



Department  
for Work &  
Pensions



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Social Research

# Applicants' Journeys to Claiming PIP

Improving the understanding of how and why people choose to apply for Personal Independence Payment to improve the support that DWP provide to their customers.

May 2025

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

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# Executive summary

Personal Independence Payment (PIP) is a benefit which can help with extra living costs where someone has a long-term physical or mental health condition or disability which impacts their ability to do certain everyday tasks. From the moment when an individual first learns about PIP, a number of different possible 'claim' journeys are open to them. Their journey from that point may result in them submitting an application for the benefit or it may not, and either alternative may take a varying amount of time and will be subject to a number of influencing factors. The aim of this research is to learn more about these journeys and what shapes them, in order to understand how some applicant journeys can be better supported, and what differentiates those who apply (applicants) from those who may be eligible for PIP but do not submit an application (non-claimants).

This project included multiple research strands to try and build a rounded picture of journeys taken, and the people and factors which influence them. Research among both **applicants** and **non-claimants** highlights some notable similarities in their understandings (and, sometimes, misunderstandings) of what claiming PIP involves, as well as some common challenges to applying. There are a number of common misconceptions around the benefit, including that eligibility is in some way affected by working status or income, or that it is only available for people with particular health conditions or disabilities. These misconceptions can present barriers to people applying for PIP. It is also common for people to struggle to reconcile their own self-identity with their preconceptions of 'someone who is disabled' or 'someone that claims benefits'. It is generally either heightened need or encouragement from an outside source that makes a difference here, spurring some on to apply while others decide not to. Finally, there is also a cost-benefit assessment that is made when deciding whether or not to apply for PIP; many non-claimants do not submit an application because they think the process will be difficult and they believe they are unlikely to receive an award at the end of it.

Interviews with both applicants and non-claimants highlight the influence that outside agents can have on a person's PIP journey. This project specifically engaged **advisors** – people who give advice on PIP in either a formal or informal capacity – to better understand how these influential figures are informed and what motivates them to give advice. Some formal advisors work for organisations that specialise in benefits advice (e.g. charities offering advice services for particular communities or patient groups) and draw on training and experience when advising their clients. In other cases, medical professionals, social workers and others offer suggestions around possible eligibility in the course of their work. These advisors can also be highly influential, despite benefits advice generally not being a specific part of their job. Informal advisors can be friends, family members, colleagues or even just acquaintances whose suggestion of PIP as a possible source of help comes to a potential applicant at just the right time.

Some who are considering PIP are then prompted to conduct further research of their own, often turning to online sources to learn more. An accompanying study was conducted into **online search behaviours around PIP** which reveals some of the

most common questions people have about the benefit, and which sites they access to answer these questions. The role of social media – in particular content from people with experience of applying – also seems to be notable in either helping applicants refine their application, or putting some off applying altogether.

Analysis of the journeys people take after first learning about PIP shows there are many potential challenges to both understanding and progressing through a claim journey, and **multiple factors which shape the experience**. The most influential of these include the nature of the health condition or disability they are experiencing, the length of time they have been experiencing it, and the extent to which they have access to an advisor. The role of advisors in prompting action, tackling misconceptions, and offering targeted advice throughout the application process is significant in a number of journeys, and journeys without such an advisor are more likely to end before an application is made. Other influencing factors include a person's experience of and views towards the benefits system (as mentioned above, identity challenges can make people delay or rule out an application), their working status, and the presence or absence of emotional support. This project and previous work among applicants and customers has shown that the process is often emotionally demanding, and those without support networks to call on are less likely to successfully navigate the application process.

These factors, and some others, have been accounted for here in the process of identifying seven **common journeys to claiming PIP**. This project also incorporates qualitative findings from interviews with applicants, advisors, and non-claimants to better inform understandings of how people progress from the point of first learning about PIP, how some people end up applying (drawing on various sources of information and support) and some do not. It is clear that there is no clear rule to determine who applies and who does not, but rather a number of barriers and challenges common to all considering PIP which some are able to overcome and some are not.

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# Abbreviations

DLA – Disability Living Allowance

DWP – Department for Work and Pensions

HCP –Healthcare Professional

PIP – Personal Independence Payment

UC – Universal Credit

# A note on language

Some of the terminology used in this report is defined below.

- **Advisors:** Anyone providing advice or guidance around PIP, either to applicants or non-claimants. Advisors may be informal (e.g. friends or colleagues), formal (i.e. working for an organisation where their role includes giving benefits advice), or professional (i.e. engaging with applicants/non-claimants in a professional capacity, but whose role does not formally involve benefits advice, e.g. a medical professional).
- **Applicants:** Anyone who has submitted or is preparing an application for PIP.
- **Customers:** Anyone who is currently claiming a DWP benefit, in this case PIP.
- **Disability and/or health conditions** – A term used in the report to collectively describe the underlying reasons for a customer receiving a disability benefit. It encompasses a range of physical, mental, sensory, or cognitive differences or challenges that may impact an individual's day-to-day behaviour or experience. This term has been chosen to acknowledge that the distinction between a disability and a health condition can be subjective and personal to each participant.
- **Non-Claimants:** Anyone who is not currently claiming PIP.

# 1. Introduction

## 1.1 Background

As of July 2024, there were 3.5 million claimants entitled to Personal Independence Payment (PIP) in England and Wales, with a further 130,000 claims with entitlement for people living in Scotland.<sup>1</sup> PIP registrations and clearances continue to increase, with 210,000 registrations and 240,000 clearances for new claims in the quarter to July 2024. In helping to best support people who need to access PIP, the Department for Work and Pensions (DWP) commissioned this research to understand why, how and when people with disabilities and long-term health conditions decide to apply for PIP.

Previous PIP Claimants' Experiences (2018)<sup>2</sup> research addressed the experience of customers once they are claiming but explored little about their journey to deciding to claim. The research highlighted that there was limited understanding amongst customers about PIP as a benefit. Further, it showed several misconceptions around what the benefit is intended for and who is eligible. This included the misunderstanding that PIP was only for people with health conditions which affect their mobility, and that PIP was solely intended for people who cannot work as a result of their disability. These misunderstandings have also been found in more recent work undertaken by Basis Social.<sup>3</sup>

A question in the Customer Experience Survey (2020/21)<sup>4</sup> showed that PIP customers primarily use medical professionals, GOV.UK, friends and family, and charities to decide if they are eligible to claim. However, this does not tell us how many customers are *not* making use of a source of advice, or whether they need the advice. This leaves an evidence gap around how people use advice, and how it impacts on applications.

In addition to understanding more about the journeys that applicants take to put forward a claim for PIP, this project also aims to capture the experience of those living with a long-term condition who may be eligible but have not applied. This latter group includes those claiming other benefits (e.g. Universal Credit or Employment Support Allowance) but extends well beyond this; the latest Family Resources

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<sup>1</sup> DWP (2024b), 'Personal Independence Payment: Official Statistics to July 2024', available [online](#). Between March and August 2022, the Scottish Government replaced PIP with the Adult Disability Payment (ADP) for new claims in Scotland. Since August 2022, existing PIP customers in Scotland have also begun transferring to ADP. Consequently, this report (and all statistics relating to PIP after August 2022) refer to England and Wales only.

<sup>2</sup> DWP (2018), 'Personal Independence Payment Claimant Research – Final Report', available [online](#)

<sup>3</sup> DWP (2024c), 'Experiences of PIP Applicants Who Received Zero Points at Assessment, available [online](#).

<sup>4</sup> DWP (2023), 'DWP Customer Experience Survey: benefit customers 2020 to 2021', available [online](#).

Survey statistics show that 23% of working age adults have a disability or impairment that substantially affects them day-to-day, amounting to approximately 8.6 million people.<sup>5</sup> Although PIP is not intended as a benefit for disabled people and is a measure of needs rather than a measure of disability, DWP wishes to address an existing evidence gap around disabled people who have not claimed PIP and how they are different from those who have claimed.

The intention for this project is therefore to develop a more detailed picture of the different journeys applicants take with regard to PIP. This includes both applications which are awarded PIP, those which are not awarded, and those who considered but did not submit an application. These broad categories span a wide range of experiences and levels of engagement with DWP and its services, all of which influences each individual 'customer journey'. By exploring these various groups in more detail, we have built up a picture of some 'typical' customer journeys and the key factors which influence them. These are intended to inform DWP service design and provision in future.

## 1.2 Research aims

The overall aim of the research was to understand the journeys people take from first learning about PIP to claiming that benefit. This includes adding nuance to existing DWP understandings of how these journeys play out with a view to making improvements to the application process. This overarching objective is underpinned by a number of subsidiary research questions. These include:

1. How do PIP customers end up deciding to claim? What do their journeys look like? What are the types of PIP customer?
  - 1.1. How do they hear about the benefit?
  - 1.2. How long do they have a health condition before deciding to claim and what triggers them to act?
  - 1.3. What influences their decision to claim? What sources of information/advice do they use to decide whether (eligibility) and how to claim (e.g. what evidence to provide)?
  - 1.4. How does employment status interact with decisions to claim?
  - 1.5. How do they decide how to claim (what strategies to apply to claiming if any)?
  - 1.6. How do journeys to claiming PIP vary?

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<sup>5</sup> DWP (2024a), 'Family Resources Survey: financial year 2022 to 2023', available [online](#). The term "disability" in this survey follows the core definition of disability in the Equality Act 2010 which states that a person is considered to have a disability if they have a physical or mental impairment that has 'substantial' and 'long term' negative effects on their ability to do normal daily activities.

2. How accurate is each type of customer's understanding of PIP? What misunderstandings are there?
  - 2.1. What are the different (mis)understandings of PIP, how much do they matter/impact on claim?
  - 2.2. What are the sources of understanding and misunderstandings?
  - 2.3. What levels of confidence do customers have in getting an award?
3. How do the sources of advice (both formal and informal) about PIP get informed?
  - 3.1. What are the views/knowledge of PIP of people who act as informal advisors/sign posters? (medical staff, JCP, etc)
  - 3.2. How are those giving advice to PIP customers informed?
  - 3.3. What is the role of different sources of information, (media, social media, official sources, charities etc) on the broader understandings of PIP?
4. What are the differences between people with disabilities and/or health conditions who claim PIP and those who don't?
  - 4.1. What are the groups of disabled people who have not claimed PIP?
  - 4.2. What are their reasons for not applying?
  - 4.3. What are the reasons for dropping out during PIP claim (not returning PIP2 form, or failing to attend assessment)?
  - 4.4. Are they likely to apply in the future?

## 1.3 Methodology

The research was divided into three strands, one focused on each of the different audiences to be included in the research (PIP applicants, people with disabilities who do not claim PIP, and those giving advice to both current and potential applicants in either a formal or informal capacity). Findings from all three strands are combined in this report to address the research questions outlined above.

To help inform the research design, an initial scoping stage was conducted involving a rapid and focused review of relevant literature, both from previous DWP insight work and wider sources (published and unpublished). Findings from the scoping stage were used to inform the design and development of research instruments. Where relevant, reference has been made in this report to published external sources included in the scoping stage. Where no reference is given, the findings relate to the primary research conducted for this project.

To provide guidance throughout this project, an Advisory Group was convened who were consulted on the research design, drafting of research materials (such as interview topic guides) and reflecting on emerging findings. This group was made up

of individuals with professional experience of conducting research with disabled people (including DWP staff) and those with lived experience of a disability or health condition. They provided valuable feedback on language and framing, as well as broad insight into existing discourse in the disabled community and best practice on conducting research with disabled people. The representation of evidence included in this report, and any implications of this evidence, are those of the research project team, rather than those of the members of the Advisory Group. Membership of the Advisory Group is detailed in Appendix A.

**Strand 1: Interviewing current PIP applicants**

Between March and September 2024<sup>6</sup>, in-depth interviews were undertaken by researchers from Basis Social with PIP applicants who had recently initiated a PIP claim. A total of 50 interviews were conducted by telephone or over MS Teams, depending on the preference of the participant, each lasting approximately 60 minutes. To ensure diversity across groups of interest, quotas were set around age, gender, ethnicity, nature of health condition/disability, employment status, and whether they receive support to carry out day to day activities or not. The sample itself was drawn by DWP and was provided to Basis Social to recruit from. All participants received a shopping voucher as thanks and in recognition of their time.

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

**Table 1: Strand 1 (Applicant Strand) Sample summary**

Sample Category	Sample Subgroup	No. of participants
Gender	Male	26
	Female	24
	Identifies another way	0
Age	16-24	18
	25-49	17
	50-65	15
Ethnicity	People from ethnic minority backgrounds	28

<sup>6</sup> Fieldwork for this project was suspended between 22 May and 4 July 2024 due to the announcement of the UK general election.

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

Nature of disability / health condition	Move differently	10
	Sense differently	0
	Think/feel differently	24
	Other long-term health condition	16
Personal Support Status	Receives support from carer / family / friends	38
	Receives no support	12
Employment status	Working	17
	Not currently working	33

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

- Familiarity and understanding of PIP
- Decision making processes across their PIP claim journey
- Information, advice, and support received
- Questions and concerns throughout their PIP claim journey
- Confidence in putting in an application
- Beliefs around who qualifies for PIP, and how to navigate the process

To better understand the role of informal advisors (i.e. those offering applicants advice or information around their PIP claim in an entirely informal capacity, e.g. a family member, friend, or colleague), at the end of each interview applicants who had mentioned being supported by an informal advisor were invited to share Basis Social's recruitment information so that they could be interviewed as part of the Advisor Strand. Applicants were offered an additional shopping voucher in recognition of the additional time and effort this would entail.

## **Strand 2: Interviewing advisors**

Between April and May 2024, in-depth interviews were undertaken by researchers from Basis Social with informal advisors, formal welfare benefits advisors, and professionals that could advise on PIP as part of their role (e.g. a social worker, or occupational therapist). A total of 31 interviews were conducted by telephone or over MS Teams, depending on the preference of the participant, each lasting approximately 60 minutes. Informal advisors were recruited through applicants that took part in strand 1 and given a shopping voucher in recognition of their time.

Formal advisors were found using the Turn2Us database; an open call for participation was sent via email to organisations listed as providing welfare benefits advice. Professional advisors were recruited by recruitment partner Criteria, and were offered between £50-£80 for their time. A summary of the sample for Strand 2 is detailed in table 2.

**Table 2: Strand 2 (Advisor Strand) Sample summary**

Sample Category	Sample subgroup	No. of participants
Informal Advisor	Friends or family members	2
Formal Advisor	Welfare or benefit advisor working within a law centre, welfare or advice service, or disability charity	11
Professional	Roles included: GP (n4), occupational therapist (n3), nurse (n1), care worker (n6), and social worker (n4)	18

In addition to the above interviews, a number of additional small group discussions were held with formal and professional advisors. Rather than interviewing them on the advice they give to their clients, these discussions were used to review emerging findings around the different journey types experienced by customers. Organisations represented in these discussions included both local- and national-level organisations, those focused on specific communities and general advisory services. Their feedback was incorporated into the development of the journey types presented here in section 2.2. A standardised discussion guide was developed for use with advisors in conjunction with DWP. This is included in Appendix C of this report.

At this stage, a complementary research project was conducted into online searches around PIP. Carried out by Tenrec Analytics, this project sought to develop a more detailed and comprehensive understanding of information-seeking behaviour among the public. This was focused on analysis of Google and YouTube analytics data, exploring the search terms relating to PIP that are used on each platform, the frequency of their use, and the results they return.

### **Strand 3: Focus groups with non-claimants**

Between July and August 2024, focus groups were conducted with members of the public with a diagnosed long-term health condition who were not currently claiming PIP<sup>8</sup>. A total of 12 groups were conducted online via Zoom by researchers from Open Inclusion. Groups lasted 90 minutes and contained an average of 5 participants per

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<sup>8</sup> Participants could be claiming another DWP benefit, such as Universal Credit or Employment Support Allowance, and still qualify for these groups.



group. To ensure diversity across groups of interest, quotas were set around age, gender, ethnicity, nature of health condition/disability, and income level. Participants were recruited both from DWP-provided sample and using free-find recruitment techniques. Groups were organised according to two factors: age of participants, and how long their health condition had impacted their ability to carry out day-to-day activities. A summary of the groups is provided in Table 3. All participants received a shopping voucher in recognition of their time.

**Table 3: Strand 3 (Non-claimant Strand) Sample summary**

<b>Sample Category</b>	<b>Sample Subgroup</b>	<b>Length of condition impact</b>	<b>No. of groups</b>	<b>Total no. of participants</b>
Age	18-30	Less than 3 years	2	7
		3 years or more	2	11
	25-49	Less than 3 years	2	11
		3 years or more	2	12
	50-65	Less than 3 years	2	8
		3 years or more	2	10
Benefits status	Claiming another benefit (e.g. UC)	n/a	n/a	35
	Not claiming another benefit	n/a	n/a	24

In addition, two depth interviews were conducted as part of Strand 3, one with an individual and one with an appointee (someone appointed to handle the benefit claims of a third party).

A standardised discussion guide was developed for use with members of the public in conjunction with DWP and Open Inclusion. This is included in Appendix D of this report.

## **Analysis**

All interviews were recorded, and notes taken from moderator review of the audio recording. The research team used framework analysis<sup>9</sup> as a method for organising and managing data through a process of summation and synthesis, resulting in a

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<sup>9</sup> Ritchie, J., et al. (2014), 'Qualitative Research in Practice'. Sage: London. (2nd Edition).

series of themed matrices tied to the topic guide (and aims for the research). Individual matrices were created for each research strand.

Through detailed analysis and interpretation of qualitative data<sup>10</sup>, patterns of responses and relationships were identified, leading to well-supported conclusions. This was supplemented by regular brainstorming between members of the field team to identify and sense-check themes and conclusions.

Verbatim quotes have been used throughout this report to help illustrate points made in the main narrative. These have been labelled according to the type of participant (i.e. 'Applicant', 'Advisor', or 'Non-claimant') and relevant recruitment information. For the applicant strand this is age and nature of disability / health condition, for the advisor strand this indicates the type of advisor and, where relevant, their role or organisation type, for the non-claimant strand, this indicates the age range of the focus group participants and the length of time they have had their condition. Some quotations have been modified slightly for readability, but their overall content is unedited.

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<sup>10</sup> It is important to note that qualitative research is designed to be illustrative, detailed, and exploratory. It offers insights into the perceptions, feelings, and behaviours of people rather than quantifiable conclusions from a statistically representative sample.

