be **simple, clear and easy**; **open and trustworthy**; and **reassuring and supportive**.

Examples of what this might mean in practice included: having clear upfront explanations of PIP's purpose and eligibility criteria; avoiding repetition of similar questions within claim forms; allowing the individual to choose the channel via which they communicate with DWP; and clear explanations of how decisions were reached and validated by quality-assurance.

The third set of values is about ensuring the individual receives **appropriate treatment** within the claims process. To do this, individuals felt that the process needed to be **respectful and empathetic**; **flexible and personalised**; and allow the individual to be **recognised and heard**.

In practice, this would ideally mean maintaining an adult-to-adult tone throughout communication with individuals and avoiding sceptical treatment of individuals; allowing individuals to express their situation and support needs in an open-ended way; 'playing back' to individuals what they have already said; and building in opportunities to review, amend and add to evidence.

As reported in earlier chapters, individuals were asked to describe an ideal benefits application process, drawing on their experiences – both positive and negative – of previous application processes¹². By interpreting this evidence – i.e. through the identification of common themes – the

¹² As noted, these discussions included – but were not limited to – discussions of benefits claims processes. Although the majority of those taking part in the research were claiming Disability Living Allowance (DLA), a small number were not – i.e. in order to represent potential future claimants of PIP. Where previous experiences of benefits application processes were discussed, these related not only to DLA, but also to Employment Support Allowance (ESA) and before that Incapacity Benefit (IB).

research team have developed a set of values that should ideally underpin the development of the PIP claims process. This chapter details these underpinning values and provides a brief summary of the evidence for including each of these (reiterating some of the information provided in Chapters 3, 4 and 5).

These underpinning values have been grouped into three broad categories, according to what they would bring to the PIP process (Table 6.1). The remainder of this chapter explores each of these values in turn.

Table 6.1 Values to underpin the ideal claims process for PIP

Underpinning value	What this delivers to a benefits claims process
Professionalism and expertise Consistency	Credibility
Simplicity, clarity and ease Openness and trustworthiness Reassurance and supportiveness	Transparency
Respectfulness and empathy Flexibility and personalisation Allowing individual to be recognised and heard	Appropriate treatment

6.1 Credibility

The first set of values is those that can help to make the process credible, from the individual's perspective. Within this category, there is a need to ensure that the process delivers **professionalism and expertise**.

Foremost in a desire for professionalism was the perceived need for involvement of appropriate medical expertise, ideally through DWP consulting directly with individuals' GPs and/or other medical professionals involved in their care.

There was also a desire for DWP staff to embody this value by:

- handling their own claims process expertly;
- being sufficiently aware of specific conditions to understand and respond intelligently to what individuals tell them (not necessarily by having advanced medical expertise, but ideally through having a degree of familiarity).

Delivering the latter request might entail having specialist DWP teams in the frontline delivery of PIP or – alternatively – it may mean managing claimant expectations of DWP staff by clearly positioning DWP staff as 'non-medical', i.e. expert in administering the benefits process, and in the relevant interpersonal skills (e.g. asking questions and actively listening).

The second underpinning value that will build credibility is **consistency**. Consistency was seen as important from two perspectives. Firstly, to ensure consistent decisions across all individuals, by:

- clearly communicating the focus of PIP being on support needs, rather than condition;
- clearly and consistently explaining the PIP eligibility criteria, and how each decision made relates back to these;
- applying quality assurance to minimise the chances of inconsistent decisions being made – particularly in the early days of the process; and

- minimising the chances of new evidence emerging after the decision has been made (as, when this results in overturning the original decision, this has potential to shake confidence that decisions were correct in the first place).

Secondly, individuals desired consistency in how the DWP deals with them as an individual. This could be delivered through:

- ‘playing back’ to individuals their previous PIP claims history and/or information given in the current process so far, so that they do not need to repeat themselves;
- remembering and applying their previously expressed preferences for contact channel.

6.2 Transparency

The second category of underpinning values relates to transparency in the PIP claims process.

Within this, there is a need for **simplicity, clarity and ease**. This was evident from the following issues:

- Current benefit claim forms were generally seen as confusing and repetitive, with this repetition causing individuals to fear they have made mistakes or that DWP is trying to ‘catch them out’.
- Many wanted to be able to complete their application at their own pace and in several sittings, and control the pace of conversations.
- Some described experiences of forms being sent back due to missing pieces of information (when DWP could, they felt, have called or emailed to obtain the missing information).
- A few suggested listing at the start of the application form, all of the information that the applicant will need to have to hand.
- Some suggested fast-tracking of the terminally ill and those with more ‘clear-cut’ cases or progressive illnesses.

Individuals therefore requested a claims process that is simple, clear and easy. This could be delivered through:

- giving individuals advance warning of what they will need to do, to claim PIP, and clear instructions;
- enabling fast-tracking of certain groups of individuals (e.g. those with a terminal illness or whose condition means their support needs are clear-cut);
- allowing individuals to control the pace of conversations;
- taking care over the structure and wording of questions, so as to avoid posing specialist medical questions that individuals are unlikely to be able to answer; eliminating repetition of similar-sounding questions; and making routing on paper forms as clear as possible; and
- offering channel flexibility, so that individuals can express preferences for communication channel; but can also deviate from these on an ad hoc basis where this helps the individual (e.g. providing hard copy confirmation of information given by the individual over the phone or online).

There may be an operational benefit in delivering this, as – if the individual is confident they have expressed their needs and circumstances fully and accurately – it could increase the likelihood of individuals accepting the decision on their claim (and therefore minimise the chances of them appealing the decision).