# 2. Research Findings

## 2.1 Introduction

This research highlights the wide diversity of attitudes and experiences towards PIP among people in England and Wales who are living with a long-term health condition which impacts their ability to perform day-to-day activities. Discussions with members of this group who are claiming PIP, those who are not claiming, and those who offer advice to both has informed our understanding of the different ‘journeys’ taken to accessing this benefit.

While each individual will have a journey that is unique to them, this research has enabled the identification and exploration of a set of key factors that influence these journeys. In the following sections, we will present the findings from all three research strands and discuss their implications.

## 2.2 Journeys to Claiming PIP

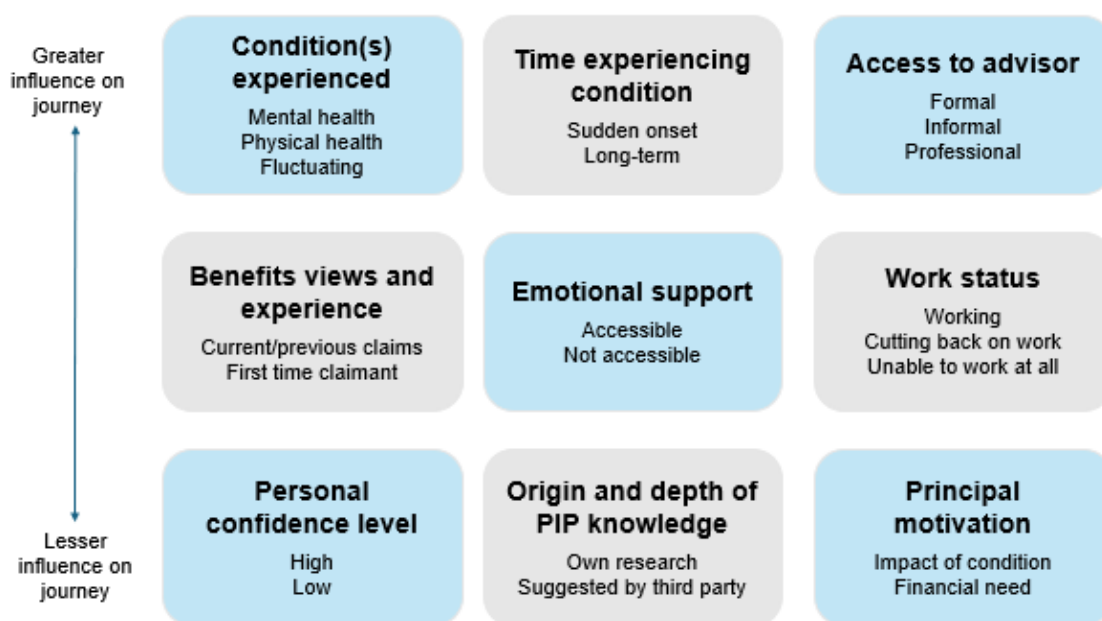
A key objective of this research was to produce a qualitative typology of archetypical applicant journeys to illustrate the diversity of applicant experience and present the key factors and characteristics that differentiate common journeys from each other. This is to inform DWP understanding of applicant experiences, with the intention of enabling targeted improvements to service provision in future.

The intention behind this typology of journeys is to add nuance to DWP understanding of journeys to claiming PIP, and to identify areas where processes can be improved to better support applicants (and prospective applicants). It is not to eliminate or play down the nuances of individual cases, or to produce a restrictive list of categories that does not respect the range of contexts in which people apply for PIP.

This represents a typology of journeys, not of applicants themselves, and we acknowledge that any given individual may start off on one of the journeys we have identified before changing to another. We also acknowledge that every applicant journey will be influenced by highly individual factors, which cannot be reflected in a typology but should be understood within the context of each individual claim.

### **Key factors influencing applicant journeys**

Based on our analysis of interviews with applicants, we have identified a number of key factors which influence applicant journeys. It is important to recognise these factors intersect, and can compound one another, influencing if and how people may progress a PIP claim. These are summarised in Figure 1 and explained in more detail below.



**Figure One: Key factors influencing applicant journeys to claiming PIP**

### **Nature of health condition or disability experienced**

This includes both the health condition on which the PIP claim is based, but also any additional conditions which applicants may or may not mention in their application. Research showed that experiences vary significantly between those experiencing physical health conditions and those with mental health conditions, with many applicants reporting multiple interacting conditions. The extent to which symptoms vary (in the short- or long-term) is also significant, with conditions that fluctuate significantly over time presenting a number of additional challenges. For example, fluctuations may impact motivation, physical or cognitive ability to commence or progress a claim, particularly in completing the PIP2 application form.

### **Length of time experiencing a health condition or disability**

There is a notable difference in experience between those who have been experiencing the impact of their condition for multiple years (including those with progressive or degenerative conditions) and those for whom symptoms have begun suddenly and recently (e.g. as the result of an accident or injury). Those with a sudden-onset condition are often trying to manage a number of significant simultaneous changes to their lifestyle and living conditions, which often influences their claim journey. Those who have been experiencing a health condition or disability for a longer period of time could be less likely to consider themselves as 'disabled' and to have developed a wide range of coping mechanisms to address longer-standing needs.

"[I'm] hesitant to apply because I didn't want to feel restricted...or like I can't do stuff...and I'm not disabled. I don't want to be labelled as disabled" (Applicant, 25-49, Move differently)

### **Access to practical support via an advisor**

As outlined above, this research examines the role of different types of advisors on applicant journeys: informal (e.g. friends, family, colleagues), formal (e.g. welfare and benefits advisors), and other professionals (e.g. medical practitioners, social workers). These advisors might be involved in a journey only briefly (e.g. a single conversation which prompts an applicant to look into PIP) or could play a significant part (e.g. in supporting an applicant to request and complete their PIP2 form, supporting during an assessment or appeal) but the extent to which applicants can access them significantly impacts their journey. This factor is of particular relevance in cases where applicants have low levels of literacy, struggle to process written information, and/or have difficulty writing. These applicants generally struggle to complete an application without practical support from an advisor of some kind.

“Over 50% of our clients cannot read or write, so we’re having to do a lot for them with that form.” (Formal advisor – Community-specific advice service)

### **Views and experience of the benefits system**

This factor incorporates both practical and ideological elements. Applicants who have previous experience of claiming benefits (which could be personal or secondary, e.g. through friends and family members) often have greater knowledge of what the benefits system can provide and to whom. It is also common – although not universal – for them to express greater openness towards claiming benefits to which they are entitled. Those who have never previously claimed any benefits often demonstrate lower awareness and report ignorance of ‘the system’, feeling confused and overwhelmed by the related administrative requirements. There is also often an emotional or ideological barrier for this group, as they do not associate themselves with the benefits system and often report resistance to seeking state support of any kind which they have not previously needed.

"I've never claimed anything from social or anything like that, never even been in a dole office. I've always tended to look after myself." (Applicant, 50-65, Move differently)

### **Emotional support networks**

The extent to which applicants have access to an emotional support network in the form of friends or family is a highly significant factor. Those who lack a source of emotional support to help them through the application process tend to report significantly more challenging experiences and are more likely to struggle to complete the application process.

“My wife helps me a lot.” (Strand 1, 25-49, Other condition type)

“I have no one here...I’ve lived here for ten years and I have never asked someone for help. At the moment I have literally no one to ask for help.” (Applicant, 25-49, Think/feel differently)

## **Work status**

An applicant's work status and closeness to the labour market is a significant influencing factor in a number of ways. Firstly, there is often a financial element as those who have to reduce or restrict the amount or nature of work they can do due to their health condition(s) often experience increased financial difficulties as a result. Secondly, it can relate to the amount of time or mental capacity they have available to devote to their application, including their ability to e.g. contact DWP during working hours. Thirdly, elements of personal identity are often bound up with work status and it is not uncommon for this identity to complicate a person's feelings towards claiming benefits in general, particularly for those who are currently in employment or seeking to return to employment.

"I kind of fobbed them off at the start [colleagues suggesting PIP]. I said, 'Well, I am able to work... I don't want that, I'm not lazy'. I thought, I can go to work, I don't need it." (Applicant, under 25, Move differently)

## **Personal confidence level**

This factor relates to the level of confidence an individual feels in their capacity to complete the PIP application as a process. This could relate to administrative capability, available capacity, confidence reading and writing, and access to necessary support. It does not relate to confidence in their eligibility, or in the final decision being in their favour. It is important to recognise that confidence levels may fluctuate and can be impacted by a wide range of factors (e.g. the advice given by a formal or informal advisor, or fluctuations in a health condition).

"I don't have a lot of confidence [...] I don't know, I'm always doubtful... I can't work, I can't do anything else." (Applicant, under 25, Think/feel differently)

"I'm pretty clued up. I don't think support or guidance would be much [help] for me." (Applicant, under 25, Other condition type)

## **Origin and depth of knowledge of PIP**

There is significant variation between journeys on this point, as some journeys begin with extensive pre-existing knowledge or recent research into PIP and others are initiated by a brief suggestion from a friend in passing. Research shows differentiated experiences based on where applicants first heard about PIP (e.g. those who were conducting their own independent research, those who heard about it from an informal connection, and those who were informed by a formal advisor or other professional) and the level of knowledge they have in the early stages of the process. This knowledge can relate to the application process itself in terms of what to expect at each stage, but also to eligibility criteria.

"I think I'd just leave it [if I was not awarded PIP]. I've been through MR [Mandatory Reconsideration]<sup>11</sup> with my husband and it's not something I want

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<sup>11</sup> When an applicant receives their outcome decision from DWP, they can request that this decision be reviewed and their case reconsidered. This is known as Mandatory Reconsideration, or MR.

to go through... I just feel like it's quite a negative experience." (Applicant, 25-49, Think/feel differently)

### **Principal motivation for claiming**

As PIP is a financial benefit for those experiencing a condition which impacts their daily life, all applicants are motivated by a combination of financial need and impact of their health condition. However, interviews highlight differences between journeys which are initiated in response to more urgent financial need and those triggered by changes to how a health condition or disability impacted someone day-to-day.

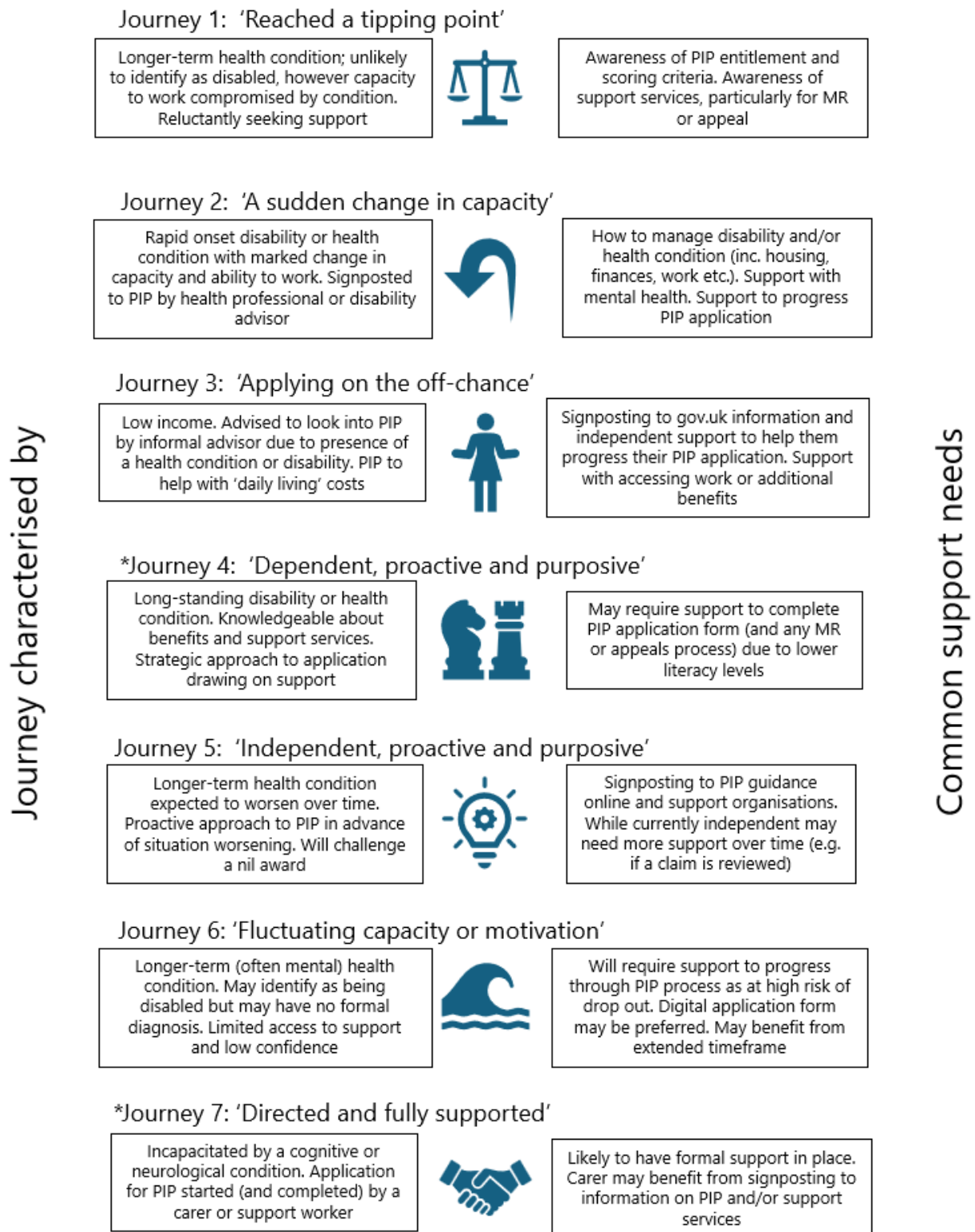
"My worry was that I'm not going to get my salary, I have lots of bills to pay, I have to try something to get some help." (Applicant, 25-49, Move differently)

"That was the tipping point, where it [the pain] started to be noticeable every day." (Applicant, under 25, Move differently)

### **Common journeys to claiming PIP**

The key factors outlined above combine and interact in different ways in each individual customer journey. However, analysis of the qualitative evidence collected during the Applicant Strand and, to a lesser extent, the Advisor Strand, generated some common journey types that were repeatedly evidenced in this research. These are illustrated in summary within Figure Two and detailed further below.

**Figure Two: Overview of common journeys and their support needs**



Journeys 1-3 and 5-6 were amply represented in the Applicant strand findings, with the experiences of multiple participants relating to each journey type. Journeys 4 and



7, as will be explained below, are based on discussions with formal and professional advisors and not represented in the sample of applicants interviewed.

### **Journey 1: Reached a tipping point**



This journey is more common among those with a relatively long-standing health condition or disability. They have often had this condition for five years or more and are more likely to have adapted to this and/or developed coping mechanisms which help to reduce some of the additional needs/challenges they may face day-to-day. They are less likely than those on some other journeys to identify as ‘disabled’, to be claiming other benefits, and awareness of PIP is lower than average (also reflecting that they are less likely to be engaged in any formal or informal networks relating to their health condition or disability). They are also more likely to have been in employment up until relatively recently.

“Even with my condition, I always try to be very independent...While I can do things, I am not going to bother anyone else [for help].” (Applicant, 50-65, Move differently)

This group are often reluctant to ask for financial help due to perceived stigma and/or discomfort in identifying as someone who claims benefits (e.g. ‘I’ve always worked and never taken anything from the system’). As is discussed in Section 2.6, these feelings can be enough to put people off applying entirely, but among eventual applicants this reluctance generally delays their application until the impact of any disability or health condition becomes notably more significant. This then often coincides with a severe reduction in their ability to work (i.e. they reach a ‘tipping point’) and impacts their ability to meet day-to-day living costs.

“I think if you’re working, you shouldn’t apply for [PIP]. If I was fit enough, I would be working. I would not even be thinking about PIP.” (Applicant, 50-65, Move differently)

This journey often involves signposting to PIP from an informal advisor (e.g. friend or family member). Due to the common reduction in work capability, this journey can involve greater financial vulnerability. This journey does not tend to involve a particular ‘strategy’ towards the application but may involve some fairly light-touch research (e.g. on GOV.UK and/or and disability-related searches) to confirm eligibility. As DWP is seen as the arbiter of eligibility, this journey is less likely to see an applicant who receives a nil-award going on to challenge a decision.

“I won’t be disheartened if I don’t get it... And I won’t be appealing and all this business.” (Applicant, 50-65, Move differently)

### **Journey 2: A sudden change in capacity**



The recency and speed with which a condition has begun is the key influencing factor on this journey. Whether the result of an accident or a sudden-onset condition, this journey starts ‘out of nowhere’ for applicants who generally have not previously struggled with their health.

The impact of this new condition is generally sufficiently severe that they have had to significantly change multiple aspects of their lifestyle, including the extent to which they are able to work. Those on this journey are therefore often negotiating financial challenges alongside all the other adaptations they are having to make as they come to terms with the nature of their disability and their new circumstances. As such, they could benefit from a wide range of advice and support on topics such as housing and managing their finances, as well as support with their mental health.

“My mental health is down now, because [it’s] quite bad - at 40 years old - to feel [you’re] becoming a burden to family.” (Applicant, 25-49, Other condition type)

Due to their lack of previous engagement with the benefits system, awareness of benefits available (and processes involved) is generally low for those on this journey, requiring input from an outside source such as an advisor (often a medical professional). In some cases, people on this journey retain the capacity to conduct their own searches/research, and only require the initial suggestion of PIP from a third party. They can then progress an application on their own.

“When I damaged my back, I went to the GP and got a sick note. After that I started looking for answers – what to do in this situation.” (Applicant, 50-65, Think/feel differently)

In some cases, however, people on this journey will need to be supported through the process by somebody else. Due to their assessment of the impact of their condition as severe, and the fact that the suggestion of their eligibility for PIP often comes from a medical source, those on this journey are often confident in the outcome of their claim and may be more likely than some other groups to challenge a DWP decision they felt was not appropriate.

### **Journey 3: Applying on the off chance**



The main motivation in seeking benefits on this journey is financial support, as this group are more likely to be struggling to make ends meet and discussing benefit options with an informal or formal advisor (e.g. Housing Officer, Social Worker, often Jobcentre staff). PIP is generally flagged as an option by an advisor if there are any health conditions or disabilities present, but the financial need precedes the impact of the condition in terms of motivating factor behind the claim. This leads to some speculative applications, as applicants are often unsure if the impacts they experience will be considered severe enough.

“I need the help...We filled it in and hoped for the best.” (Applicant, under 25, Think/feel differently)

In keeping with their financial motivations, those on this journey tend to suggest any PIP award would generally go towards daily living costs, rather than anything specifically relating to their condition or symptoms. It is generally perceived as a ‘top up’ to any other income and would be allocated accordingly.

“I qualify for it because I struggle to work the full-time hours that are required nowadays...And a little top up would go a long way.” (Applicant, under 25, Move differently)

Having received the initial suggestion to apply from a third party, this journey generally involves completing the application without support, and without any particular strategy in mind. It generally does not involve extensive research (beyond perhaps a brief visit to the official PIP page on GOV.UK) and, given the lack of additional resources or guidance to draw on, most are unlikely to take on the additional effort required to challenge a decision if the outcome is not as desired. In the context of this journey, DWP are generally seen as the authority on eligibility and if ‘telling the truth’ on the application is not enough, most on this journey would not pursue the application any further.

“I think I'd probably fight for it a little bit... I'd look at how much effort is it to take it further. If it's a massive thing that's going to take a long time, then I probably wouldn't bother.” (Applicant, under 25, Move differently)

#### **Journey 4: Dependent, proactive and purposive**



Advisors we interviewed gave examples of some communities and groups where longstanding health conditions or disabilities are prevalent and many have prior experience of interaction with the benefits system.

These communities are often subject to multiple layers of deprivation and have established support networks (e.g. charities and organisations focused on their specific needs) which they depend on to support them. Applicants on this journey are generally dependent on a representative of these networks to support them through all stages of the application, from first suggesting PIP as an option to helping them complete forms. Practical support with paperwork is often already established by these support services due to lower-than-average levels of literacy, and higher than average levels of digital exclusion.

Applicants on this journey may have claimed PIP or Disability Living Allowance (DLA) in the past, are likely to be currently receiving Universal Credit (UC), and are less likely to be employed (either due to health conditions or wider circumstances); many will have been unemployed for a relatively long period of time. Financial vulnerability is often high but familiarity with the benefits system (either first- or second-hand) is also likely to be high.

“Within our client base, 90% [are eligible for PIP] because of the [poor] health outcomes [...] There's quite an awareness of PIP... because almost every family will have at least one person on PIP already.” (Formal advisor – Community-specific advice service)

Given the close interaction with advisors who have generally supported a number of similar claims, this journey may involve an application ‘strategy’ of sorts, but this will be co-ordinated by the advisor and based on learnings from previous successful applications. Systems are also likely to be in place in the event of an unfavourable

outcome meaning this journey is more likely than some others to involve formally disputing an unfavourable decision, with the applicant fully supported throughout.

## **Journey 5: Independent, proactive and purposive**



This journey is more common among those who have a health condition or disability that they can see getting progressively worse (e.g. Multiple Sclerosis (MS), cancer) and/or where the impacts are becoming more pronounced over time. They may be currently in employment, however expecting further degeneration of capacity in future, this journey begins with applicants independently taking the initiative to discuss options with friends, family members and/or professionals, as well as conducting their own research (e.g. via condition-specific charities/organisations). Knowledge of PIP is generally compiled from a combination of these sources and is proactively gathered in advance of more acute need (including expecting to have to leave the labour market and/or reduce hours).

“[I’m applying for PIP] because my life has changed from what it was two years ago. I cannot do things I used to do before...and it looks like it’s not going to get any better.” (Applicant, 50-65, Move differently)

This journey is more likely than some others to involve proactively seeking support, often through an organisation with a specific focus on supporting those with the relevant health condition. However, this support is accessed in a more targeted way than on some other journeys, and the applicant themselves is more independent, calling on multiple sources rather than depending on e.g. one advisor. This journey often involves research into PIP applications by others in similar situations to the applicant (e.g. via social media and online forums) and using this support network to challenge an outcome that is not as desired.

“I would appeal...because it says on the website that one of the conditions that automatically qualifies someone for PIP is Fibromyalgia... So, it’s only a matter of proving that I do have it.” (Applicant, 25-49, Other condition type)

People on this journey tend to have greater confidence in their own ability to see the application process through to the end and take a long-term view to their approach. However, given the nature of their health condition(s), they may require greater support (or different types of support) over time.

## **Journey 6: Fluctuating capacity or motivation**



This journey commonly involves a mental health condition, which may or may not be formally diagnosed. Much of the applicant experience on this journey is dominated by the fluctuations they experience in their condition, i.e. periods where symptoms (and associated impact) are greater and therefore their capacity is reduced, compared to periods where impact lessens and they are more able to engage with other issues and tasks.

It is common for this journey to involve a longstanding mental health condition (notably anxiety or depression) which has disabled them for a period of time, reducing or removing their ability to work. When they experience greater symptoms, their motivation and ability to complete day to day tasks is often affected, impacting their ability to access support. The trigger to apply for PIP often comes from a chance

mention from an advisor (formal or informal) that arrives at a moment where applicants are experiencing greater capacity and are able to act on this suggestion. A digital application may be favoured by some on this journey, due to feeling more easily editable and trackable, two elements which can cause anxiety with paper applications.

Where applications are begun at the 'wrong time', i.e. where capacity is lower, it can be overwhelming and the risk of dropping out of the process is high if the necessary support is not in place. This may include requesting an extension to any submission timeframes, or just emotional support in the form of a friend or family member to encourage them to complete the process.

"There was just a lot of information [online], and for someone like me reading all of that really confused me, especially as I have a learning disability."  
(Applicant, under 25, Think/feel differently)

This journey can involve a quick online search to confirm eligibility before submitting an application. Despite this, understanding of PIP (both in terms of eligibility and process) is often limited. As applicants are used to plans being interrupted by fluctuations in their condition(s), confidence in reaching a successful outcome is also often low.

"I'm on medication for my ADHD and I'm on medication for depression and when I went on the PIP site it told me to apply." (Applicant, under 25, Think/feel differently)

"My thought was there's no harm in applying. If they say no, then maybe I don't need it." (Applicant, 25-49, Think/feel differently)

### **Journey 7: Directed and fully supported**



Formal and professional advisors and appointees also outlined their experience of a seventh journey type, associated with extreme impacts. This journey is generally taken by applicants who are fully dependent on a third party (which could be a relative, other advocate, or organisation) to manage their benefit claims because they lack the emotional and/or cognitive capacity to personally engage in the process of a PIP application. They are often receiving full-time care and may have a formal appointee to manage their claim for them. The likelihood of receiving an outcome that does not meet expectations is relatively low – due to the high impact that can be demonstrated – but the likelihood to challenge a decision should this be required is entirely dependent on the capacity of this third party to pursue this.

"When they're in a 24-hour staffed hospital, a long-term placement, usually they no longer are eligible for PIP." (Professional advisor - HCP)

## 2.3 PIP Applicants: Understanding who applies for PIP, why, and how

### First awareness and understanding of PIP

As highlighted in section 2.2, the circumstances in which applicants first learn about PIP can significantly influence not only the level of information with which they start their journey, but many subsequent aspects of the journey itself. This includes factors such as an applicant's awareness of the process from the outset, their expectations of the outcome, their understanding of their eligibility, and the extent to which they are aware of possible sources of help (including advisors) to support them during their application.

Previous research has suggested that most customers first learn about PIP via word of mouth; this often includes friends, family and colleagues – cited as the original source of information by 1 in 4 new customers in a DWP survey – or a GP or health professional, cited by 1 in 5.<sup>12</sup> Both sources are commonly mentioned by participants in this research, but our analysis shows an important distinction in terms of when this first mention of PIP is made. There is a marked contrast in expectations and overall approach between those whose awareness of PIP pre-dates their own need (and those who learn about it once they are looking for support for themselves personally).

In the former group, people are aware of PIP before it is something that is relevant to themselves. Most commonly, this is through a friend or family member who has applied (either successfully or unsuccessfully). These experiences, especially when they are of long-standing (e.g. a family member who claimed for many years) or were particularly noteworthy (e.g. a friend who had to go through an extensive Appeal process), often profoundly shape people's understanding and expectations of PIP as a benefit.

"Heard about it from my mum, because she gets it. I looked it up a little more and ended up applying to see if I'll get it or not." (Applicant, 25-49, Think/feel differently)

"[On mother's failed PIP application] She didn't get it because she didn't make it sound as worse as it is." (Applicant, under 25, Think/feel differently)

This includes not only their perceptions of the process – whether it is likely to be e.g. difficult, time-consuming, etc. – but also their framing of eligibility requirements, DWP's approach to awards, and likely outcomes. Where conditions or experiences are similar to that of the friend or family member, this is likely to encourage confidence in eligibility. Where experiences notably differ, however, it can require applicants to overcome their already set ideas of PIP and who it is for. For example, someone whose family member received PIP while terminally ill with cancer may struggle to see the relevance to themselves, a young person with depression and

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<sup>12</sup> DWP (2018).

anxiety. The broad range of conditions that can make people eligible for PIP is a common point of confusion (discussed further below), and those with prior knowledge of this kind are most likely to have preconceived ideas around eligibility which may be challenged.

The second group – those who first become aware of PIP when they are struggling to manage the impact of a health condition and/or seeking sources of help – are more likely to be able to pinpoint a specific conversation or interaction in which they first learned about PIP, and this is often of very short duration. Examples of this are particularly prevalent in journeys 1 and 3, where a chance mention of PIP at the right time can be highly influential. Many applicants (notably on journey 1) cite a mention of PIP from a friend or acquaintance in passing which then prompts them to conduct further research of their own. The proximity of the relationship to the source of information is relatively insignificant here, a close friend is as likely to be mentioned as the receptionist at the Jobcentre, or a colleague. Such mentions are normally made in the course of a conversation either around the applicant's condition (e.g. talking through symptoms) or their financial hardship (the latter is particularly true for those on journey 3). This context does seem to be influential in their perceptions of PIP later on, affecting the extent to which they view it as a general financial benefit (to be used for meeting day-to-day living costs), or as one for people experiencing specific medical conditions.

“

My sick pay is running out this month, so I don't know where I'm going to get any money from to pay bills. She [the neighbour] mentioned, 'Try PIP, because they help with bits and bobs

(Applicant, 50-65, Move differently)

”

While most applicants first hear of PIP through some kind of personal interaction, there is a minority who come across it in the course of their own research (e.g. on journey 5). As with the conversations outlined above, this generally involves online searching around either their specific condition (e.g. condition-specific charities or forums) or around searches for benefits and financial support.

“I found information about PIP on the Universal Credit website. You can go to a calculator, and you can check what benefits you can apply for. There I went to PIP, because I was just curious about it.” (Applicant, 25-49, Think/feel differently)

Understanding of PIP as a benefit is highly variable from person to person, and this can be observed not only among applicants but also among non-claimants (see section 2.6 for more). In general, by the point at which they are initiating their own



claim, most applicants have been made aware that it is a benefit available to people impacted by one or more disabilities or health conditions, but in some cases their understanding does not much exceed this. Awareness of the process itself is generally very low, especially among those who first heard about PIP relatively recently. Few research anything beyond their own likely eligibility before initiating the process, expecting to be informed of different requirements as they go on.

“I couldn’t tell you [who PIP is for], somebody just told me it’s the Personal Independence Payment [...]” (Applicant, 50-65, Move differently)

“

I didn’t know about PIP either. They gave me the telephone number to call, and I just called  
(Applicant, 50-65, Other condition type)

”

On the other hand, there are other applicants (often who have a close friend or family member with personal experience of applying) who are familiar with the stages of the process, the assessment criteria, and the award amount from the outset.

“My understanding of PIP is, there’s two parts to it: one is mobility, one is daily life [...] As far as I know, you start a claim over the phone, they send you the form, you fill it and send it back. You could possibly be asked to attend an independent medical assessment or something.” (Applicant, 25-49, Think/feel differently)

As is discussed in more detail below, there are some commonly held misconceptions around PIP. The most common of these relate to eligibility requirements around work (i.e. it is only for people who cannot work, or those who are working but not full-time) and certain conditions (i.e. that it is primarily for people who condition affects their mobility).

## Sources of information and support

As mentioned in the preceding section, family and friends are common and influential sources of information around PIP, but they are often also crucial figures of support throughout the application process. While some (notably those with prior personal experience) may be highly informed, they are more often mentioned by applicants as central to encouraging and motivating applicants to complete the process, providing both practical and emotional support. Practical support may involve physically completing the form, helping applicants to compose their answers, and supporting them through phone calls. This is particularly important for those with literacy

difficulties, or whose capacity and/or motivation may fluctuate over time (e.g. on journey 6). It is also not uncommon for applicants to mention the role their friends or family play in helping them to identify and articulate the areas of their life which a disability or health condition is having an impact (discussed further below).

“The guidance on the website wasn’t as comprehensive as the guidance from my friends who had gone through the process.” (Applicant, 50-65, Move differently)

“My wife will have to look into [the form] as well, because there’s some things I just don’t understand [...]” (Applicant, 50-65, Move differently)

While they may not be known personally to applicants, the experiences of others with similar conditions or experiences are also often cited as sources of information and they have the potential to shape applicant expectations of the application process. When this is via an online forum or similar, it may also involve interactions with others (e.g. members of the same Facebook group) which can provide support and encouragement, as well as information. Research on such sites is particularly common for more independent applicants such as those on journey 5.

“[The comments on the forum put] the fear in my mind that they [DWP] would be out to get you. They would be out to belittle you. They have targets and you’re just a number.” (Applicant, 25-49, Think/feel differently)

“From what I’ve heard and seen on Facebook, these things take 4-5 months to complete. I don’t think it’s going to come through. Even if it does, it’s not going to be in a reasonable time frame.” (Applicant, under 25, Think/feel differently)

Applicants also mention using other online sources while looking for information around PIP, including the PIP page(s) on GOV.UK, Citizens Advice, and a number of condition-specific sites. Previous DWP work has suggested that use of the GOV.UK site is less common among PIP customers than among claimants of other benefits such as UC, but it was fairly commonly mentioned by participants in this project.<sup>13</sup> The accompanying Google analytics research showed GOV.UK to be the single most-commonly discovered site through PIP-related searches; around 1 in every 5 ‘clicks’ that searchers made after entering PIP-related search terms took them to this site.<sup>14</sup> A minority of applicants interviewed suggest they would be wary of using any ‘non-official’ sources of information on PIP, feeling DWP (and associated government pages) would be the best source of accurate and up-to-date information. Citizens Advice was found to be the second most commonly returned site through online searches (securing just under 1 in 10 ‘clicks’), with the next UK-wide site being Turn2Us (under 1 in 20 ‘clicks’). Participants mention using online ‘checkers’ to assess their eligibility (both DWP and Turn2Us have online tools for this) and a number recall either actively searching for or coming across lists of eligible conditions, which many found particularly encouraging in terms of reassuring them of

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<sup>13</sup> DWP (2023).

<sup>14</sup> See section 2.5 for more on online search behaviours around PIP.

their likely eligibility. More information on online search behaviours can be found in section 2.5.

“I heard about it then and I typed it online and read about it and once I read what they do, I applied.” (Applicant, under 25, Think/feel differently)

“ [I searched online and] just found the criteria to apply, and my condition was listed.  
(Applicant, 25-49, Other condition type) ”

Formal advisors (i.e. those whose role is specifically related to giving benefits advice) and other professionals are also highly influential sources of information, as is discussed in more detail in Section 2.4. Both are generally seen as authoritative sources in their respective fields and their suggestion that an applicant would be eligible for PIP is given a high degree of corresponding weight both in terms of setting expectations and in influencing any decision to challenge a nil- award decision. Formal advisors and others with extensive experience of previous applications are generally assumed to only recommend PIP to people whose applications are likely to succeed and are particularly influential where they have an existing relationship with the applicant or their community (e.g. on journey 4). Medical professionals are also commonly cited as a source of supporting evidence, but generally not on the application process itself. Many assume that DWP will consult professionals they name in their application.

“All she [my Personal Advisor<sup>15</sup>] really said was I’m going to need a lot of evidence.” (Applicant, under 25, Think/feel differently)

“They’re [DWP are] going to want to talk to my GP and know that I’ve been diagnosed with it, and obviously how it affects me.” (Applicant, 25-49, Think/feel differently)

“[To see evidence] It’s up to them [DWP] to ask my neurologist.” (Applicant, 50-65, Move differently)

## Triggers to starting a claim

The time between an applicant first learning about PIP and initiating their own claim can vary from less than one day to several years. It is highly influenced by the context in which they hear about the benefit; naturally, those who learn about it in relation to a friend or family member before they themselves experience any impact from a disability or health condition may recall a big gap here. There is also a notable

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<sup>15</sup> Personal Advisors support young people when they leave the foster care system.

subgroup who learn of PIP and begin the process very soon afterwards (this is common, for example, among those on journey 3 and 4). Whether the gap is long or short, the trigger to starting their own claim is likely to come from a conversation with a formal or informal advisor, prompted by either increased impact of their condition (e.g. worsening symptoms, reduced capability) or a change for the worse in their financial circumstances (e.g. no longer being able to work, sick pay coming to an end).

However, even those who have PIP suggested to them as a possible means of support may delay starting an application for months or years. This delay in initiating an application is most commonly caused by a lack of motivation, a perceived lack of urgency, and/or not wanting to ask for help (often linked to not wanting to claim state benefits). It is not uncommon for applicants to report waiting as long as possible – and exhausting all other alternatives – before beginning their PIP claim. This group then often have additional emotional challenges throughout their journey, as their financial and health-related needs by this time can be quite acute. This is particularly common for those on journey 1, for example.

“I feel I exhausted all measures... The eczema got bad a whole year ago, and I still kept fighting... but when things got so bad that my daily living was impacted, I just couldn't work...” (Applicant, under 25, Other condition type)

“

I kept avoiding PIP and worked and worked, until I couldn't do it anymore.

(Applicant, 50-65, Move differently)

”

Applicants who feel this reluctance often report that it takes an additional prompt from a friend or family member for them to begin an application. This may be accompanied by an offer of help with the application itself. For others, it may relate more to increased capacity as symptoms temporarily ease and they feel able to confront the administrative process involved in commencing and progressing the PIP application.