The second underpinning value in this category is **openness and trustworthiness**. The need for openness was evident from the fact that:

- many current DLA claimants perceived the introduction of PIP as a cost-cutting exercise: some wanted upfront acknowledgement of this;
- the majority of current DLA claimants perceived receipt of DLA as a sign of eligibility for PIP, and most expected to be ‘transferred across’;
- some were concerned about the subjectivity of the decision-making process, with a few fearing that mistakes would be more likely to be made in the early days of a new benefit;
- many welcomed explanations of the rationale behind questions;
- some were concerned that everything they said and did within an assessment would be judged, and feared being penalised for efforts made with their appearance or in reaching the venue;
- the consensus was that DWP should be upfront about how long processes will take, and should be proactive and open in informing individuals of delays; and
- some reported previous decision letters using confusing language and/or explaining decisions in terms of ‘points’, leading some to conclude that the implication was that there was ‘nothing wrong with them’.

From the individual perspective, an open and trustworthy claims process would therefore be one that:

- gives clear upfront explanations of the purpose of PIP, its eligibility criteria and why some current DLA recipients may not be eligible for receiving it;
- is transparent about where each individual is within the claims process, and how long each stage is likely to take/when the individual can expect a response;
- explains in advance what will be involved in any face-to-face assessment; and is clear about the boundaries of the assessment (e.g. to reassure individuals there are no ‘penalties’ for efforts made in personal appearance or initiative in reaching the assessment venue);
- provides a clear explanation of the decision, expressed in terms of how the individual’s support needs relate to the eligibility criteria (rather than as points); and
- acknowledges that the claims process is new and requires quality assurance; and explains how this quality assurance has been done.

Again, there may be operational benefits in achieving openness. Through explaining the purpose of introducing PIP, its eligibility criteria and why some DLA recipients may not be eligible it may be possible to minimise nugatory claims. Through delivering transparency in terms of where the individual’s claim is in the process, and when they can expect a response, there is the potential to minimise unnecessary inbound contact (i.e. individuals choosing to contact the DWP). In addition, through clear explanations of the parameters of assessments, how decisions were reached and how these have been quality-assured, there is scope to build ‘buy-in’ to decisions, and so minimise appeals¹³.

The third underpinning value in this category is **reassurance and support**. This underpinning value helps to make the claims process transparent but also helps ensure the individual receives

¹³ Although as discussed earlier in the report, the rate of appeals is likely to depend heavily on advice given by intermediaries and the success rate of appeals lodged in the months immediately following the introduction of PIP.

appropriate treatment when claiming PIP. The need for reassurance and support was evident from the fact that:

- most DLA claimants wanted plenty of warning of the application process, e.g. six months to one year before DLA ends;
- many current DLA claimants wanted reassurance that there would be no gap between DLA and PIP payments;
- many reported feeling daunted by the typical length and complexity of benefit claim forms and felt they would need assistance with them, particularly those with mental health problems or learning difficulties; and
- some suggested that decision letters should signpost individuals to other relevant avenues of support.

Delivering a reassuring and supportive application process could involve:

- giving plenty of detail of processes and timescales to individuals in advance, so as to minimise worries arising from uncertainty as to what is going to happen and when;
- proactively offering help with the claims process via the individual's preferred channels;
- adopting a reassuring and supportive tone in interactions with customers;
- recognising the importance of DLA payments to current recipients, and reassuring them as to whether there will be any 'payment gaps', e.g. if DLA payments will cease while the individual is applying for PIP;
- signposting individuals to other relevant sources of support, particularly if their claim for PIP has been unsuccessful; and
- encouraging individuals to seek external sources of support – such as family, friends or intermediaries – as early as possible in the process, so as to maximise the chances of the individual fully and accurately expressing their situation/needs and receiving an appropriate decision first time.

There may be operational benefits to encouraging individuals to seek external support at an early stage of their claim. This could help to minimise appeals, by achieving a transition from external support being used to challenge decisions at appeal (i.e. the tendency at present) to external support being used to help reach the right decision first time, and reassure the individual that the decision has taken account of a full and accurate expression of their situation/needs.

6.3 Appropriate treatment

The final set of underpinning values are about ensuring the individual receives appropriate treatment within the claims process.

The first underpinning value in this category is **respectfulness and empathy**. This value was one of the most emotive and powerful for individuals:

- Most felt that previous benefit claims experiences had given an impression of scepticism that their claim was genuine.
- A few DLA claimants felt burdened by negative stereotyping of individuals as 'scroungers'.
- Many had either had negative experiences of 'difficult' or 'humiliating' tasks at assessments, or knew someone who had.

- The consensus was that DWP should adopt a sympathetic tone in communications and recognise that the individual may be unwell.

Delivering a respectful and empathetic claims process therefore would entail, firstly, treating all individuals as genuine, until proven otherwise, and recognising that they would rather live their lives without the need for any support at all. This may require staff training, but also a shift in wider media messages, i.e. from stories of ‘benefits scroungers’ to stories of how PIP has helped people live independent lives. Related to this was the need to display empathy for the fact that some individuals feel very unwell, or have days in which they are more/less able to handle stages of the application process. One way of recognising this would be to allow individuals a degree of control by allowing them to postpone a discussion with the DWP if having a bad day.

Finally, there was a need to take care with language and imagery, so that:

- an adult-to-adult tone is maintained in conversations, even when the individual has requested an alternative explanation of something;
- language and imagery is inclusive, i.e. it avoids focusing on certain conditions at the expense of leaving other people feeling excluded. For instance, those with mental health problems and ‘hidden’ conditions reported often feeling excluded by the language used in relation to current disability benefits.

The second underpinning value is **flexibility and personalisation**. The need for this was evident from the:

- view that the application process should recognise the wide variation in individuals’ conditions and how they affect them;
- fact that individuals cited a range of preferences for the channel they would prefer to use in claiming; and
- fact that many suggested highlighting which questions are irrelevant and can be skipped.

Individuals ideally wanted a flexible and personalised claims process for PIP. This primarily involves tailoring of communications channels, for example by:

- Establishing, remembering, and adhering to, the individual’s primary preferences for how they interact with the DWP.
- Allowing the individual to request confirmation communications, and reminders (and choose the channels for these).
- Enabling the individual to request a re-contact (and choose timing and channel for this).
- Tailoring questioning, help with the claims process and signposting to other sources of support, to ensure relevance.