"There was a streak where I was feeling better... [I thought] maybe I'll be able to tackle it." (Applicant, 25-49, Think/feel differently)

## **Views towards entitlement and eligibility**

The extent to which applicants understand, or question, their own eligibility for PIP varies significantly. For some, this is a key question to be addressed before

commencing an application. It can involve extensive research (e.g. on journey 5), prompting them to look up assessment criteria and lists of conditions which others have successfully applied with. The analysis of online search behaviours conducted as part of this project shows that searches around PIP eligibility are widespread (approximately 233,000 monthly searches) and highly individual, as demonstrated by the diverse range of search terms used. Analysis of these search terms shows that people seek details relating to the potential eligibility of specific health conditions or disabilities, suggesting a desire to ‘check’ their eligibility against an authoritative source. This is supported by interviews with applicants whose awareness of PIP had come more recently and from a professional source (medical or benefits related), as the suggestion having come from a third party who is perceived as authoritative is often enough for them to initiate a claim without feeling the need to do further research of their own.

“ I don’t think that I qualify, I’m just following the suggestions of people who thinks I have a certain condition. I don’t think that lady [at the job centre] would have advised me [to apply] if she didn’t think I needed it.  
(Applicant, 25-49, Move differently) ”

Where applicants have developed coping mechanisms and strategies to ‘manage’, they can struggle to identify how their capabilities are limited in comparison to someone else. For example, where applicants are used to avoiding certain activities they know they struggle with, or waiting until medication takes effect to carry out a task, they may not perceive this as a limitation any longer. Friends and family, with their personal knowledge of the applicant, are often well placed to highlight impacts the applicant themselves may overlook due to their employing coping behaviours.

“‘But I’m not disabled though,’ that’s what I said [to friend suggesting PIP as a disability benefit]. She said...if you have a long-term condition that affects your daily routine...you might be entitled to it. And I said, ‘But I can do activities though’, and she said ‘Okay, but how do you do activities?’ And I was like, ‘When I take my medication and it kicks in, and then I’m able to function.’”  
(Applicant, 25-49, Move differently)

“I don’t put myself in a situation where I could potentially have a problem.”  
(Applicant, under 25, Think/feel differently)

Where applicants do reflect on the impact of their condition, different yardsticks are used. Some compare their current situation to their own previous ability, noting changes in what they can do unassisted. Some compare themselves negatively to

others their age without similar conditions, whereas others look specifically to those with similar conditions (who may already be claiming PIP) to see if they are experiencing a similar level of impact. Many applicants downplay the impact of their condition, highlighting that there are lots of people who are worse off than them, and that plays into the level of confidence they have in their application and how they would respond should they not be awarded PIP.

“Because my life has changed from what it was two years ago. I cannot do things I used to do before. I have to take days off from work, my life has much more expenses than before, and it looks like it’s not going to get any better.” (Applicant, 50-65, Move differently)

“I think I qualify for PIP because, I feel like for a person of my age... I’m struggling and I need the help... With everything I’m going through, it’s not getting better.” (Applicant, under 25, Think/feel differently)

“I have the [same] conditions and I have suffered from the same issues that some of the people in the YouTube videos have suffered from.” (Applicant, under 25, Think/feel differently)

## **Application strategies**

When asked if they have a particular strategy for their application (in the context of demonstrating their eligibility), the overwhelming majority of applicants either outright reject the possibility of applying with a strategy, or suggest that the only possible strategy is to honestly and accurately report their condition and its impact. This is commonly expressed by those on journeys 1, 2, 3 and 6. Many express the view that the evidence they present (which they suggest would include appointment letters, sick notes, correspondence with various specialists, etc.) would ‘speak for itself’ in terms of evidencing the impacts they experience day to day.

“No type of strategy. I’m an open book. My condition is my condition. My arguments are solidified by evidence of NHS. It is written black and white.” (Applicant, 25-49, Other condition type)

“As long as I’m honest, it should work out. I think my history will speak for itself. I think my doctors will also prove the kind of stuff I need help with.” (Applicant, under 25, Think/feel differently)

“

My strategy is to go to the assessment and answer the questions honestly.

(Applicant, 50-65, Move differently)

”

Some specifically mention that any attempt to exaggerate or present themselves strategically would make them more likely to be ‘caught out’ at later stages, such as the assessment. In most cases, however, applicants express a clear commitment to honestly and transparently communicating their experience to DWP, even if this results in them not being awarded PIP.

“If I’m eligible, I am. If I’m not, I’m not.” (Applicant, under 25, Think/feel differently)

“[I’m] just going to be straightforward and submit all the information I have [...] I believe if I don’t qualify, there’s people who qualify more than me and they need more help than me.” (Applicant, 25-49, Think/feel differently)

Some suggest particular ways that they would approach completing the application, such as taking their time to compose responses, completing a draft copy that they then copied out in the version to be submitted, or asking someone (a friend, family member, or organisation) to help them.

While the emphasis on honesty remains, there is a small minority of cases where participants who have researched the experiences of others with similar conditions (e.g. via online forums) suggest that they would need to think carefully about how to phrase their responses to make clear how the impact they experience corresponds to the scoring criteria. This tends to be in cases where specific difficulties have been highlighted in those applying with a certain condition, and future applicants try to learn from their experience. This is common for those on journey 5.

"It feels like it’s definitely geared toward physical disabilities...it’s almost like you have to spin it in a certain way to fit their [criteria]... You have to work out what exact words to use so they have to give you those points [...] I need to study those [websites]...and think about the categories and try to rack my brain for something that is both true to my situation but gets the points"  
(Applicant, 25-49, Think/feel differently)

While relatively few participants in strand one were actively anticipating the decision stage, some suggested that they may revise their approach in the event of an outcome they did not desire (i.e. not being awarded PIP). A sizable number of

applicants suggest they would not wish to proceed further with an application and would take DWP's first decision as final.

"If they didn't consider it the first time, why would they consider it the second time. I'm not going to say anything different. I don't want to have to lie and beg the government for help." (Applicant, under 25, Think/feel differently)

However, some other applicants are aware from early in the process that a high proportion of new claims are rejected at first submission and are prepared to dispute a decision they do not agree with. Some are further motivated in this course of action by a lack of alternative options, and some say they will tailor their approach based on the outcome they receive (e.g. by supplying more supporting evidence, or reapplying once a formal diagnosis has been received).

"I would either lump it and get on with it, just forget about it, or one of my colleagues did say to appeal it if it gets rejected." (Applicant, under 25, Move differently)

"If it comes back negative, I will try again because I need the help [...] If they say they don't have enough evidence, I will provide more evidence." (Applicant, 50-65, Move differently)

## Common areas of confusion

There are some common misconceptions around PIP reported by applicants, and many of these overlap with those recorded among non-claimants in Strand 3 (see section 2.6). Where these misconceptions relate to the applicant's own eligibility for PIP (e.g. where they believe it applies only to mobility-related conditions and they have a mental health condition), these have generally been addressed by the time an applicant initiates a claim. This is not always the case, however, for example, confusion around whether or not people in work are eligible for PIP can remain. Some applicants wait until their situation changes before applying.

As with non-claimants, however, the main areas of confusion relate to the types of condition which may be associated with a successful PIP claim (e.g. the suitability of mental health conditions) and eligibility requirements around work and income. Both factors have occurred repeatedly in previous research too.<sup>16</sup> In this latter category, some believe that PIP is (and should be) reserved for those who are unable to work. Others believe that it is specifically for those who are still working but have had to reduce their hours or duties (generally citing other benefits as being for those who are completely out of work).

"The idea is it's there to help people that can't work properly. I mean, I'm still working part-time and [would be] using it just as a bit of a top-up, hopefully. Because I struggle to do lots of hours at work." (Applicant, under 25, Move differently)

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<sup>16</sup> E.g. DWP (2018).



“People who are not active [would qualify], not capable of managing work, I would say.” (Applicant, 50-65, Move differently)

## Levels of confidence in applications

When discussing applicant confidence, a distinction should be made between confidence in eligibility, confidence in their own ability to complete the process, and confidence in the ‘system’ (including in DWP and in the fairness of the PIP application and assessment process). All three aspects of confidence influence applicant expectations and their emotional experience of the application journey, and each varies from applicant to applicant.

Confidence in eligibility is most commonly influenced by type of condition and information sources. Applicants who research stories of others with similar conditions who have applied for PIP (e.g. as part of journey 5) generally find these to be very influential; where they correlate with successful applications this is highly encouraging and where previous applicants have struggled this is generally discouraging. In general, those with physical conditions that can be seen from the outside are more confident than those with ‘invisible’ conditions (notably those relating to mental health, cognition and neurodiversity).

“If it qualifies on injury, and day to day basis, I will qualify for sure. I’ve only got one arm!” (Applicant, 50-65, Move differently)

“I saw on the website that if you have fibromyalgia, and incontinence and chronic pains you are eligible, and I have these three things... so I decided to apply.” (Applicant, 25-49, Move differently)

Where the recommendation to apply has come from (or been supported by) a medical professional, this also boosts confidence in eligibility.

“I think my history will speak for itself. I think my doctors will also prove the kind of stuff I need help with.” (Applicant, under 25, Think/feel differently)

Previous research has shown that confidence in one’s eligibility is a key determinant of behaviour taken following an unfavourable decision. Those who are more confident in their eligibility are more likely to consider challenging a decision or re-applying in the future, but those who were less confident were more likely to want to move on from the experience.<sup>17</sup> ).

Confidence in one’s own ability to complete the application may also be influenced by health conditions, especially where the impact of a condition includes difficulties with memory, processing written information, or speaking to new people. Others make reference to their generalised struggles with administrative processes and deadlines, regardless of the health conditions they would include in their claim. There is a strong correlation here with previous experience of the benefits system, as those who are claiming for the first time often suggest that their lack of familiarity with ‘the system’

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<sup>17</sup> DWP (2024c).

makes it more likely that their application will be rejected, or they will fail to complete it.

“If I complete the application process to the fullest and best of my ability I would [be confident], but the process is very difficult.” (Applicant, under 25, Think/feel differently)

Confidence in the benefits system to provide for and support people in need is an additional aspect of confidence that strongly influences expectations. Those with previous experience (or second-hand knowledge of) declined applications, or successful claims which they felt to be unworthy, are less confident that they can rely on DWP to provide a system which is fair and supportive.

“I’m not that confident I will get anything to be honest... I just have very little confidence in the system” (Applicant, 25-49, Other condition type)

“It got to the point [with my UC claim] where I haven’t bothered applying for anything, because I don’t get anything out of it [...] There was no help for me when I was a child [in care], I don’t see how I can get any help as an adult.” (Applicant, under 25, Think/feel differently)

“I think the government’s broke... I don’t trust them anymore [...] They have no empathy... it’s just a tick boxes.” (Applicant, 50-65, Other condition type)

There is also a minority of applicants – generally those struggling with anxiety – who do not even wish to assess their own confidence levels for fear of raising their own hopes. As with discussing application strategies, it is common for applicants to suggest that they will just complete the application form honestly and then wait and see, with no particular expectations in place.

“I don’t create expectations, so I’m not really sure of [my confidence level]. Because my stress and anxiety is at level 9 so I don’t want an extra level of stress on top of that.” (Applicant, 25-49, Other condition type)

“I don’t know what is going on to be honest. I can just try... I just pray that the form will come... and I don’t know if I’ll qualify. At the moment I don’t want to think about anything.” (Applicant, 50-65, Other condition type)

“I’m not sure about [my confidence level] ... I’ve applied for it and I’ve told them about me... I’m going to send it back and just wait for the outcome.” (Applicant, 50-65, Move differently)

## **Reasons for dropping out of the application process**

Only a very small minority of current applicants mentioned having previously initiated a claim which they later abandoned or withdrew. This was sometimes due to logistical issues (e.g. not being able to collect evidence documentation from medical professionals within the timeframe), often compounded by a lack of motivation. This lack of motivation could relate to their condition (e.g. depression) but also just to the fact that, at that previous point in their lives, the perceived (financial) value of PIP (and what that would enable) did not outweigh the effort needed to apply. In a

handful of instances, applicants mentioned anxiety around the application process – in particular a lack of clarity around what would be expected of them – was sufficiently off-putting that they abandoned a claim. There are also some journey types – highlighted in section 2.2 – where the lack of a necessary support system at a crucial point is likely to contribute to the likelihood of dropping out (e.g. if someone on journey 6 hits a difficult period and has no one to support them, or support services previously relied on by those on journey 4 are no longer available).

Some participants in the non-claimant focus groups – who are not currently claiming PIP – mentioned previously beginning an application they did not complete, see section 2.6 for more.

## 2.4 Advisors

As outlined in section 2.2, different types of advisors can play highly influential roles in an applicant's journey to claiming PIP. The initial prompt to look into PIP often comes from a third party, who may be acting in a purely personal capacity (a friend or family member, an 'informal advisor') or a professional one which may relate directly to benefits advice ('formal advisors') or incorporate an indirect reference to benefits as part of a wider conversation or relationship ('wider professionals'). In this section, we outline the different subgroups within these categories and how they most commonly interact with an applicant's PIP journey.

### Informal advisors

A small number of applicants report the influence of an informal advisor on their journey to applying for PIP. This is most commonly a friend or family member, but can also be a colleague, neighbour, or less close acquaintance. As mentioned above, these figures can provide a range of information and support; some have extensive personal experience to draw on and provide detailed information on the application process, others have no specialist expertise but offer emotional support and encouragement to complete the application. The latter is particularly crucial for certain journey types, such as journeys 1 and 6. The role of informal advisors from the applicant point of view is explored elsewhere in this report. Attempts were made to recruit informal advisors but there was limited engagement in interviews – perhaps reflecting the informal (and voluntary) nature of their support for a friend or family member. Low numbers of informal advisor participants therefore present limitations on the insight that can be gained from these interviews.

Informal advisors we interviewed do not consider themselves to be experts on PIP and would not necessarily consider giving advice to anyone who was not very close to them and/or asking directly for their help. Indeed, one of the challenges in recruiting for these interviews appeared to be that many people did not feel 'qualified' to speak on their role as an advisor, feeling their contribution had been small or that they had little to share. This contrasts quite sharply with the influence such interactions can be seen to have on applicant journeys themselves – often providing

the necessary emotional or practical support required to enable someone to complete their applications.

Some have pre-existing knowledge of PIP (perhaps from a previous application of their own) while others conduct their own research specifically to support their friend or family member through the application. This research is often online, encompassing similar sources to those discussed in section 2.5 (including GOV.UK PIP pages, forums, blogs, and the NHS website).

Informal advisors who are personally close to the applicants they support sometimes position themselves as a form of 'buffer' between the applicant and the challenges of the application process. Before encouraging the applicant to begin, such an advisor may undertake their own research to be sure that the process is likely to be 'worth it'. Being familiar with the impact a process like applying for PIP could have on their friend or family member, particularly those with mental health conditions, some feel a responsibility to inform themselves of the possible benefits before initiating the process with the applicant themselves.

"It's hard to get anything from [applicant] at the best of times, so I just thought, is it worth it? [...] Am I just pushing her through another torturous ordeal to then be told, 'You're not going to get it?' [...] I have to manage her mental health, to make sure this doesn't cause a downward spiral." (Informal Advisor)

This may also involve making executive decisions to spare the applicant themselves stress; one informal advisor said that they would not support their applicant through the process of disputing a decision, knowing in advance that they – the applicant – would not have the patience or resilience to cope with those additional stages of the process.

Due to this sense of responsibility, informal advisors are also very aware of the gaps in their own knowledge. While these gaps may often overlap with areas of confusion and misconceptions that we observe among applicants (see section 2.3) and non-claimants (section 2.6), for those who intend to provide direct support for the application itself there are some more pressing concerns. If helping to complete the form or accompanying applicants to assessments, informal advisors want to feel prepared in terms understanding how the assessment process will work, or how the applicant's condition will be interpreted within the assessment framework. One advisor gave an example of being unclear as to how the applicant's condition – which fluctuated significantly day to day – would affect an assessor's interpretation of their condition:

"I don't understand how [DWP] are going to gauge things when you're not actually seeing everything in its entirety. You're leaving a box for us to complete...but in actual fact that can't describe the worst, best, and average situation." (Informal Advisor)

## Formal advisors

Formal benefits advisors play two key roles in relation to providing support for applicants or potential applicants of PIP. Those interviewed as part of this research strand tend to have experience of both types of responsibilities but may specialise in one. These roles are:

- **Case working:** Where benefits advisors provide ongoing practical, informational, and – to a lesser extent – emotional support for applicants as they go through different stages of the PIP application process. They may also signpost to wider support services outside of their remit.
- **General advice:** Where benefits advisors provide informational support, usually via a helpline, answering general questions related to eligibility and the PIP application process. They may also signpost to wider support services outside of their remit.

All organisations interviewed provide one or both types of services but the way in which they operate, and the level of support they offer, differs depending on which communities or categories of individual the organisation supports. Organisations can be broadly defined as falling into one of three categories:

- **General advice services:** Organisations that offer a wide range of support across several domains, such as debt or housing, as well as welfare benefits, often within a specific region or city.
- **Disability or health condition-specific advice services:** Organisations that offer support tailored to a specific health condition and/or disability (or disabilities as a whole).
- **Community-specific advice services:** Organisations that provide advice and support to a certain community or demographic group.

The key differences between the way these organisations provide advice and support is related to how they tailor their offer to the different experiences and subsequent needs of their respective client bases.

### General advice services

General advice services tend to offer the widest range of support and advice. Welfare benefits advice is just one of the services they offer, and advisors are often qualified to advise on other problems, such as debt or housing. Nonetheless, conversations about PIP are a significant part of their day-to-day workload. These advisors could be seen as ‘generalists’, with a broad range of knowledge across the welfare benefits system (and into other domains) which means they are able to tailor their approach to a wide range of support needs. Depending on the needs of the client they can offer informational, practical, and emotional support to their clients throughout their PIP claim journey and are able to signpost to wider support services. This makes them particularly likely to feature on journeys such as journey 3, where seeking general advice on financial hardship is a common starting point.

Organisations like Citizens Advice can be highly influential in terms of an applicant's journey to PIP, but previous research has shown that interactions with these organisations can also be highly variable depending on local provision and the representative individual a potential applicant interacts with, resulting in an inconsistency of experience between customers.<sup>18</sup> The biggest limitation of these services is generally that their capacity simply cannot meet demand, meaning they have to restrict their services in some way, often by limiting access to people within certain regions or localities (e.g. postcode area). It is not uncommon for applicants to report trying to access an advice service only to be told that no appointments are available in their specific area, and neighbouring areas are unable to help.

“We don't actively seek clients, because we wouldn't have the capacity to deal with them, to be fair. So, we see whoever approaches us. We don't go out looking for people because we'd never be able to see them all.” (Formal advisor - General advice service)

General advisors felt their primary source of knowledge on PIP was the experience they had accumulated over several years as benefits advisors, rather than any training they had undertaken. One general advisor reported never having undertaken any formal training in their role, instead learning from more senior colleagues and their own experience. This did not negatively affect their understanding of PIP. General advisors mentioned a range of training courses that can be undertaken, such as that delivered by Social Welfare Training, but were clear that there is no one formal training course or qualification that advisors must undergo to be qualified as a welfare benefits advisor.

“Most of the roles I've had over the years have involved giving welfare benefits advice; I've done appeals training – as much training as there is available really – but there isn't sort of a formal programme that I'm aware of like there would be for a debt specialist... where you learn all the different elements.” (Formal advisor - General advice service)

### **Disability or health condition-specific advice services**

Formal advisors that work for these organisations often have specialist knowledge of certain conditions and have developed advice services tailored to overcoming the barriers associated with managing it. The services offered within this group vary depending on the condition or disabilities they focus on. These formal advisors display a similar level of knowledge of the welfare benefits system to general advisors but were better equipped to cater to specific support needs related to a specific condition or disability. As some journey types (such as journey 5) are more likely to be influenced by a specific condition type, this category of advisor may feature more prominently than for other journeys.

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<sup>18</sup> Edmiston, Daniel et al. (2022), 'Mediating the claim? How local ecosystems of support shape the operation and experience of UK social security', *Social Policy & Administration*, 56 (5), 775-790, [available online](#).

One disability advice service carried out a benefits assessment with all new clients to determine what would best address their needs, in both the short and long term. Through this they can then support the client with an array of claims, including Blue Badges, out of work benefits like UC and PIP.

“[With a new client] I’d be starting on out of work benefits first... PIP takes a very long time to come through so PIP is not going to help them for quite a while.” (Formal advisor – Disability/healthcare advice service)

One formal benefits advisor interviewed supports cancer patients, many of whom are terminally ill. The ways in which support is tailored to their client’s specific needs can be observed from their very first encounter with a new client. When working with cancer patients, one formal benefits advisor said they would describe PIP to new clients thus:

“As benefit to help with the cost that you have cancer. Especially if you are terminally ill.” (Formal advisor – Disability/healthcare advice service)

Then, when supporting an applicant through their application, they would effectively take it out of the client’s hands where possible, for example instigating a fast-track application for someone who is terminally ill. They deliberately remove these clients from the process as far as possible due to the physical and emotional strain they would be under because of their diagnosis.

“If they’re terminal, I do the form for them. I don’t let them near it. It’s like, no, I’ll do it. I’ll do this on the phone. Go away. Don’t worry. Just give me your bank details.” (Formal advisor – Disability/healthcare advice service)

Further examples of tailoring services to a specific customer base include support with language difficulties. An organisation that primarily supports Deaf people, for example, provides specialist support using sign language to interpret and translate assessment questions and their answers. This is targeted to support the unique language barriers they commonly find are faced by Deaf people that make written forms difficult to complete.

“Most of my clients are profoundly Deaf and they face a lot of barriers when it comes to language. But I am mostly talking about grassroots Deaf people who don’t have the skills to understand the form itself and need it changed into sign language.” (Formal advisor – Disability/healthcare advice service)

Similarly to general advisors, many disability/healthcare specific advisors suggested their knowledge came from experience in their role, with training courses being seen as helpful but fragmented and varied. Some had developed their knowledge and undergone training as general advisors, before moving to disability/health specific advice services; for example, one disability advisor mentioned undergoing formal internal training in a previous role at Citizen’s Advice. Disability-specific training materials and resources were then used to further supplement their existing knowledge. Guidance delivered by Inclusion London, the Disability Rights Handbook, and the Benefits Bible (by the Disability Rights Society) were all mentioned as useful resources. Nonetheless, given the fragmented way in which it is delivered, training

was not seen as fundamental to their knowledge. One disability advisor had never received formal training, working their way from a volunteering role to a paid welfare benefits advisor. Their knowledge came from “just doing the job, day in day out”.

### **Community-specific advice services**

These organisations support clients only from specific groups or communities and feature prominently on journeys such as journey 4. Like the other types of organisations, they offer advice into several different domains and across the welfare benefits system. The support they provide is tailored to the needs of their community and they often have culturally specific understanding and expertise which informs their offer. For example, one organisation that supports Gypsy, Roma and Traveller communities explained that mental health illnesses were particularly prevalent (and a common reason for applying for PIP), but that the subject of mental health is ‘taboo’ in their community and requires handling with additional understanding and sensitivity.

“Mental health is stigmatised [in Gypsy Roma and Traveller communities] and there’s a lot of undiagnosed PTSD... our clients have seen a lifetime of racism... and general health outcomes are so awful... and there’s a huge amount of digital exclusion” (Formal advisor – Community-specific advice service)

Similarly, an organisation that supports Irish immigrants found common challenges faced by their clients. They noted that their clients often have a history of working physically demanding jobs that caused health issues in later life, and the nature of their employment means they often do not have pensions to fall back on. This adds urgency to their PIP application. In addition, they often have lower levels of literacy, are digitally excluded, and financially insecure. One way the organisation works to overcome these barriers is to run a multi-channel service to ensure that clients can engage as easily as possible in a way that suited them.

“We will work multi-channel. Most of the work that I do is actually on the phone. So, I have a kind of sub-specialism of doing telephone advice. We will communicate with clients by e-mail if they have e-mail and otherwise we've got our drop-in sessions and we've got appointments that we make with clients as well.” (Formal advisor – Community-specific advice service)

Much like other types of advisors, community-specific advisors’ knowledge on the PIP application process came from a mixture of experience and training. Like the other advisors they may have undergone some initial training through organisations like Citizen’s Advice or the Benefits Training Company, and these were felt to be useful to a degree, particularly in relation to managing more complex parts of the process like appeals and tribunals. One advisor had attended DWP’s external stakeholder upskilling sessions for PIP but felt these were unproductive.

"Our local DWP Team that we have contact with, we know that they offer outreach sessions fairly often. They call them like 'upskilling sessions' but what we found from experience is that they really are just a reminder of how the



DWP say you should fill in a PIP form. So we find them frustrating and a bit insulting because we feel like we are doing what we've been asked to do, and people still don't get the benefit" (Formal advisor – Community-specific advice service)

However, their experience with training implied that their knowledge of their community's support needs was the result of being embedded within any given community rather than any training on the PIP application process.

Overall, all advisors, regardless of specialist area, felt that they had very few gaps in their knowledge when it came to PIP. However, this did not mean that they do not encounter challenges and frustrations with the PIP process. For example, a consistent complaint across all formal advisors was that supporting anyone on their PIP claim can be problematic because they find PIP awards to be inconsistent.

"I feel like even if you do get training, learning all of the regulations of all the things DWP is supposed to do doesn't mean anything because that doesn't mean it happens in practice... People are supposed to get PIP. They should get PIP in these situations, but they won't." (Formal advisor - General advice service)

They felt this inconsistency meant that a large proportion of their work was managing the expectations of their clients, many of whom were vulnerable in some manner, regardless of their eligibility with PIP.

“

There's such an irregularity in the way in which it is awarded, it does make it almost impossible as advisors. So, I feel it's a benefit where we have to be very factual with people.

(Formal advisor – Community-specific advice service)

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Some also recalled negative experiences with assessors and DWP staff. They argued that some assessors were trying to 'catch out' their clients and one advisor that helped terminally ill clients with the SR1 process was routinely frustrated with DWP staff's lack of knowledge.

"It would be nice to actually have staff that actually know what they are talking about. I have to tell them what they are doing and why they are doing it and that's the specialist on the phoneline for the SR1" (Formal advisor – Disability/healthcare advice service)

## Wider professionals

There are a wide range of professionals that may advise people before and during an applicant's PIP claim journey. Advising on PIP is not a formal responsibility for these professionals, but due to the nature of their work and the groups of people they support they are often a key point of contact for applicants seeking information and guidance. They are a common source of information across journey types, but are likely to play a key role in journeys such as journey 2 where there has been a sudden change in an applicant's health situation which may have also impacted their living situation and/or care needs.

As part of this research strand, we spoke with three categories of professional advisor:

- **Healthcare professionals (HCPs)** including General Practitioners, Nurses, and Occupational Therapists.
- **Social and support workers** including those working in different settings, including a hospital, homeless shelter, and local authority.
- **Care workers** or care assistants working in both domiciliary care and residential care.

### Healthcare professionals

Whilst there are differences in the ways in which different HCPs interact with patients, the ways in which they advise and support them through PIP claims are generally consistent. Advice is largely limited to providing basic information before signposting to either social prescribers or formal benefits advisors in organisations such as Citizen's Advice. For example, GP's conversations about PIP are usually initiated by either the patient or the GP briefly at the end of a 10-minute consultation, where the GP will generally explain what PIP is, and refer them on to the social prescriber within the practice. Similarly, during an Occupational Therapy assessment, finances are a standard part of the conversation, and as part of this Occupational Therapists will often ask if patients are receiving any welfare benefits. Depending on the individual's needs, they are able to inform them about which welfare benefits they might be eligible for and signpost to organisations for further support. It is unusual for HCPs to go beyond these introductory conversations but, where they do so, it is dependent on time available and the level of information they have at their command, rather than a professional obligation.

"I just let them know it is a payment that replaced the DLA and can help with living costs and has two parts of it... daily living and the mobility part"  
(Professional Advisor – HCP)

HCPs encounter conversations regarding PIP regularly. This can range from once per week to multiple times per day. Some HCPs report that the number of conversations they are having around PIP had increased since the COVID-19 pandemic and are increasingly associated with mental illness.

“I think the mental illness point increasing is true” (Professional Advisor – HCP)

HCPs receive minimal guidance and training on how to advise on PIP. A baseline level of knowledge of the welfare benefits system is generally included as part of their initial training processes, but this can be quite outdated depending on when they qualified. Most of their knowledge comes from their own research, learning from more experienced colleagues, and their own experience with patients over several years. As a result, HCPs often report significant gaps in their knowledge about PIP, in particular beyond the PIP1 and PIP2 stages. This means HCPs are generally careful not to over commit themselves into a patient’s PIP claim journey.

“Benefits aren’t a part and parcel of our training. That’s why it’s sometimes hard to do these forms, because you’re writing things and patients aren’t happy with what we’re writing. Not because it’s wrong but we’re potentially writing things that couldn’t go in their favour.” (Professional Advisor – HCP)

### **Social workers**

The social workers we interviewed only provide limited information and support to their clients when it comes to PIP. Their role in an applicant’s PIP journey mostly consists of providing the first information or introduction to PIP as a benefit, before the applicant initiates a claim. This would usually be when carrying out general health and wellbeing assessments after first meeting a client. Finances are a standard part of this conversation, and by extension any welfare benefits they may be entitled to. Where appropriate, they will discuss PIP and whether they might be eligible, before signposting them onto further support services if necessary. One participant said they would go beyond this and provide practical support with PIP1 or PIP2 stages on rare occasions, but wherever possible would signpost instead.

“

I'm not the one assessing those needs, I'm not doing that PIP assessment, so I wouldn't want to potentially stop someone from receiving PIP just because I may think that they may not be eligible. It's not my decision to make so I always make the referral [to further support services] anyway  
(Professional Advisor – Social worker)

”

The regularity of conversations around PIP is dependent on where they work and the clients they tend to support. One social worker works in a hospital on complex discharge cases, where they need to ensure that patients have adequate support measures in place in order to be discharged. These clients are often older, and

learning to live with new yet complex and long-term health conditions, making them more likely to be eligible for PIP. In contrast, other social workers worked as part of the local authority and had far fewer conversations around PIP because clients are generally referred to them *after* they have engaged with health and social services. This means most of their clients that might be eligible are already in receipt of PIP, or are awaiting a decision, by the time they carry out an initial health and wellbeing assessment.

Social workers report receiving no formal training on PIP, and their knowledge varies depending on how regularly they have to advise on it. Those that are having more regular conversations about PIP cite gaining knowledge from senior colleagues and conducting their own research through GOV.UK websites. Those that are less frequently talking to clients about PIP have general knowledge of the welfare benefits system but are more likely to feel they have gaps in their knowledge. These gaps are often related to how the later stages of the process play out, meaning they do not feel well placed to set expectations around assessments or decisions.

### **Domiciliary care workers**

Some journey types (e.g. journeys 2, 5 and 7) are more likely than others to involve interactions with care workers. Whilst conversations between care workers and their clients around welfare benefits are not uncommon, care workers provide limited support on PIP applications for their clients. Conversations tend to be focused on eligibility before an application is initiated.

“I advised her and said yes, you should be entitled to something.”  
(Professional Advisor – Care worker)

Care workers often report trying to ensure that clients who they are confident would be eligible for some level of support are engaging with the welfare benefits system to get support they need to fund their care. However, they generally signpost to other sources rather than providing active support and try and direct next of kin to lead on applications if possible.

“They know they are entitled... there’s a reason they are in care.”  
(Professional Advisor – Care worker)

Supporting clients on PIP falls outside of their work responsibilities, and many are often limited in the amount of extra time they can devote to clients outside of their immediate care needs. Lacking the knowledge, training, and time to deliver this kind of support, care workers generally play a relatively restricted role. Where care workers do feel knowledgeable, this is due to personal experiences and those of other long-term clients. In cases they see as extreme and where clients have no wider support network to help, some will consider trying to help further, but this is exceptional.

“I don’t think I could commit to making a phone call [to DWP] ... some residents only have 20 mins” (Professional Advisor – Care worker)

## 2.5 Online Search Behaviours

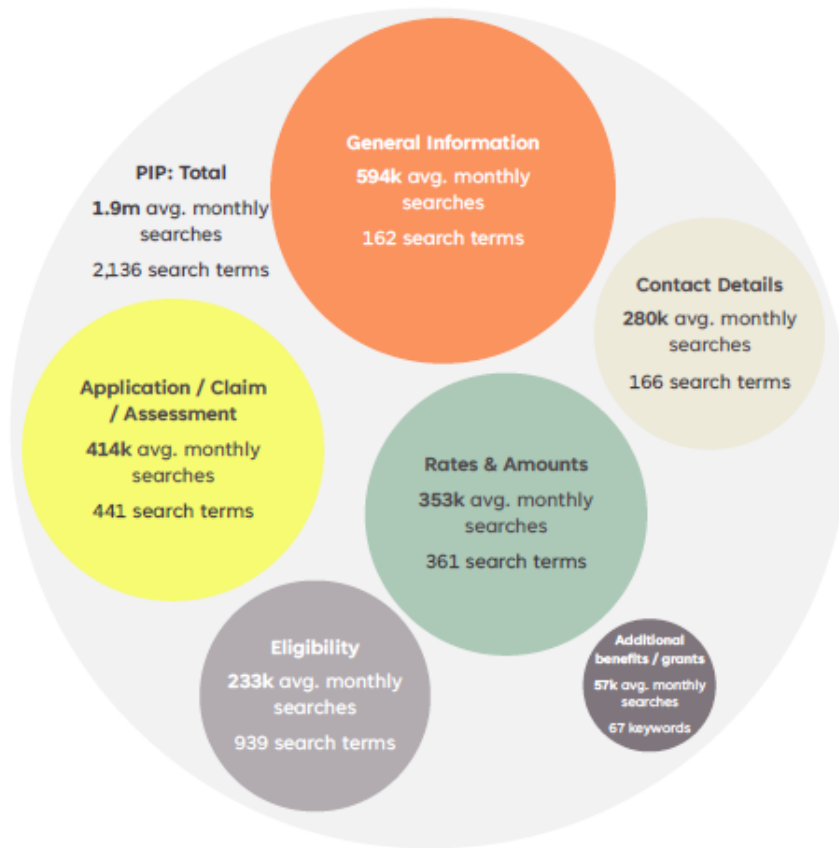
The preceding sections of this report highlight how applicants and advisors source information to develop a more detailed understanding of their potential eligibility and the process for applying for PIP. To help expand on this and develop a more detailed and comprehensive understanding of information-seeking behaviour additional analysis was undertaken by a specialist company (Tenrec Analytics) of online searches people conduct around PIP. This analysis was of aggregated data of Google searches, with no access or use of personally identifiable information.<sup>19</sup> This means that it is not possible to tell what is being searched for by applicants, by potential applicants, or by advisors. The results of these additional analyses are detailed in a standalone report for DWP, but relevant findings are summarised in this section.

Just under 2 million online searches relating to PIP are conducted each month, using 2,136 different search terms. Grouped by theme, the five most common search topics are summarised below with examples of the search terms used within each.

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<sup>19</sup> Analysis is based on Google Search Tools data as of April 2024. For more details on methodology and approach, see the report by Tenrec Analytics, 'Online Search for Personal Independence Payment'.

**Figure Three: Most common PIP-related searches made via Google, including frequency and number of search terms**

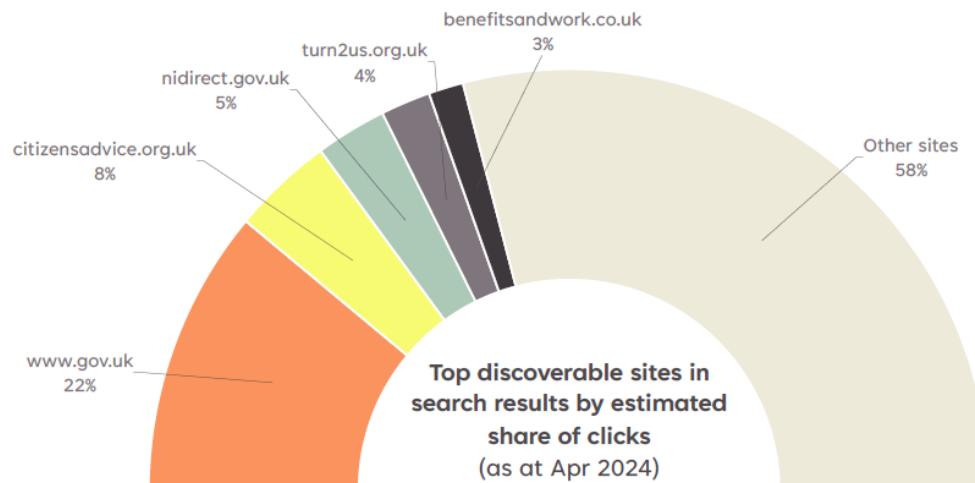


- General information (594,000 average monthly searches; 162 search terms)
  - E.g. 'pip news', 'dwp pip', 'what is pip', 'what is pip benefit'.
- Application / Claim / Assessment<sup>20</sup> (414,000 searches, 441 terms)
  - E.g. 'claim PIP', 'how to apply for pip', 'pip forms', 'pip points'.
- Rates and Amounts (353,000 searches, 361 terms)
  - 'pip rates', 'how much is pip', 'new pip rates', 'enhanced pip rates'.
- Contact details (280,000 searches, 166 terms)
  - 'pip phone number' 'pip helpline' 'address for pip'.
- Eligibility (233,000 searches, 939 terms)
  - E.g. 'pip list of medical conditions uk', 'can you work and claim pip'.