The final underpinning value is allowing the individual to **be recognised and heard**. This was another value that was highly emotive and powerful for individuals. The types of issues raised in this area included:

- Nearly all wanted the opportunity to express how their condition affects them, in an open-ended manner – and this was especially important for those with fluctuating conditions.
- Some wanted the option to complete their application in several sittings, to ensure they had expressed themselves fully and accurately.
- Many wanted to receive hard copy confirmation of telephone conversations, to facilitate checking of information given by phone.

- Some reported previous decision letters using confusing language and/or explaining decisions in terms of 'points', leading some to conclude that the implication was that there was 'nothing wrong with them'.

The PIP application process could help individuals feel 'recognised and heard' by:

- allowing individuals to express their personal circumstances and support needs in their own words. This includes allowing individuals to express the full range of what they are capable of doing and the difficulties they have, e.g. by describing both 'good' and 'bad' days;
- 'playing back' to individuals what they have said previously, and giving them chances to review, amend and add to this information prior to the decision; and
- recognising the individual's condition, even if the nature of their support needs means that their claim for PIP has been unsuccessful.

There may also be operational benefits in ensuring the individual is recognised and heard, as doing so may help to minimise unnecessary appeals by:

- building the individual's confidence that they have expressed their needs fully and accurately in the first place;
- combating the perception that PIP has not been awarded due to a mistaken belief that the individual does not have a medical condition.

7 Conclusions

This chapter summarises some of the key conclusions that can be drawn from this first strand of research conducted with the Personal Independence Payment (PIP) user centred design panel.

It is clear that the majority of current Disability Living Allowance (DLA) claimants do not feel that they have been treated particularly well in the past, within the application and renewal process and, as a result, they do not expect that they will be treated well when applying for PIP. With expectations at a low level, the introduction of PIP presents an opportunity to signal a break with perceived poor treatment in the past and to develop processes and procedures that deliver a better claimant experience.

While some of the requests for changes in the PIP application process might have significant delivery and cost implications, there is scope for considerable improvements in the claimant experience to be achieved through change in the tone of interactions throughout the process, from written correspondence, staff contacts and approach to assessment. Claimants felt that switching the overall mindset of the application process from one that gave the impression of seeking to identify fraudulent claims to one that recognised that the majority of claimants were making their application in good faith, would have a very positive impact on their experience.

Above all, claimants want to be reassured that the Department for Work and Pensions (DWP) does not doubt that they are disabled or unwell even if they are not eligible for PIP. At the moment, aspects of the DLA process – such as the perceived opaqueness of the medical assessments (where many claimants are unsure on what criteria they are being assessed or why they are asked particular questions/to perform particular tasks) and the lack of a detailed rationale for claim outcomes on decision letters – lead claimants to feel that the DWP does not believe their claim is genuine.

Some of the more structural considerations that could help to ensure a significantly more positive application experience under PIP revolve around incorporation of:

- **A better institutional memory of claimants' requirements and needs.** Claimants want to feel that the information they provide the DWP with is being recorded and taken into account so that they do not have to provide the same information on multiple occasions. This could take the form of pre-populating forms with details already held, a case-management approach to handling claims (or at least replicating this experience by ensuring details of previous contacts are available to all staff liaising with customers) and/or adherence to communication preferences/accessibility needs when these have been provided.
- **Tailoring of the process to customer needs.** Customers ideally want the application process to include some tailoring to their circumstances. For many, negative views of the DLA process centre around the task of completing the application form/questionnaire and ideally the questions that individuals were asked to respond to at this stage would be tailored to some extent so that they do not struggle to answer questions that are not relevant to their particular situation. There was also a strong view among claimants that individuals with severe conditions (specifically terminally ill people) should be fast-tracked through the application process.
- **Building in review phases** so that claimants can check and amend/accept the details they have provided (and perhaps what has been written about them). With the current DLA process, individuals often felt that the information that they had provided had been mis-recorded or not recorded at all. Others felt that at times they had been unsure whether they themselves had provided full details of their condition and how it affects them (because of difficulties

remembering the specifics of discussions held). Making sure that processes and timescales allow individuals to review information that they have provided would help to build confidence in the accuracy of the assessment process.

- **Clear response to all evidence provided.** For individuals to have faith that their case has been properly assessed, it is critical for them to feel that all the evidence that they have provided has been considered. This would mean stating what information has been taken into account in deciding whether they are entitled to PIP (and, if they are disallowed, why the evidence was not sufficient for their case to be successful). When individuals provide details of third parties that they feel should be contacted to verify their health condition, then it is important that these organisations are contacted and that this is acknowledged in communicating decisions or, if they are not contacted, a clear explanation as to why this was not appropriate is given.

It is likely to be very important to try to involve intermediary organisations in the delivery of PIP. It may be possible that some organisations can meet some of the desire for face-to-face explanation of the implications of the introduction of PIP and face-to-face assistance in completing applications that some claimants feel that they will need. It may also be worth considering communicating the possibility of a representative from a support organisation accompanying claimants to face-to-face assessments more actively under PIP than is currently the case under DLA. At the moment, it seems that many claimants do not involve support organisations until they have had an application turned down (often when they need help with an appeal). Attempting to involve intermediary organisations earlier in the process may help to avoid appeals. However, this is likely to represent a change in the relationship between the DWP and intermediary organisations that will need to be worked through.

The outcomes of appeals lodged in the first few months following the introduction of PIP will be very important in determining how individuals respond to being disallowed PIP. At the moment individuals consider an appeal to be almost the automatic response to being disallowed. A lack of trust in the consistency of assessments and an understanding that the proportion of disallowances overturned at appeal is high leads to a widespread belief that it is generally worth lodging an appeal. For many this belief is borne out by their own experience of making appeals (and sometimes multiple appeals) either for DLA or other benefits. Claimants receive encouragement to appeal decisions from intermediary organisations and sometimes from DWP staff in Jobcentre Plus offices and elsewhere.