<sup>20</sup> Analysis suggests that some of these terms are used interchangeably, and sometimes used to refer to the entirety of the application process, rather than any specific stage within it.

General searches around PIP top the list here, and the GOV.UK site is generally returned as the top hit. Around 1 in 5 subsequent clicks (22%) are to go through to the official DWP page. Organisations with specific advice pages relating to PIP also appear in these searches, including Citizen's Advice (8%), Turn2US (4%) and Benefits and Work (3%). There is a lot of diversity in search results for these general searches, however, with over half of clicks being distributed across a wide range of smaller sites (each with a share of less than 3%).

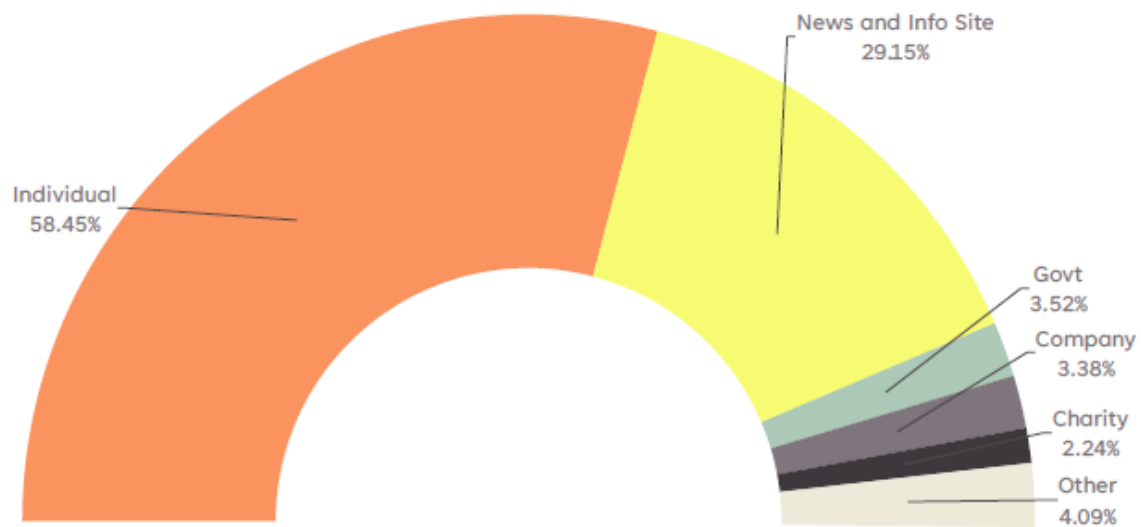
**Figure Four: Top discoverable sites in Google search results**



It is also interesting to note the relative diversity of terms used to search around each of these topics. Language used for initial and general searches appears to be more uniform (162 search terms) compared to searches around eligibility, which may include specific named conditions or symptoms (939 terms). Analysis of condition-specific search terms shows that, overall, more searches are done in relation to physical health conditions than mental health conditions, but that the top three condition-specific searches all relate to mental health (for anxiety/depression, mental health in general, and ADHD).

The study also included analysis of searches made within YouTube, identifying 97 unique videos relating to PIP which had attracted around 7.5 million views at the time of the study. This research showed that official government content (e.g. on the DWP YouTube channel) accounts for only a small proportion of views (3.5%) but is the third most common category of content creator after news and information providers (29%) and individual content creators (58%). This category of individual creators includes many documenting their personal experiences of PIP, as well as tips for navigating the application process. A relatively small number of creators dominate this category, with the top five accounting for more than half of all views.

**Figure Five: Breakdown of YouTube video views by content creator type**



Overall, this research gives valuable insight into what people are searching for when they make online searches relating to PIP, what sites and content they are likely to come across, and what videos they are likely to find if they search YouTube for PIP-related information. It also supports qualitative findings from this wider project as many of the same queries suggested by these search terms also come through in conversations with applicants and non-claimants. Both groups indicate fairly low levels of awareness at the start of their journey, which is likely to prompt general searches into what PIP is and how people can apply for it. Searches for clarity around PIP rates suggest people may be assessing cost vs benefit in advance of an application, to see if the amount they could be awarded is still valuable in their context. Questions around eligibility are also common, with queries relating to both work status and specific health conditions both coming through in this study, as well as the qualitative research. When approaching the application process and looking for tips to improve the likelihood of success, personal testimonies (such as those shared in videos by content creators on YouTube) have been found to be influential.

## 2.6 Understanding decisions not to claim PIP

As the third and final research strand of this project, we conducted focus groups with participants who are living with a long-term physical or mental health condition but are not currently claiming PIP. The intention was to better understand their reasons for not claiming, including their awareness and understanding of the application process and any potential barriers to claiming PIP. The following sections summarise views of the participants from the focus groups.

### **Awareness and understanding of PIP among non-claimants**

High-level awareness of PIP as a disability benefit which is not specific to any one health condition is fairly high among focus group participants, with some variation relating to previous experience. This includes both their personal experiences (some



participants had previously applied themselves) and indirect knowledge gained through hearing about the experiences of others. However, much like there is among applicants, there is notable variation in levels of knowledge and understanding of PIP among non-claimants. Those who have previously applied for PIP or know someone who has gone through the process have a deeper understanding, while others base their knowledge on second-hand information from different sources including the wider media and may have only surface-level knowledge of the benefit.

One apparent difference between applicants and those who might consider a claim but have not applied is simply awareness of PIP as an option. When asked why people who are potentially eligible may not apply for PIP, participants cite a lack of publicity of the benefit. PIP not being suggested as an option by services perceived as 'official' (e.g. a GP, carer) is seen to contribute to people's lack of awareness. There is almost an expectation that if they were to be eligible then a professional would have signposted them to it already, or that they would be contacted by DWP. This emphasis on hearing from sources perceived as authoritative mirrors the findings from the research among applicants where signposting from professional advisors (especially medical professionals) was often highly influential. The absence of such signposting from a potentially expected source can make consideration of an application less likely.

"I've been to various doctors' appointments and haven't been notified of it... People don't claim because they haven't heard of it." (Non-claimant, 50-65, condition for less than 3 years)

Amongst those who are aware of PIP but do not claim it, there is a lack of comprehensive knowledge about the benefit and a number of misconceptions which lead potential applicants to assume they are ineligible.

Firstly, many participants associate PIP with permanent (and often mobility-related) disabilities, which can deter those with non-chronic or fluctuating conditions from applying. This misconception is compounded by a second common misunderstanding that PIP is intended for those who are unable to work, or are in and out of work, leading employed individuals to feel ineligible. A few participants also expressed the belief that PIP is means-tested, i.e. dependent on an applicant's income. This puts those earning any kind of income off applying for it as they, again, commonly assume their ineligibility. As can be seen from section 2.3, many of these misconceptions are also common among applicants and the lack of access to (or motivation to seek out) evidence to the contrary may be all that prevents an eligible non-claimant from becoming an applicant in some cases.

"If you're off sick from work you can receive payments. I don't know what you would get." (Non-claimant, 18-30, condition for less than 3 years)

Overall, participants from the focus groups have more questions than answers when it comes to their understanding of PIP and its eligibility criteria, which makes them sceptical about putting in an application. Some questions raised by a small minority of participants include a perceived lack of clarity around the age limit for applying

and, among those who have searched for or come across lists of health conditions associated with successful applications, whether someone with a health condition that is not included on such a list could still be considered eligible. Concerns are raised around whether having a support system, such as family members or caregivers, would affect their eligibility to apply. Finally, participants question if individuals already claiming other benefits could apply for PIP, and how receiving multiple benefits might impact their entitlement.

“It doesn’t make it clear whether you can get the two benefits – if you are on limited capability and you apply for PIP, does it override, or do you get an element of both?” (Non-claimant, 25-49, condition for more than 3 years)

## **Barriers to claiming PIP**

Participants who are not claiming PIP identified several barriers to claiming which can be grouped into three sub-categories: those relating to the application process itself, a lack of clarity around the eligibility of certain conditions, and ‘internal’ barriers associated with stigma and self-identity.

### **Concerns relating to the application process**

Non-claimants – notably those with higher levels of knowledge around PIP or previous experience of applying – expressed a number of concerns around different aspects of the application process. In some cases, these are drawn from direct comparisons with other benefits (e.g. the relative wait time for a UC claim compared to a PIP claim) but not always. In general, those with higher levels of knowledge are more likely to view a PIP application as more demanding than some other benefits they may have experience of. Many mention feeling discouraged by negative media coverage around the application process, covering topics such as the wait time between stages, the points system and the bias towards physical disabilities over mental health conditions, as well as stories of unsuccessful claims shared on social media. This is particularly likely to affect potential applicants who struggle with anxiety.

“

You hear so much and read so much; I am afraid there is a lot of negativity. The bad press that surrounds a claim really puts off those of us that have anxiety.

(Non-claimant, 50-65, condition for less than 3 years)

”

Those with some knowledge of the application process commonly express the view that the assessment criteria used seem tailored towards physical health/mobility

conditions and do not account sufficiently for mental health. They emphasise that the questions on the PIP2 form and those asked at the assessment are restrictive, failing to provide adequate space to explain the specific impact of mental health conditions. Participants believe that it is unfair to use the same set of questions for both mental and physical disabilities, as the needs and challenges differ greatly. Some make reference to having heard about the experiences of unsuccessful applicants with mental health conditions via online disability communities and forums.

“Physical and mental disabilities are so different; I think it is unfair that they are in the same areas for eligibility. It is one big questionnaire for everyone, it is unfair to give the same questionnaire to everyone.” (Non-claimant, 18-30, condition for less than 3 years)

The PIP2 form is also raised by some participants as a daunting aspect of the application process. There is a particular perception that the form has the potential to cause anxiety among those pre-disposed to experiencing it, and this is generally expressed either by those with mental health conditions or those whose information source (e.g. a family or friend who previously applied) has a mental health condition. The potential of the form to induce or exacerbate anxiety was seen as likely to make already anxious potential applicants want to disengage from the application process altogether. Other issues raised in relation to the application form include the perception that completing it requires one to be articulate, and that the questions feel like they are designed to catch the applicant out. This poses a particular challenge for those who struggle with processing written information, or whose first language is not English. Moreover, being forced to recollect the details of their ‘worst days’ puts potentially eligible applicants off going through the process, in the fear that it might trigger negative thoughts or memories which might worsen mental health symptoms.

“When it came to doing it, I wanted to give up. I found it hard to think about my worst days.” (Non-claimant, 18-30, condition for less than 3 years)

Some participants also suggested the assessment could be off-putting to potential applicants with long-term health conditions, as well as unexpected among those with experience of benefits that do not require it (e.g. DLA). As has been highlighted in previous research, fluctuating conditions (where individuals experience both good and bad days) are also perceived as more difficult to claim for, a potential barrier to qualifying for PIP due to their unpredictability.<sup>21</sup> Participants worry that if their assessment falls on a ‘good day’, it may not provide an accurate reflection of their overall condition, potentially jeopardising their chances of receiving the benefit. This concern is compounded by the belief that assessors may not view fluctuating conditions as equally debilitating as chronic ones, deterring people from applying altogether.

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<sup>21</sup> DWP (2018); DWP (2024d), ‘The Impact of Fluctuating Health Conditions on Assessment’, available [online](#).

“I think it’s a barrier because if you have one bad day a week and it’s debilitating, you’re less likely to get PIP over someone who has it bad every day.” (Non-claimant, 18-30, condition for more than 3 years)

Some also query the qualifications of DWP assessors to conduct assessments, leading them to question their capability to make accurate judgments of PIP applications. This makes some apprehensive of engaging with the PIP process, suspecting assessors will not be sufficiently informed to make fair judgements on their claim.

“[A] lady called me on my phone asking how long I will [have] my condition. We should be assessed by doctors, consultants and people who understand you and not a DWP person calling me and asking how long my condition will last.” (Non-claimant, 25-49, condition for less than 3 years)

Anxiety around the PIP application process can also be exacerbated by hearing the negative experiences shared by others who have undergone the process (e.g. on disability forums, or via friends and family). Participants with knowledge of the process also express concerns over the frequency with which applications are rejected the first time, forcing applicants to formally dispute decisions. The possibility of facing a tribunal if the outcome is unfavourable is seen as intimidating and mentally exhausting. Furthermore, the risk of losing their existing benefits is highly anxiety-inducing for some, leading them to favour the status quo.

“I have never applied for PIP; I am too scared. I am staying on what benefits I have. I am so scared of risking what I have, of being cut off. I have left it as is for years. I am scared of rocking the boat.” (Non-claimant, 50-65, condition for more than 3 years)

Participants also discuss the dearth in availability of support, and a lack of transparency in being signposted to support services that help with the application process. This lack of knowledge about the support available – or the inability to access it, for example due to services being over-subscribed – deters people from applying for the benefit.

The comparatively lengthy duration of an average PIP application is also cited as a barrier, often leading to people dropping out of the process midway. Participants emphasise that the extended time between each stage can be demotivating, leaving applicants feeling exhausted and disheartened, and by the time they reach the final stage, many lose the motivation to continue.

“It takes too long. Let’s say you get accepted, that can still take like... 3 or 4 months. Someone who is applying for PIP clearly needs it. It’s someone who could do with the money for whatever they need.” (Non-claimant, 25-49, condition for more than 3 years)

Beyond the individual steps of the process, a key barrier to applying for PIP is the lack of trust in the system that designs and enacts it. Focus group participants who are familiar with the points-based evaluation system perceive it as a game they are forced to navigate, rather than a fair assessment of their needs. This leads to feelings

of frustration and scepticism, as some believe the process is made intentionally complex to reduce the number of successful applications. As a result, people feel demoralised and discouraged from applying, fearing that the system is designed to deny rather than support them.

“I have always avoided claiming for it because it seems to be a very prohibitive process... It feels like they don't want to give the money. This is very stressful, especially when you are sick, and when your life depends on it.” (Non-claimant, 50-65, condition for more than 3 years)

### **Lack of clarity around eligibility**

As mentioned above, there is a lack of clarity around some aspects of PIP eligibility which can pose a barrier to non-claimants considering an application. One notable aspect of this affects those with mental health conditions who believe that PIP is primarily for individuals with visible physical disabilities, leading them to assume they do not qualify. This, combined with the notion that only the most severe conditions are considered, often discourages people from applying.

“

PIP is more for people with slightly more severe disabilities, rather than the mental health side of things. Slightly more [for] physical disability is the impression I've always had of it.

(Non-claimant, 25-49, condition for more than 3 years)

”

There is also a minority who feel unprepared to apply because they lack what they expect to be necessary evidence to prove their condition, such as evidence of a formal diagnosis. This is particularly likely to be cited by those with mental health conditions which are seen as harder to 'prove' to an assessor.

“I don't know how to prove my other conditions such as PTSD, I don't go to the doctors. I just don't have that evidence that will support my application.” (Non-claimant, 50-65, condition for less than 3 years)

The recency of a diagnosis also appears to impact likelihood to apply for PIP. Some participants suggest that in the case of newly diagnosed individuals, their disability might not yet have a significant impact on their lives, leading them to believe they should wait until their condition worsens before applying.

“People who apply might be suffering for a long time, however I have only just received the diagnosis.” (Non-claimant, 18-30, condition for more than 3 years)

## **Identity and stigma**

Focus group discussions also reveal some challenges around PIP relating to self-identity and perceived social stigma. There is also a notable identity barrier for some who struggle to reconcile their image of themselves with the image they may have of a benefit claimant, or a disabled person. Participants, specifically those who have had their condition for a long time, find it hard to acknowledge their need for support as it can evoke feelings of inadequacy.

“My daughter told me to apply, and I was offended. I’m not that bad thank you very much! It makes you feel inadequate.” (Non-claimant, 26-35, condition for less than 3 years)

These feelings are also observed among applicants and can be associated with people delaying an application until the point of acute need. Among non-claimants, they may never be overcome, preventing potentially eligible people from submitting a claim.

Employment history was often an influencing factor here, as those who have been employed throughout their lives often struggle to accept the idea of seeking financial assistance through PIP. There is often interplay here between an image of oneself as a ‘working person’ and a belief that much of the public have a negative perception of people who claim benefits which participants do not wish to associate themselves with. Participants mention negative press reports of apparently undeserving claimants and benefit ‘cheats’. As has been found in previous research on benefits, this sense of stigma can lead to people being embarrassed to claim a benefit like PIP, or even admit to considering it.<sup>22</sup>

“I think there is such a bad stigma attached to people and benefits, I would worry about it. If I got PIP or something like that, I wouldn’t tell anyone.” (Non-claimant, 18-30, condition for less than 3 years)

There is a contrasting but fairly widespread sentiment among the focus group participants that they personally are in fact undeserving of benefits because they know people with more severe conditions and/or experiencing greater impacts who they see as being more in need than themselves. Some mention ruling out the possibility of a PIP application on this basis, feeling it would be inappropriate for them to receive it. For some, there is a correlating age factor here; some suggest that younger individuals are less likely to apply, assuming that older applicants are more likely to be in greater need, and therefore have a great chance of being awarded PIP.

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<sup>22</sup> Joseph Rowntree Foundation (2021), ‘How social security can deliver for disabled people in Scotland’, [available online](#).