Some of the suggestions outlined above will help to build confidence in the assessment process which might help to reduce appeal rates. However, it will also be important to ensure that the Tribunals Service is interpreting the eligibility criteria for PIP in the same way as DWP Decision-Makers. It will be important to ensure that any training on delivering consistent decisions (for all parties) is delivered well in advance of the introduction of PIP to mitigate against a situation where large numbers of decisions are over-turned at appeal in the first few months.

PIP is a new benefit and rather than being about the disability/condition itself, it is about helping a person with their specific day to day needs. One of the more notable observations of the fieldwork was that people did not understand what DLA was for, therefore making it very difficult to explain or justify any decision made. In order to build trust in the process including decisions, it is essential that the purpose and eligibility criteria are transparent and accessible to everyone involved.

Appendix A

Group discussion topic guide

J5042 Date 4/4/12

DWP PIP – Strand 1

Group discussion guide – FINAL

Topic coverage

1. Introduction

- Introduce self.
- Introduce IFF Research – about us and the panel.
- Subject:
 - A new benefit for disabled people (Personal Independence Payment) is to be launched from 2103/14. This will replace the current Disability Living Allowance benefit for those of working age (16-64).
 - The precise process of how people like yourself will apply for the benefit are still being designed.
 - It is in this context that DWP has commissioned IFF to understand the views of people who will be affected by the change. This is your opportunity to help shape the process of applying for the benefit.
- Confidentiality:
 - Taking part in this research will not impact on your current benefit in anyway.
- Recording.
- Explain if anyone is viewing the group.
- ‘Rules’ of group – i.e. no right or wrong, need to hear from everyone etc.
- Introductions:
 - Working status/who they live with.
- Warm up:
 - Who do you talk to for advice about important matters and decisions?
 - Networks? Support groups?
 - Do you discuss your condition with anyone? Who? In what circumstances?

2. Design principles

Before we begin I'd like you to think about the process of applying for things, and think about things that are important to you during this sort of process.

- What good experiences have you had of making applications? What was good about this?
 - Probe for experiences beyond just benefit applications, to wider experiences of claims or applications (e.g. insurance claims, applying for loan or bank account, applying for passport or driving licence)?
- What is important to you throughout this sort of process? If you were designing an application process, what sort of things would you put in place to make sure applicants got the right outcome. What would make you confident in and trust the outcomes?
- Collect spontaneously then probe for:
 - Trust/confidence?
 - Easy to understand?
 - Clear?
 - Fair?
 - Channels/Accessibility? Timescales?

3. Background

GIVE BRIEF OVERVIEW OF THE REFORMS USING SHOWCARD

- Before we asked you to join our panel how aware were you of these reforms?
- What are your initial thoughts on these reforms? Probe: Positive? Negative? Why?
- What/Who do you think it is for?

Explain to participants that rest of group is going to focus on the process of claiming the benefit. Introduce 'journey' board and explain that the basic framework is in place but that the boxes under each stage are blank because we want them to fill them in.

We'll be talking about each of these stages in turn.

NB: Throughout the following sections try to get the group to come up with their ideal process – try to push them beyond what they know about current/past benefits processes.

4. Deciding whether to apply (pre-claim)

I'd like you to imagine you all have to consider making a claim for the new PIP payment. I'd like you to tell me how you think that process should work – there are no right or wrong answers here.

- EXISTING DLA (Personas 3-9): It is envisaged that DWP will contact you to inform that DLA is drawing to a close and you can apply for the new benefit.
- How do you would you like to be informed?
 - Preferred channels? Multiple methods/occasions?
 - Why?
- When would you want to know? How far in advance?

- What information would you need to decide whether or not to make a claim?
- Would anything put you off/encourage you making a claim? What? Why?
- Would you seek any help, advice or guidance in deciding whether to make a claim?
- If DWP were to develop guidance to help people work out if they'll be entitled to claim, would you use this?
 - Preferred channels? What would make people trust this?

5. The application process (claim experience)

I'd like you to imagine you have all the information you need and you decide to make a claim for the new benefit. Again, I'd like you to tell me how you think that process should work:

- How would you want to go about making claim? Describe your ideal process. (NB: doesn't need to be based on what they know about DLA or other claim process – i.e. what about if there was no form and they went straight to an assessment after a phonecall? Would this be better/worse?)
- It is envisaged that the process will initially involve a pre-claim check involving filling in some details online or talking through some details over the phone. These details would be things like age and residence information and would be to check whether you're able to claim.
 - How do you feel about this process? Good/bad idea?
- After the initial call it is possible that you will be asked to give more details of your condition.
 - How would you prefer to do this? (if telephone, probe for whether they want to complete the whole claim on the phone or just have a helpline for when completing a paper form).
 - If a form, what should this form look like?
 - What information would you expect to give?
 - Would you seek any help, advice or guidance?
 - Should information from GPs and/or other medical professionals be submitted at this point? Who?
- How easy or difficult do you find it to talk about your condition with other people?
 - How do you prefer to do this?
 - How could the DWP design the claim process in a way which lets you fully express how your condition impacts on you? What information do you need to get across? What might you struggle to get across?
- Would you seek any help, advice or guidance during this stage of the process?

6. Awaiting the decision (journey to decision)

Having submitted your claim I'd like you to tell me what you think would happen next....

- What information or support (if any) would you expect while your claim is being processed?
- Why? Who from? Channels?

Although the final process for assessing PIP claims is still being designed it is envisaged that in many cases part of the process will involve a meeting with an independent assessor.

- How do you feel about this element of the process?
- What would you expect this meeting to involve? What would you like it to involve?
- Where would you want the meeting to take place?
- Would you seek any help, advice or guidance during this stage of the process?

7. The decision (and next steps)

- How should the decision be communicated to you?

Let's assume you are granted the PIP payment...

- Would information would you want/expect?
- Would you expect any further follow up from DWP?

Supposing your claim was refused by DWP/the amount you were awarded was not what you expected.....

- What do you think you would do?
- What would you want/need to know?
- What support would you need? From who?

ENCOURAGE SPONTANEOUS DISCUSSION – AND THEN COVER THE FOLLOWING:

- Would you expect any information about how the decision was reached?
 - What type of information – how would you expect this to be given?
- Let's assume that someone gets a decision that is correct but it is not the outcome they were hoping for – what do you think they should do?
 - What do you think they should do?
 - How would they decide whether or not to appeal?
 - What could the DWP do/say to them at this point to communicate that the decision was correct/fair/everything had been taken into account.

8. Ongoing relationship

- Once you've been awarded PIP, what sort of communication, information or support would you want with the DWP going forward?
 - When you have a change in circumstances? What do you think your responsibilities should/will be around this? Channels?

9. Summing up

We've talked about all stages of a claim process from early consideration to final outcome and you've told me what's important to you at each stage.

- Is there anything we've missed?
- What points are crucial for building trust? What is the most important thing for the DWP to get

right?

- Thinking about the overall ideal process we've discussed, which bits make you think the process is....?
 - One you could trust.
 - Easy to understand.
 - Clear.
 - Fair.
 - Credible.

10. Thanks and wrap up

Appendix B

Depth topic guide

J5042 Date 4/4/12

DWP PIP – Strand 1

Depth topic guide

Topic coverage

1. Introduction

- Introduce self.
- Introduce IFF Research – about us and the panel.
- Subject:
 - There are a number of reforms to the benefit system that are likely to be introduced as part of the Welfare Reform bill. In this context we'd like to discuss how application processes for new benefits should be designed.
- Confidentiality.
 - Taking part in this research will not impact on your current benefit in anyway.
- Recording.
- Introduction:
 - Working status/who they live with.
 - Nature of their condition.
- Warm up:
 - Who do you talk to for advice about important matters and decisions?
 - Who do you see most regularly?
 - Networks? Support groups? Online? Telephone?
 - Do you discuss your condition with anyone? Who? In what circumstances?

BACKGROUND

USE MATERIAL A – BRIEF OVERVIEW OF THE REFORMS

MATERIAL A: Hand out on laminates/on a large A1 poster and having alternative arrangements in place as necessary.

2. Design principles

As I mentioned, this discussion is about helping DWP design the process of the new payment to ensure it fully meets their customers' needs.

Before we begin I'd like you to think about the process of applying for a benefit and think about things that would be important to you during this process.

Q1. What bad/good experiences have you had of making applications?

- Probe for experiences beyond just benefit applications, to wider experiences of claims or applications (e.g. insurance claims, applying for loan or bank account, applying for passport or driving licence)? Online?

Q2. How do you tend to access online resources?

- What browser do you use?
- Do you use any specialist programs?
- What types of accessibility options would you expect when accessing online resources?

Q3. What is important to you throughout this sort of process?

- Collect spontaneously then probe for:
 - Trust/confidence?
 - Easy to understand
 - Clear?
 - Fair?
 - What else?

3. Introduce different stages of the journey

USE MATERIAL B – LARGE POSTER OF THE STAGES

MATERIAL B: Stages are 'unveiled' on a poster (from left to right) showing the very basic structure of the journey with a sliding arrow so we can highlight what stage we are thinking about as the discussion develops.

We'll be talking about each of these stages in turn.

4. Deciding whether to apply (pre-claim)

With this journey in mind, I'd like you to imagine you have to consider making a claim for the new PIP payment. I'd like you to tell me how you think that process should work – there are no right or wrong answers here.

Q4. It is envisaged that DWP will contact you to inform that DLA is drawing to a close and you can apply for the new benefit.

- How would you like to be informed?
 - F2F? By phone? By letter/email? Multiple methods?
 - Multiple methods/occasions?
 - Why?

- When would you want to know? How far in advance?
- How would you feel/how would you react to this?

Q5. What would inform your decision over whether or not to make a claim?

- How would you find out what to do?
- Would anything put you off making a claim? What? Why?
- Would anything encourage you to claim? What? Why? Who?
- When do you think you would make a claim?
 - As soon as you hear from DWP? Why? Why not?

Q6. Would you seek any help, advice or guidance in deciding whether to make a claim?

- Who from? Why? Where?
 - Friends/family? Colleagues?
 - Professional sources?
 - GP? Accountant? Solicitor? Citizens advice? Support workers (e.g. mental health worker, social worker) Other intermediaries?
 - DWP? JCP? PDCS?
 - Use of internet/phone/face to face sources?
- What sources? Direct Gov? Library?
- Have you sought help from them before? When?
- What sort of information would you need?
- If no support wanted/needed – why not?

Q7. What information (if any) do you think you would need when deciding whether to claim?

- Overview of the benefit?
- Instructions on how to apply?
- Example answers?
- Eligibility criteria and assessment criteria?
 - How would you expect to access this information?
 - What would you need to know?

Q8. What information would you expect to be provided from DWP?

- How much information would you expect?
- How would you prefer this to be provided?
- What channels would you expect to be given information from DWP?
 - In person? Letter? Website? Leaflet? Telephone?

Note for Q9: When interviewing an organisational appointee refer to ‘the recipient’ not ‘you’.

Q9. Would you want to include specific information about you/the recipient from GPs/and other medical professionals at this stage?

- Why? Why not?
- Who specifically would you like to provide evidence about your condition?
- Probe GP, social worker, mental health professional, physio, nurse, consultant etc

Q10. If DWP could develop guidance to help people work out whether they would be eligible and are likely to be entitled to the benefit how useful do you think it would be?

- How do you feel about this?
- Would you be likely to use the guidance? Why? Why not?
- What form would you expect it? Online? Paper?
- What guidance/information would put you off making an application? Why?
- Would you trust it?