“A friend has more disabilities than me, so I didn’t think I deserved it based on a comparison with them.” (Non-claimant, 50-65, condition for less than 3 years)

## **Assessment of cost and reward**

In the focus group discussions, participants seem to naturally focus more on the challenges of a PIP application and the issues it may raise, rather than any potential benefits it could bring. This is something of a contrast to discussions with applicants where, even when reservations were expressed, the benefits that PIP could bring were also commonly acknowledged. Given the fairly widespread perception among non-claimants of the PIP application process as relatively demanding, and the perceived risks applying may pose to other benefit claims or social standing, it is understandable that potential applicants consider the likely ‘costs’ of applying compared to the likely ‘reward’ for doing so. Analysis of online search behaviours shows approximately 353,000 monthly searches relating to PIP payment rates, suggesting many seek clarity around exactly what the possible ‘reward’ would be. However, with awareness of the likely benefits of PIP apparently low among non-claimants in our focus groups, it is perhaps unsurprising that many become focused on the costs (or assume they would be unsuccessful in any attempted application) and see them outweighing the benefits).

In many cases, this assessment is a significant barrier to applying for PIP; many participants from the focus groups feel that the payment awarded, even at the maximum level, does not justify the effort required to navigate the challenging application process, leaving them questioning whether the outcome is ‘worth it’. This perception leads to frustration, with some viewing the payment as insufficient and merely tokenistic.

“It’s tokenism on how much money people get paid. It doesn’t pay enough for people to come in and help.” (Non-claimant, 50-65, condition for less than 3 years)

# Discussion and implications

This research sought to understand the journey people take from first learning about PIP to putting forward an application, as well as why people who may be eligible for PIP have not applied for the benefit. In this final section we discuss the findings in relation to the core research questions, and highlight emerging implications for consideration by DWP and organisations working to support people to manage the impact of disabilities and long-term health conditions.

## **How do PIP customers end up deciding to claim? What do their journeys look like? And what are the types of PIP customer?**

This research has helped identify that there are no specific ‘types’ of customer but rather a range of journeys to claiming PIP which are in turn influenced by a variety of intersecting factors. These include the nature of the health condition or disability, the length of time an individual has been experiencing their condition, personal confidence levels, motivations for claiming, and sources of support and advice available to people. Through understanding how these various factors intersect to influence the choices available to people, we were able to identify **seven different types of journey** to applying for PIP. Each of these is characterised by different routes to and through a PIP application, and has different implications in terms of support needs.

An implication of this research is for DWP to consider, alongside key support organisations such as Citizen’s Advice, **how this journey typology may be used to both identify and inform the type of support that is made available** to individuals with an identified disability or health condition. For example, within DWP there is the opportunity to look at how HCPs and decision makers are accounting for the journey that someone is likely to have taken to putting forward a PIP claim, and the potential support they may need to gather and present their case (including medical evidence) in applying for PIP. DWP’s Health Transformation Programme is developing a personalised case management approach for PIP applications – and this typology could be a tool in achieving that. Additionally, it needs to be acknowledged that not all journey types were equally present in our sample and it was not our intention to determine the proportions of these journey types within this (qualitative) research. **DWP may wish to consider commissioning further (quantitative) research to validate and size journey types, this in turn could be used to identify people who may be more in need of particular types of support.**

**People apply for PIP primarily to receive financial support.** In some cases, the additional income from PIP is seen as better enabling access to support or services that help people to manage the impact of a health condition. However, in many cases PIP is seen as a benefit for individuals whose conditions affect their ability to work or



manage day-to-day living costs<sup>23</sup>. It is a benefit that people are often first becoming aware of and accessing because they are experiencing (actual or perceived) financial detriment. As such, it is often the case that the money is seen as helping people to feed, clothe and house themselves in the way they are used to, as opposed to addressing specific needs relating to their health condition. Nonetheless, from the perspective of both applicants and advisors, there is an argument that addressing basic needs is critical in preventing further deterioration of health conditions (and any corresponding impact on people's ability to complete day-to-day tasks).

One potential implication of this research is that people who are eligible for PIP would benefit from **greater awareness** of the benefit, in particular to address the misconception that it is only for people who cannot work due to the impact of a disability. In this context PIP might support them to manage the impact of their health condition or disability at an earlier point in time.

While the motivation for applying for PIP is typically financial, the actual **trigger for commencing a PIP application is often signposting or encouragement to apply from friends, family, a healthcare professional or welfare advisor** (often in response to identified financial need). In most cases there is acknowledgement – by both applicants and advisors – of the lack of clarity around likely entitlement, but a view that if someone is potentially eligible then it is worth their putting an application forward. In the vast majority of cases, formal advisors and professionals would always recommend that someone who is eligible for PIP puts forward an application, not wishing to pre-emptively rule someone out based on their own judgement. An implication of this research is that if DWP want to better inform people about eligibility and entitlement, to manage or set expectations about the process and outcomes, or to encourage people to access support in progressing a PIP claim, then **formal advisors and professionals are a critical set of stakeholders to engage with**.

While many people are prompted to apply by others, the vast majority of applicants that we spoke with **progressed their application with minimal support or reference to information or guidance**. Beyond a general Google search (often using quite general terms like 'what is PIP' or 'claim PIP') and accessing PIP information on GOV.UK, most journey types do not involve further research before commencing a claim. However, our analysis of PIP-related searches made via Google do show that over three-quarters of searches result in people accessing sites other than GOV.UK. While some of these will contain authoritative and accurate information (e.g. Citizens Advice), there is also a lot of content being accessed where the information provided may be based more on opinion and conjecture. Applicants in this research highlighted how the volume of conflicting information online can be confusing, leading them to limit the amount of time spent searching and instead just progressing with an application. Another implication of this research is **maximising the proportion of people that view PIP eligibility information on GOV.UK** through search engine optimisation on both search and social media platforms. **Further**

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<sup>23</sup> Living costs which may be argued to be higher for a disabled person, but which were not necessarily reflected on in this way by the participants in this research.

**research into social media content could also be revealing** here, as applicants mention seeking information and support from online forums and groups where people share their application experiences, sometimes within groups or communities focused on specific conditions.

Having commenced an application, **personal confidence** is seen as crucial, impacting an applicant's ability to progress through the application process, and potentially to contest a decision. Confidence can be influenced by many factors, in particular the practical, informational and emotional support of formal or informal advisors. It may also fluctuate throughout the process due to changes in the impact of health conditions and/or how these intersect with aspects of the application process. One very tangible example of this is the difficulties many people report facing in writing in depth about the (often debilitating) impact of a health condition. The journey typology highlights the types of support that people might benefit from at different stages of the application to help empower them to see the application process through to completion. DWP and organisations providing support to people might look to **ensure that applicants with conditions that fluctuate receive signposting to support, and suitable concessions** (such as extra time to complete their application form). The recent research report on additional support needs in the PIP claim journey<sup>24</sup> provides useful further information on the types of additional support that PIP claimants may benefit from.

### **How accurate are applicant's understanding of PIP? What misunderstandings are there?**

Applicants generally understood that PIP was a benefit available to people impacted by a disability or health condition. Beyond this, understanding was extremely variable, influenced by the sources of information they had accessed or people spoken to. Common however was a high degree of confusion around entitlement as relating to the presence and experience of a condition, rather than specifically the impact this has on mobility and day-to-day activities. There is therefore a **strong need for much clearer guidance** on who, why and when someone would be eligible for and entitled to PIP.

Challenges relating to fluctuations and how mental health is accounted for within this context, and how work status and income may impact eligibility, could all benefit from being more clearly addressed in information and communications to potential applicants. There is a clear and consistent view that a person is more likely to be awarded PIP if they are impacted by a physical condition in contrast to a more 'invisible' (and often under-diagnosed) mental health condition. This is less a misunderstanding per se, and more a view that is accepted based on conversations held with informal or formal advisors about their experience, and commonly voiced on social media (including YouTube and forums such as Benefits and Work). It is **unclear from this research how much influence or credibility is placed in some**

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<sup>24</sup> <https://www.gov.uk/government/publications/additional-support-needs-in-the-personal-independence-payment-claim-journey>

**of the social media content** advising people on navigating the PIP process and we would recommend that further research is undertaken here.

It will require a proactive communications campaign to address this head-on, coupled with additional guidance specifically targeted for those with mental health conditions to help them better understand how to relate their condition to the questions being asked within the application and assessment.

### **How do sources of advice (both formal and informal) about PIP get informed?**

This research involved speaking with informal advisors, formal benefits advisors and then wider professionals (e.g. GPs or social workers). These sources of advice were critical in that they were often the first place where people heard about PIP and therefore **helped set expectations about both PIP entitlement and the process**.

Informal advisors such as family and friends often gained PIP knowledge through firsthand experience of having applied or supported others to apply, as well as through online research using similar sources to those used by PIP applicants themselves. We were unable in this research to engage many informal advisors (recruited through snowballing from applicants) so **DWP may wish to consider additional research specifically with informal advisors** who support people to complete their PIP applications.

Formal benefits advisors typically gained their PIP knowledge through a combination of (often many years) experience supporting PIP claims and (often internal) training. They were often specialists in PIP specifically and helped people to complete an application. While these benefits advisors are typically extremely confident in their understanding of entitlement, there is frustration at seeming inconsistencies in PIP awards. Virtually all benefits advisors would encourage anyone with a disability or health condition to put forward an application, but could be more purposive at encouraging or discouraging people following a zero award to request a Mandatory Reconsideration or appeal an outcome based on their understanding of entitlement.

Finally wider professionals often provided basic information about PIP and signposting to formal advice services. Their knowledge of PIP is primarily gained through their professional training, experience working with clients, learning from colleagues, and conducting their own research. They often report significant gaps in their knowledge, particularly beyond the initial application stages.

While each of these sources of information and advice are important, some are easier for DWP to engage than others, and some are disproportionately influential. In particular, wider professionals are often the first point of signposting toward PIP for people with a health condition. Given their relatively lower levels of awareness or knowledge around PIP there is a danger that people's expectations are not being managed as well as they may be, or that they are not being signposted toward the most authoritative sources of information or to formal benefits advisors. Developing a better **understanding of the knowledge of wider professionals** around PIP, who it is for and who is eligible may help mitigate the risk of inappropriate signposting (or a lack of signposting people who may be eligible).

## **What are the differences between disabled people who claim PIP and those who don't?**

For those participants with a long-term disability or health condition who had not applied for PIP, the key barrier related to the perception of the process as being one which was difficult, protracted, in some cases unfair, and often resulted in an undesired outcome. In this sense the **cost of progressing an application of PIP was felt to outweigh the benefits**, with the financial reward not deemed sufficiently motivating (or needed, for those we spoke with). An implication here is to **focus on how processes could be improved to both improve the customer experience as well as to improve trust in the PIP award system**. Examples here might relate to reducing the emotional strain on applicants by looking at how information on health conditions (including antecedents of these) or impacts of health conditions might be pre-populated by professionals, or how the process might be expedited for individuals in highly vulnerable circumstances. A lot of focus was placed on concerns around the variability of assessments, the 'qualifications' of HCPs and how information provided was recorded and accounted for. Acknowledgement of this (perceived) variability and setting out ways in which this might be mitigated going forward would help to address these concerns. DWP's Health Transformation programme is undertaking work that aims to address these types of issues by simplifying and automating the PIP journey, and by enabling online applications. It aims to give an improved customer service experience, getting more decisions right the first time and improving trust.

The other key barrier which stopped or delayed applications for PIP was the **discomfort in asking for help** (and accepting financial help from the government). For many people this was a firm line in the sand that they had never crossed in their lives and struggled to reconcile with their personal identity as someone who was independent, paid their way and didn't 'take' from the system.

Conversely, those people we spoke with that had applied for PIP felt that the **process was worth going through – they had (some) hope of a positive outcome**. This may be because they had less information or understanding of the process itself (including what information they would need to provide and what an assessment would involve), less information on the likely outcome of their application, or because they were financially in a very difficult situation and saw PIP as a way of gaining some control over aspects of their life (be that their daily living costs or paying for treatment for their condition).

Again, we would like to finish this report by thanking all those who gave up their time to speak to us. These discussions often involved people talking about highly personal and sensitive subject matter, and they did so with the intention of helping inform future DWP policy and services in respect of disability benefits.

# Appendix A: Advisory Group Membership

To provide guidance throughout this project, an Advisory Group was convened who were consulted on the research design, drafting of research materials (such as interview topic guides) and reflecting on emerging findings. This group was made up of individuals with professional experience of conducting research with disabled people (including DWP staff) and those with lived experience of a disability or health condition. They provided valuable feedback on language and framing, as well as broad insight into existing discourse in the disabled community and best practice on conducting research with disabled people. The representation of evidence included in this report, and any implications of this evidence, are those of the research project team, rather than those of the members of the Advisory Group.

## Advisory group members

Josef Baines, Insight Manager at London Sport

Dr Lauren White, Lecturer in Social Research Methods at the University of Sheffield

Lucy Glazebrook, Social Researcher at DWP

Professor Sarah Marie Hall, Professor in Human Geography at the University of Manchester

# Appendix B: Applicant Topic Guide

Time	Content
0-5 mins	<p><b>Introduction (5 mins)</b></p> <p>Thank you all for agreeing to speak.</p> <p>I work for Open Inclusion. We are an independent research agency who are working on behalf of the Department for Work and Pensions.</p> <p>We are speaking with people who have a health condition or disability about the Personal Independence Payment (also known as PIP). It is important to say that we don't expect you to have any prior knowledge about PIP coming into this discussion today. We are interested in hearing your views, regardless of how much certainty you have around them. The intention is not to test or judge your knowledge – there are no right or wrong responses to any of the questions we will cover with you. The intention of this work is to help DWP to improve the ways in which people who need additional support are able to access benefits in the future.</p> <p>It is important to say that everyone here today has a diagnosed health condition and or a disability. Everyone will experience these differently and brings different life experiences that will influence their views. We want to hear these and ask everyone to be respectful of the views of others. We will do what we can to support your full participation in this discussion, but if there is anything that we are doing or not doing that makes this difficult for you please do say. [NAME] is here to help me with this and you can reach out using the chat function or just by raising with us at any point in the discussion.</p> <p>We will take a short comfort break after the first 45 minutes of the discussion.</p> <p>[IF OBSERVER IS PRESENT]: We also have [NAME] who is observing our discussion today. They won't be participating and are just here to hear from people firsthand.</p> <p>I want to reassure you that whatever you say in this group will be treated confidentially – you will not be identified in anything we produce for DWP. Please be as open and honest as you can.</p> <p>I would like to audio record and take typed notes of the discussion today [IF ONLINE – this recording will also involve the conversation being transcribed on Teams]. This is purely so we have an accurate record of what you tell us today. The notes and recording will be shared with our research partners, the research agency Basis Social. Any notes and recordings will be deleted at the</p>

	<p>end of the project. Are you okay with this? We will also use the closed captioning function on Zoom as we find this can be helpful for people.</p> <p>Participation in this discussion is completely voluntary and you can withdraw your consent to participate at any point in the process, including following the session itself.</p> <p>Is everyone happy to continue with this discussion on this basis?</p> <p><b>MODERATOR TO CONFIRM CONSENT AND COMMENCE RECORDING.</b></p> <p>Do you have any questions before we start?</p>
<b>5-15 minutes</b>	<p><b>Introductions (10 mins)</b></p> <p><b><i>Objective: this section is to help introduce participants to one another to support a more open discussion.</i></b></p> <ol style="list-style-type: none"> <li>1. To start off, I would like to introduce myself and for you all to have the opportunity to say Hello to one another. If we can go around the room and say your name, perhaps where you are from, one thing you are really good at and one thing you need support with. I will kick us off...</li> </ol>
<b>15-40 minutes</b>	<p><b>Awareness and understanding of PIP (25 mins)</b></p> <p><b><i>Objective: this section is to help us to understand incoming levels of awareness, understanding and views toward PIP.</i></b></p> <ol style="list-style-type: none"> <li>2. Great. Lovely to meet everyone. To start off with, I would like to just a quick show of (physical or virtual) hands: how many of you were aware of the Personal Independence Payment (PIP) benefit before being invited to take part in this research?</li> <li>3. For those of you that already had some awareness of PIP, where (and when) did you first hear about PIP?</li> <li>4. OK, I'd like to just do a short exercise with you all, regardless of how confident you are in your knowledge of PIP you can participate in this. This is called a sentence completion activity. You can either use the chat for this, or you speak it out loud in a minute when I ask. I want you to complete the following sentence: 'PIP is a benefit for people who...' <i>Probe:</i> <ul style="list-style-type: none"> <li>• Where heard / sources of information</li> <li>• Levels of confidence</li> <li>• Examples of people that might be eligible for PIP</li> <li>• Examples of people <i>most likely to receive</i> an award</li> </ul> </li> <li>5. What about people that are not eligible, or less likely to receive an award? Are there any common factors or characteristics that might make someone less eligible or less like to be awarded PIP?</li> </ol>

	<p>6. Thanks. I just want to dig into this a little more now. Talk me through what you know about PIP. Imagine you are explaining what it is to someone who had never heard of PIP before, how would you describe it in your own words? <i>Probe:</i></p> <ul style="list-style-type: none"> <li>• What heard about PIP</li> <li>• Sources of information</li> <li>• Levels of trust/confidence in what heard</li> </ul> <p><i>Moderator to explore differences in views between people.</i></p> <p>7. How do you think decisions are made around eligibility and entitlement for PIP? <i>Probe:</i></p> <ul style="list-style-type: none"> <li>• What they think the process of applying for PIP involves</li> <li>• Anything about that process that would concern them, if they were themselves to ever apply for PIP</li> </ul>
<b>40-50 minutes</b>	<b>BREAK (10 mins)</b>
<b>50-70 minutes</b>	<p><b>Considerations (20 mins)</b></p> <p><b><i>Objective: this section unpicks why people have or have not (and would or would not) consider applying for PIP.</i></b></p> <p>8. Has anyone considered applying for PIP themselves? If so, can I ask what were the circumstances that led you to consider applying? <i>Explore in depth:</i></p> <ul style="list-style-type: none"> <li>• Motivations for considering (i.e. what was happening in their life, when was this?)</li> <li>• Support accessed/available</li> <li>• How far they got with the process (e.g. seeking information, PIP1/PIP2 etc.)</li> <li>• What stopped them going forward with their application</li> <li>• Would you consider applying again in the future? Why/why not?</li> </ul> <p>9. For those of you that haven't applied, is there a reason for this? <i>Probe around following (use as a projective exercise if needed, i.e. other people have said....):</i></p> <ul style="list-style-type: none"> <li>• recency of their health condition</li> <li>• predictability/manageability of their health condition</li> <li>• support networks helping to manage</li> <li>• employment status (i.e. in work)</li> <li>• financial resilience (i.e. not financially in need)</li> <li>• financial value of PIP</li> <li>• lack of knowledge around PIP</li> <li>• capability of progressing a PIP application (e.g. due to condition or challenge of process)</li> </ul>