Q11. Thinking about the overall process of making the claim, what would need to happen for you to think the process was....?

- One you could trust.
- Easy to understand.
- Clear.
- Fair.

5. The application process (claim experience)

I’d like you to imagine you have all the information you need and you decide to make a claim for the new benefit. Again, I’d like you to tell me how you think that process should work.

Q12. How would you want to go about making claim?

- What would the process be?
- Would it be online? a written application? face to face?
 - Security issues online? Level of security?
- What information should you have to provide?

Q13. It is envisaged that the process will initially involve filling in some details online or talking through some details over the phone.

- How do you feel about this process?
- What information would expect to give?
 - Name? Address? Bank details?
 - Age? Residence?
 - Your condition?
 - If already claim DLA – would you still expect to provide these details?

Q14. Would you want to include specific information about you from GPs/and other medical professionals at this stage?

- Why? Why not?
- Who specifically would you like to provide evidence about your condition?
 - Probe GP, social worker, mental health professional, physio, nurse, consultant etc?

Q15. Would you seek any help, advice or guidance at this stage?

- Who from? Why? Where?
 - Friends/family? Colleagues?
 - Professional sources?
 - GP? Accountant? Solicitor? Citizens advice? Other intermediaries?
 - DWP? JCP? PDCS?
 - Use of internet sources?
 - What sources? Direct Gov?
 - Library?

Q16. After the initial call it is possible that you will be asked to complete a form giving more details of your condition:

- What should this form look like?
- How do you feel about this process?
- What information would expect to give?
- Would you seek any help, advice or guidance?

Q17. How easy or difficult do you find it to talk about your condition with other people?

- How do you find talking to medical professionals/the government about it? How do you prefer to do this?
- How far do you travel to talk to professionals?
 - Where do you meet them?
 - What times do you prefer? Why?
 - Do you have 'good' 'bad' days?

Q18. What information about your condition do you think it is essential for DWP to have in order for them to make an informed decision over your claim?

- What should DWP know in order for you to have confidence in their decision?
- How should this information be provided? Who should it be provided by?
 - You? GP? Other professional?
 - Carers? Friends/family?
 - In what form should it be provided?

Q19. Thinking back to other experiences you may have had about submitting a claim with DWP – what could have made the process easier for you at this stage of the process?

- Why?

Q20. Thinking about this stage, what would need to happen for you to think the process was....?

- One you could trust.
- Easy to understand.
- Clear.
- Fair.

6. Awaiting the decision (journey to decision)

Q21. Having submitted your claim I'd like you to tell me what you think would happen next?

- Would you want/expect to meet someone face to face at any stage?
 - Where would you want to meet them?
 - What times do you prefer? Why?
 - Do you have 'good' 'bad' days – what impact would this have on meeting someone face to face/ your claim?
- Would you want to be able to follow/check the status of the claim?
- How long would you expect the process to take?
- What information would you want when the claim is being processed?

Q22. What would be the best way for DWP to keep in touch with you?

- Through what channels? How often?
- Why? Why not?

Q23. What support (if any) would you expect while your claim is being processed?

- Why? Who from?

Q24. Although the final process for assessing PIP claims is still being designed it is envisaged that in many cases part of the process will involve a meeting with an independent assessor.

- How do you feel about this element of the process?
- Why do you say that?
- How would you expect to be informed about the meeting with an assessor?
- Through what channels? Why? SMS reminder?

Q25. What would you expect this meeting to involve?

- What would be discussed?
- What would you like to discuss? Why?
- Where would you want the meeting to take place?
- In home? In offices?

- times do you prefer? Why?
 - Do you have ‘good’ ‘bad’ days? How would these affect you?
- Q26. Thinking back to other experiences you may have had when waiting for a claim with DWP to be processed – what could have made the process easier for you at this stage?

- Why?

Q27. Thinking about this stage, what would need to happen for you to think the process was....?

- One you could trust.
- Easy to understand.
- Clear.
- Fair.

7. The decision (and next steps)

Q28. How should the decision be communicated to you?

- Why?
- Do you think it should be communicated differently depending on whether your claim was accepted or rejected? Why? How should it be communicated?

I’d now like you to assume that DWP have informed you of their decision – let’s assume you are granted the PIP payment.

Q29. What information would you want/expect at this stage?

- Would you expect any further follow up from DWP?
- What would happen next?
- Regular reviews?
- E mail/phone/postal contact/text message? What about and why?
- What type of information – how would you expect this to be given?

Q30. Under what circumstances might you wish to contact DWP?

- Would you know how to contact them?

And thinking hypothetically, supposing your claim was refused by DWP/the amount you were awarded was not what you expected.....

Q31. How would you feel? What do you think would happen next?

- What do you think you would do?
- What would you want/need to know?
- What support would you need? From who?

ENCOURAGE SPONTANEOUS DISCUSSION – AND THEN COVER THE FOLLOWING:

- Would you expect any information about how the decision was reached?
- What type of information – how would you expect this to be given?

Q32. Let's assume that someone gets a decision that is correct but it is not the outcome they were hoping for – what do you think they should do?

- Why do you say that?
- What do you think they would actually do (if its different from what they should do)?
- How do you think they would feel?
- Who do you think they would turn to?
- What about disputing the decision? How would they decide whether or not to appeal?
- Would they expect a phone call? Before? After?
- Do you think their reaction would be different depending on whether the claim was refused/ or the amount awarded was lower than expected?

Q33. What reassurance do you think the person would need to give them confidence that the decision is correct/fair?

- What could the DWP do or say at this point to give you (or others in this situation) confidence in the process?
- How should this process work?

Q34. Thinking about this stage, what would need to happen (apart from a different outcome) for you to think the process was.....?

- One you could trust.
- Easy to understand.
- Clear.
- Fair.

8. Ongoing relationship

- Once you've been awarded PIP, what sort of relationship would you want with the DWP going forward?
- How important is this?

9. Wrap up

Thank you very much for your time, it has been very much appreciated – we discussed the whole process of making a claim – from early consideration to final outcome. Is there anything else you would like to add?

Once again stress that their current benefit will not be impacted by taking part in the study/joining the panel.

THANK RESPONDENT ON BEHALF OF THE DWP AND IFF RESEARCH AND CLOSE INTERVIEW

I declare that this survey has been carried out under IFF instructions and within the rules of the MRS Code of Conduct.

Moderator signature:

Date:

Finish time:

Interview Length

Mins

Appendix C

Transitional depth topic guide

J5042 Date 28/09/11

DWP PIP – Strand 1

Transitional Depth topic guide

Quota 4: Transitional customers

Topic coverage

1. Introduction

- Introduce self.
- Introduce IFF Research – about us and the panel.
- Subject:
 - There are a number of reforms to the benefit system that are likely to be introduced as part of the Welfare Reform bill. In this context we'd like to discuss how application processes for new benefits should be designed.
- Confidentiality:
 - Taking part in this research will not impact on your current benefit in anyway
- Recording.
- Introduction:
 - Working status/who they live with.
 - Nature of their condition.
- Warm up:
 - Who do you talk to for advice about important matters and decisions?
 - Who do you see most regularly?
 - Networks? Support groups? Online? Telephone?
 - Do you discuss your condition with anyone? Who? In what circumstances?

2. Overarching themes

As I mentioned, this discussion is about helping DWP design the process of the new payment to ensure it fully meets their customers' needs.

Before we begin I'd like you to think about the process of applying for a benefit and think about things that would be important to you during this process.

Q35. What bad/good experiences have you had of making applications?

- Probe for experiences beyond just benefit applications, to wider experiences of claims or applications (e.g. insurance claims, applying for loan or bank account, applying for passport or driving licence)? Online?

Q36. How do you tend to access online resources?

- What browser do you use?
- Do you use any specialist programs?
- What types of accessibility options would you expect when accessing online resources?

Q37. What is important to you throughout this sort of process?

- Collect spontaneously then probe for:
 - Trust/confidence?
 - Easy to understand?
 - Clear?
 - Fair?
 - What else?

3. Experiences when turned 16

I'd like you to think back to when you (or your child/the young person you look after) turned 16 and anything that happened in terms of your (their) benefit claims around this time.

Thinking specifically about your Disability Living Allowance claim, can you tell me what you remember about the process that you went through during this time to move you on to an adult DLA award.

Q38. How did you first hear about moving on to adult DLA.

- When was this? How long before your birthday? Was this too early/too late? When would have been a better time?
- Was this communication clear? Why/why not? Was there a better way that they could have communicated with you?
- How did you feel at this stage?

Q39. Do you have a formal representative such as a parent or guardian for your DLA claim or is all the communication from the DWP with you?

- How did you decide which approach to use?
- Why did you make this decision?

Q40. Did you have other assessments for other benefits or other services going on at around this time as well?

- Did you have any school/educational based assessments? What were these?
- What assessments? What did they involve? How far in advance of your 16th birthday did these things happen?

- Were they spread out or all at once?
- How did you feel during this period?
- Were the arrangements that these other organisations made better or worse than those for DLA? In what way?
- What could have been done to make this period easier?

Q41. Did you seek any advice or guidance about your DLA claim at this point?

- Who from? Why? Where?
 - Friends/family? Colleagues?
 - School/education professionals e.g. SEN co-ordinators.
 - Professional sources?
 - GP? Accountant? Solicitor? Citizens advice? Support workers (e.g. mental health worker, social worker) Other intermediaries?
 - DWP? JCP? PDCS?
 - Use of internet/phone/face to face sources?
- What sources? Direct Gov? Library? School?
- Have you sought help from them before? When?
- What sort of information would you need?
- If no support wanted/needed – why not?

Q42. What were your key priorities during this period? What things were you most worried about?

4. Brief overview of the reforms

MATERIAL A: Hand out on laminates/on a large A1 poster and having alternative arrangements in place as necessary.

NB- Assessment for PIP is designed for those aged 16 and above.

To ensure a productive depth – if there is negative feedback/cynicism about the reforms we will explain that it's very useful to have their candid feedback but for the remainder of the discussion we are going to be exploring the process of applying for the benefit itself – not the way it is assessed or the rationale for the reforms.

5. Introduce different stages of the journey (c. 2 mins)

USE MATERIAL B

MATERIAL B: Stages showing the very basic structure of the journey with a sliding arrow so we can highlight what stage we are thinking about as the discussion develops

We'll be talking about each of these stages in turn.

DECIDING WHETHER TO APPLY (pre-claim)

People who are receiving DLA at the moment but who turn 16 after the introduction of the PIP will need to make a new claim for PIP. Using your recent experience, I'd like you to tell me how

you think that process should work – there are no right or wrong answers here. So imagine you are approaching your 16th birthday and will need to make a claim for PIP...

Q43. How should this process start?

- How would you like to be informed?
 - F2F? By phone? By letter/ email? Multiple methods?
 - Multiple methods/occasions?
 - Why?
- How would you feel/ how would you react to this?

Q44. When would you want to know about needing to apply for PIP?

- How far in advance should this be?
- What should the trigger be?

Q45. What information would you need to support you at this stage?

- When would you want this information?
- How would you find out what to do?
- Would anything put you off making a claim? What? Why?
- Would anything encourage you to claim? What? Why? Who?
- When do you think you would make a claim?
 - As soon as you hear from DWP? Why? Why not?

Q46. What information (if any) do you think you would need when deciding whether to claim?

- Overview of the benefit?
- Instructions on how to apply?
- Example answers?
- Eligibility criteria and assessment criteria?
 - How would you expect to access this information?
 - What would you need to know?

Q47. What information would you expect to be provided from DWP and when would you expect to receive it?

- How much information would you expect?
- How would you prefer this to be provided?
- What channels would you expect to be given information from DWP?
 - In person? Letter? Website? Leaflet? Telephone?

Q48. Thinking about the overall process of this first step, what would need to happen for you to think the process was....?

- One you could trust.

- Easy to understand.
- Clear.
- Fair.

THE APPLICATION PROCESS (claim experience)

I'd like you to imagine you have all the information you need and you decide to make a claim for the new benefit. Again, I'd like you to tell me how you think that process should work.

Q49. How would you want to go about making claim?

- What would the process be?
- Would it be online? a written application? face to face?
 - Security issues online? Level of security?
- What information should you have to provide?

Q50. It is envisaged that the process will initially involve filling in some details online or talking through some details over the phone.

- How do you feel about this process?
- What information would expect to give?
 - Name? Address? Bank details?
 - Age? Residence?
 - Your condition?
 - If already claim DLA – would you still expect to provide these details?

Q51. Would you want to include specific information about you from GPs/and other medical professionals at this stage?

- Why? Why not?
- Who specifically would you like to provide evidence about your condition?
 - Probe GP, social worker, mental health professional, physio, nurse, consultant etc?

Q52. Would you seek any help, advice or guidance at this stage?

- Who from? Why? Where?
 - Friends/family? Colleagues?
 - Professional sources?
 - GP? Accountant? Solicitor? Citizens advice? Other intermediaries?
 - DWP? JCP? PDCS?
 - Use of internet sources?
 - What sources? Direct Gov?
 - Library?

Q53. After the initial call it is possible that you will be asked to complete a form giving more details of your condition:

- What should this form look like?
- How do you feel about this process?
- What information would expect to give?
- Would you seek any help, advice or guidance?

Q54. How easy or difficult do you find it to talk about your condition with other people?

- How do you find talking to medical professionals / the government about it? How do you prefer to do this?
- How far do you travel to talk to professionals?
 - Where do you meet them?
 - What times do you prefer? Why?
 - Do you have ‘good’ ‘bad’ days?

Q55. What information about your condition do you think it is essential for DWP to have in order for them to make an informed decision over your claim?

- What should DWP know in order for you to have confidence in their decision?
- How should this information be provided? Who should it be provided by?
 - You? GP? Other professional.
 - Carers? Friends/family?
 - In what form should it be provided?

Q56. Thinking back to other experiences you may have had about submitting a claim with DWP – what could have made the process easier for you at this stage of the process?

- Why?

Q57. Thinking about this stage, what would need to happen for you to think the process was....?

- One you could trust.
- Easy to understand.
- Clear.
- Fair.

6. Awaiting the decision (journey to decision)

Q58. Having submitted your claim I’d like you to tell me what you think would happen next?

- What would be the key priorities for you at this stage?
- Would you want/expect to meet someone face to face at any stage?
 - Where would you want to meet them?
 - What times do you prefer? Why?
 - Do you have ‘good’ ‘bad’ days – what impact would this have on meeting someone face to face/ your claim?

- Would you want to be able to follow/check the status of the claim?
- How long would you expect the process to take?
- What information would you want when the claim is being processed?

Q59. What would be the best way for DWP to keep in touch with you?

- Through what channels? How often?
- Why? Why not?

Q60. What support (if any) would you expect while your claim is being processed?

- Why? Who from?

Q61. Although the final process for assessing PIP claims is still being designed it is envisaged that in many cases part of the process will involve a meeting with an independent assessor.

- How do you feel about this element of the process?
- Why do you say that?
- How would you expect to be informed about the meeting with an assessor?

Through what channels? Why? SMS reminder?

Q62. What would you expect this meeting to involve?

- What would be discussed?
- What would you like to discuss? Why?
- Where would you want the meeting to take place?
- In home? In offices?
- What times do you prefer? Why?
- Do you have 'good' 'bad' days? How would these affect you?

Q63. Thinking back to other experiences you may have had when waiting for a claim with DWP to be processed – what could have made the process easier for you at this stage?

- Why?

Q64. Thinking about this stage, what would need to happen for you to think the process was....?

- One you could trust.
- Easy to understand.
- Clear.
- Fair.

7. The decision (and next steps)

Q65. How should the decision be communicated to you?

- Why?
- Do you think it should be communicated differently depending on whether your claim was accepted or rejected? Why? How should it be communicated?

I'd now like you to assume that DWP have informed you of their decision – let's assume you are now moving onto PIP.

Q66. What information would you want/expect at this stage?

- Would you expect any further follow up from DWP?
- What would happen next?
- Regular reviews?
- E mail/phone/postal contact/text message? What about and why?
- What type of information – how would you expect this to be given?

Q67. Thinking about this stage, what would need to happen for you to think the process was....?

- One you could trust.
- Easy to understand.
- Clear.
- Fair.

8. Ongoing relationship

- Once you've been awarded PIP, what sort of relationship would you want with the DWP going forward?
- How important is this?

9. Wrap up

Thank you very much for your time, it has been very much appreciated – we discussed the whole process of making a transitional claim – from early consideration to final outcome. Is there anything else you would like to add?

Once again stress that their current benefit will not be impacted by taking part in the study/joining the panel

THANK RESPONDENT ON BEHALF OF THE DWP AND IFF RESEARCH AND CLOSE INTERVIEW

I declare that this survey has been carried out under IFF instructions and within the rules of the MRS Code of Conduct.

Moderator signature:

Date:

Finish time:

Interview Length

Mins

Department for Work and Pensions (DWP) Insight commissioned this User Centred Design research to ensure that claimants are central to the design and development of Personal Independence Payment. It was conducted by IFF Research on behalf of the DWP.

The report findings illustrate the first part of an ongoing programme of research. This consisted of 21 focus groups and 46 face-to-face in-depth interviews, conducted in September and October 2011.

If you would like to know more about DWP research, please contact:
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DWP Department for
Work and Pensions

Published by the
Department for Work and Pensions
May 2012
www.dwp.gov.uk
Research report no. 794
ISBN 978-1-908523-56-3