	<ul style="list-style-type: none"> <li>• stigma attached to benefits</li> </ul> <p>10. Are there any circumstances under which you would consider starting a PIP application (again)?</p>
70-85 minutes	<p><b>PIP assumptions (15 mins)</b></p> <p><b>Objective: this section looks to check on views/acceptance of common views expressed by PIP applicants in past research to understand extent to which influences their own perceptions.</b></p> <p>11. I wanted to get your reflections on some examples of feedback from PIP applicants about their experience claiming for PIP. [MODERATOR TO SHARE <a href="#">STIMULUS 1</a> ON SCREEN OR READ OUT]</p> <p><i>Group 1</i></p> <ul style="list-style-type: none"> <li>• ‘In assessing you for PIP, DWP will look at what other disability benefits you are on.’</li> <li>• ‘PIP is the same as DLA. If you’ve had DLA you should get PIP.’</li> </ul> <p><i>Group 2</i></p> <ul style="list-style-type: none"> <li>• ‘Working is fine as long as you can still prove the difficulties exist, regardless of what job you do. Just be careful not to contradict yourself.’</li> <li>• ‘You need as much medical evidence as possible to back up your claims.’</li> </ul> <p><i>Group 3</i></p> <ul style="list-style-type: none"> <li>• ‘Certain health conditions automatically qualify you for PIP.’</li> <li>• ‘The difficulty with anxiety and depression is that it fluctuates so much. I don’t think PIP takes that into account.’</li> </ul> <p><i>For each of the above, probe extent to which they have heard these before and, if so, whether these have influenced the way they are progressing their own application.</i></p>
85-90 minutes	<p><b>CLOSE</b></p> <p>That is all my questions. Is there anything else you would like to add?</p> <p>Thank you very much for your time. This has been very helpful and will be used to inform the way in which PIP information is provided to people in the future.</p> <p>If you have any questions please do get in touch with us by email or phone. [NOTE THEY WILL HAVE RECEIVED THESE DETAILS ON THE INFORMATION AND CONSENT FORM – PROVIDED BELOW FOR REFERENCE]</p> <ul style="list-style-type: none"> <li>• Email: <a href="mailto:dwp.PIP@basisresearch.com">dwp.PIP@basisresearch.com</a></li> <li>• Phone: 08000 489 375</li> </ul>

	There is a £50 shopping voucher to thank you for your participation. This will be processed in the coming week.
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# Appendix C: Advisor Topic Guide

Time	Content
0-5 mins	<p><b>Introduction (5 mins)</b></p> <p>Thank you for agreeing to speak.</p> <p>I work for Basis Social. We are an independent research agency who are working on behalf of the Department for Work and Pensions.</p> <p>We have been speaking with people who have applied for the Personal Independence Payment (also known as PIP) to find out more about what prompted them to apply for PIP, how they found out about it and their expectations in applying. Some mentioned having received advice from an organisation like yours, and we are now looking to interview people who offer advice to current or potential PIP applicants to better understand the role advisors like yourself play in this journey.</p> <p>Whatever you say to me will be treated confidentially and your name will not be shared with DWP. As mentioned, Basis Social is an independent research agency and we do not work within DWP. Please be as open and honest as you can.</p> <p>I would like to audio record and take typed notes of the discussion today – this recording will also involve the conversation being transcribed on Teams. This is purely so we have an accurate record of what you tell us today. The notes and recording will be kept strictly to the Basis Social team. Any notes and recordings will be deleted at the end of the project. Are you okay with this?</p> <p>In our report, we would like to be able to refer to your organisation in general terms when contextualising any points raised in our conversation today. This would not be specific enough to identify your particular organisation (e.g. a ‘disability advocacy charity’). Is that OK?</p> <p>Basis are a company partner of the Market Research Society (MRS) and abide by their code of conduct. Participation in this interview is completely voluntary and you can withdraw your consent to participate at any point in the process.</p> <p>Are you happy to continue with this interview on this basis? MODERATOR TO CONFIRM CONSENT AND COMMENCE RECORDING.</p> <p>Do you have any questions before we start?</p>
5-15 minutes	<p><b>Organisation and role (10 mins)</b></p>

	<p><b>Objective: to help us to understand participants' current role, their organisation, their client base, and the services they offer.</b></p> <p>1. To start off, could you tell me a bit more about your organisation and the work it does? <i>Probe:</i></p> <ul style="list-style-type: none"> <li>• What are the main services offered by your organisation? What do your clients come to you for?</li> <li>• [If not mentioned] To what extent does the work of the organisation relate to disability/ health benefits?</li> <li>• Thinking about the PIP benefit specifically, what types of support does your organisation offer to people?</li> </ul> <p>Click or tap here to enter text.</p> <p>2. And it would be good to know a bit more about your role specifically.</p> <ul style="list-style-type: none"> <li>• What are your main responsibilities within your role?</li> <li>• Is there a particular group or type of client that you typically work with?</li> <li>• [If not mentioned] How much of your work involves having conversations with people relating to PIP (or health and disability benefits more widely)?</li> </ul> <p>Click or tap here to enter text.</p> <p>3. And in terms of the people you/your organisation works with:</p> <ul style="list-style-type: none"> <li>• What are their day-to-day lives like?</li> <li>• Are there any common characteristics they share? (e.g. <i>specific location, specific health condition, working/not working, common challenges</i>)</li> <li>• (If not mentioned) Do you work with people who have additional language / access needs? (inc. <i>both health/disability related needs and those with a first language other than English</i>)</li> <li>• Is there a "typical" profile of person that would seek support in their PIP application or assessment through your organisation? And has this changed at all over the last few years?</li> </ul> <p>Click or tap here to enter text.</p>
<p><b>15-30 minutes</b></p>	<p><b>Understanding and awareness of PIP (15 mins)</b></p> <p><b>Objective: to establish participant's understanding of PIP, understand general awareness among their client base, establish who initiates conversations around PIP, when and with whom.</b></p> <p>4. Before we focus in on the support provided, talk me through what you know about PIP. Imagine you are explaining what it is to someone who had never heard of PIP before, how would you describe it in your own words? <i>Probe:</i></p> <ul style="list-style-type: none"> <li>• Who do you think PIP is for?</li> <li>• Can you give me any examples of people that might be eligible for PIP? What about people that would be less likely to receive an award?</li> </ul>

Click or tap here to enter text.

5. And where does your knowledge of PIP come from? (*Personal / professional experience, elsewhere*)

- Have you ever had any formal training or guidance about PIP? (*from your organisation, from DWP, elsewhere*)
- Do you have any questions or gaps in your knowledge about PIP? Anything you are unsure of?

Click or tap here to enter text.

6. Among the clients you typically work with, what would you say is the general level of awareness of PIP before they interact with your organisation? *Probe:*

- Do people come to you already aware (e.g. wanting help completing their application) OR do most of your clients first hear about PIP from your organisation?

Click or tap here to enter text.

7. How regularly are you having conversations with clients/patients about PIP? *Probe:*

- Has this changed at all in recent years? If so, why might this have been the case?

Click or tap here to enter text.

8. Does your organisation have standardised guidance / advice for clients around PIP?

- Has your policy around signposting to PIP changed at all (e.g. over the last ~3 years)?
  - IF YES: Why, and in what way? (*Probe: internal / external drivers – e.g. capacity, numbers of people approaching org for help, cost of living, NHS issues*)
- Do you and your colleagues approach conversations like this in the same way?
- Do you proactively reach out to anyone to signpost them to PIP and to offer support, or do you wait for people to approach you?
  - IF PROACTIVE: to whom, and why?
- Are there particular groups of people you do not advise to apply for PIP?
  - IF YES: who, and why? (*Probe: working/lesser financial need, any particular health conditions?*)

Click or tap here to enter text.

9. Do you/your colleagues work with people throughout the entire claim journey (i.e. from initiating a claim through to receiving a decision), or do you only interact with clients at a particular stage?

	<ul style="list-style-type: none"> <li>• (If particular stage) Which stage(s)?</li> <li>• Among the people your organisation advises on PIP, do you have a sense of what proportion go on to submit a completed claim? And what proportion are successful?</li> <li>• (If not mentioned) Do you also work with people who want to challenge a decision (i.e. mandatory reconsiderations and appeals)?</li> </ul> <p>Click or tap here to enter text.</p>
30-45 minutes	<p><b>PIP Advice Process (15 mins)</b></p> <p><b><i>Objective: to build a detailed understanding of how the advice process works in this organisation and how clients are directed to PIP, what other sources or information or support advisors direct clients to.</i></b></p> <p>10. Now I would like to try and build a picture of how the advice process might work for a new client who comes to your organisation for help. I have a couple of scenarios here, and I would like you to just react as you would if a client came to you.</p> <p><i>MODERATOR – USE 2-3 AND ADAPT AS APPROPRIATE (e.g. if already discussed client base would make a scenario irrelevant, do not discuss)</i></p> <p><i>FOR EACH SCENARIO USED, ESTABLISH:</i></p> <ul style="list-style-type: none"> <li>• <i>Initial response to scenario: what is the first thing they would say/do?</i></li> <li>• <i>What questions would they have for/about this person? Why? (demographic information, health condition, other characteristics?)</i></li> <li>• <i>What options would they offer this person – just PIP? Others? In what order? Why?</i></li> <li>• <i>Would they direct them elsewhere – to a person, or an information source? If so, what?</i></li> <li>• <i>Would they be confident in advising this person to apply for PIP? Why/why not?</i></li> </ul> <p><u>Scenario A</u></p> <p>I am struggling to make ends meet, even though I work full-time. I'd like to know if there are any benefits or financial support I can access.</p> <p>Click or tap here to enter text.</p> <p><u>Scenario B</u></p> <p>I was recently injured at work and I now cannot do the job I was previously doing. I am worried about not being able to pay my bills.</p> <p>Click or tap here to enter text.</p> <p><u>Scenario C</u></p> <p>I live with [specific condition related to organisation] and I am struggling without [relevant adaptation]. I've come to ask if your organisation can fund this for me.</p>

	<p>Click or tap here to enter text.</p> <p><u>Scenario D</u></p> <p>I have just heard about PIP from a friend who is claiming it, and I am wondering if I might be eligible too. I get severe asthma attacks and also sometimes feel depressed.</p> <p>Click or tap here to enter text.</p> <p><u>Scenario E</u></p> <p>I've started this 'How your disability affects you' [PIP2] form and am really struggling to understand what to write. I would like somebody to help me to complete it.</p> <p>Click or tap here to enter text.</p>
<b>45-57 minutes</b>	<p><b>Common advice and perceptions (12 mins)</b></p> <p><b><i>Objective: to test awareness/use of common messages around PIP</i></b></p> <p>11. I wanted to get your reflections on some examples of feedback from claimants about their experience claiming for PIP. We'll talk through these one by one [MODERATOR TO SHARE SCREEN]</p> <ul style="list-style-type: none"> <li>A. 'If you're still filling in the form then just write from the perspective that every day is your worst day.'</li> <li>B. 'In assessing you for PIP, DWP will look at what other disability benefits you are on.'</li> <li>C. 'Working is fine as long as you can still prove the difficulties exist, regardless of what job you do. Just be careful not to contradict yourself.'</li> <li>D. 'They reject everyone the first time, you will just have to appeal.'</li> <li>E. 'Be careful in assessments as some assessors will try to catch you out. For example, if you're claiming for depression and you "sound cheery" they will fail you.'</li> <li>F. 'You need as much medical evidence as possible to back up your claims.'</li> <li>G. 'The difficulty with anxiety and depression is that it fluctuates so much. I don't think PIP takes that into account.'</li> </ul> <p><i>For each of the above, probe extent to which they have heard these before (whether from colleagues or claimants). Do any relate to advice they give?</i></p> <p>Click or tap here to enter text.</p>
<b>57-60 minutes</b>	<p>Those are all the questions that I wanted to ask today. Is there anything else you would like to add that we haven't touched on?</p> <p>Thank you very much for your time.</p> <p>If you have any questions, please do get in touch with us by email or phone.</p> <p>[NOTE THEY WILL HAVE RECEIVED THESE DETAILS ON THE</p>

	<p>INFORMATION AND CONSENT FORM – PROVIDED BELOW FOR REFERENCE]</p>
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- Email: [dwp.PIP@basisresearch.com](mailto:dwp.PIP@basisresearch.com)
- Phone: 08000 489 375

Thanks again.

**CLOSE**



# Appendix D: Public Topic Guide

Time	Content
0-5 mins	<p><b>Introduction (5 mins)</b></p> <p>Thank you all for agreeing to speak.</p> <p>I work for Open Inclusion. We are an independent research agency who are working on behalf of the Department for Work and Pensions.</p> <p>We are speaking with people who have a health condition or disability about the Personal Independence Payment (also known as PIP). It is important to say that we don't expect you to have any prior knowledge about PIP coming into this discussion today. We are interested in hearing your views, regardless of how much certainty you have around them. The intention is not to test or judge your knowledge – there are no right or wrong responses to any of the questions we will cover with you. The intention of this work is to help DWP to improve the ways in which people who need additional support are able to access benefits in the future.</p> <p>It is important to say that everyone here today has a diagnosed health condition and or a disability. Everyone will experience these differently and brings different life experiences that will influence their views. We want to hear these and ask everyone to be respectful of the views of others. We will do what we can to support your full participation in this discussion, but if there is anything that we are doing or not doing that makes this difficult for you please do say. [NAME] is here to help me with this and you can reach out using the chat function or just by raising with us at any point in the discussion.</p> <p>We will take a short comfort break after the first 45 minutes of the discussion.</p> <p>[IF OBSERVER IS PRESENT]: We also have [NAME] who is observing our discussion today. They won't be participating and are just here to hear from people firsthand.</p> <p>I want to reassure you that whatever you say in this group will be treated confidentially – you will not be identified in anything we produce for DWP. Please be as open and honest as you can.</p> <p>I would like to audio record and take typed notes of the discussion today [IF ONLINE – this recording will also involve the conversation being transcribed on Teams]. This is purely so we have an accurate record of what you tell us today. The notes and recording will be shared with our research partners, the research agency Basis Social. Any notes and recordings will be deleted at the end of the project. Are you okay with this? We will also use the closed captioning function on Zoom as we find this can be helpful for people.</p>

	<p>Participation in this discussion is completely voluntary and you can withdraw your consent to participate at any point in the process, including following the session itself.</p> <p>Is everyone happy to continue with this discussion on this basis?</p> <p>MODERATOR TO CONFIRM CONSENT AND COMMENCE RECORDING.</p> <p>Do you have any questions before we start?</p>
5-15 minutes	<p><b>Introductions (10 mins)</b></p> <p><b><i>Objective: this section is to help introduce participants to one another to support a more open discussion.</i></b></p> <p>12. To start off, I would like to introduce myself and for you all to have the opportunity to say Hello to one another. If we can go around the room and say your name, perhaps where you are from, one thing you are really good at and one thing you need support with. I will kick us off...</p>
15-40 minutes	<p><b>Awareness and understanding of PIP (25 mins)</b></p> <p><b><i>Objective: this section is to help us to understand incoming levels of awareness, understanding and views toward PIP.</i></b></p> <p>13. Great. Lovely to meet everyone. To start off with, I would like to just a quick show of (physical or virtual) hands: how many of you were aware of the Personal Independence Payment (PIP) benefit before being invited to take part in this research?</p> <p>14. For those of you that already had some awareness of PIP, where (and when) did you first hear about PIP?</p> <p>15. OK, I'd like to just do a short exercise with you all, regardless of how confident you are in your knowledge of PIP you can participate in this. This is called a sentence completion activity. You can either use the chat for this, or you speak it out loud in a minute when I ask. I want you to complete the following sentence: 'PIP is a benefit for people who...' <i>Probe:</i></p> <ul style="list-style-type: none"> <li>• Where heard / sources of information</li> <li>• Levels of confidence</li> <li>• Examples of people that might be eligible for PIP</li> <li>• Examples of people <i>most likely to receive</i> an award</li> </ul> <p>16. What about people that are not eligible, or less likely to receive an award? Are there any common factors or characteristics that might make someone less eligible or less like to be awarded PIP?</p> <p>17. Thanks. I just want to dig into this a little more now. Talk me through what you know about PIP. Imagine you are explaining what it is to someone who</p>

	<p>had never heard of PIP before, how would you describe it in your own words? <i>Probe:</i></p> <ul style="list-style-type: none"> <li>• What heard about PIP</li> <li>• Sources of information</li> <li>• Levels of trust/confidence in what heard</li> </ul> <p><i>Moderator to explore differences in views between people.</i></p> <p>18. How do you think decisions are made around eligibility and entitlement for PIP? <i>Probe:</i></p> <ul style="list-style-type: none"> <li>• What they think the process of applying for PIP involves</li> <li>• Anything about that process that would concern them, if they were themselves to ever apply for PIP</li> </ul>
<b>40-50 minutes</b>	<b>BREAK (10 mins)</b>
<b>50-70 minutes</b>	<p><b>Considerations (20 mins)</b></p> <p><b><i>Objective: this section unpicks why people have or have not (and would or would not) consider applying for PIP.</i></b></p> <p>19. Has anyone considered applying for PIP themselves? If so, can I ask what were the circumstances that led you to consider applying? <i>Explore in depth:</i></p> <ul style="list-style-type: none"> <li>• Motivations for considering (i.e. what was happening in their life, when was this?)</li> <li>• Support accessed/available</li> <li>• How far they got with the process (e.g. seeking information, PIP1/PIP2 etc.)</li> <li>• What stopped them going forward with their application</li> <li>• Would you consider applying again in the future? Why/why not?</li> </ul> <p>20. For those of you that haven't applied, is there a reason for this? <i>Probe around following (use as a projective exercise if needed, i.e. other people have said....):</i></p> <ul style="list-style-type: none"> <li>• recency of their health condition</li> <li>• predictability/manageability of their health condition</li> <li>• support networks helping to manage</li> <li>• employment status (i.e. in work)</li> <li>• financial resilience (i.e. not financially in need)</li> <li>• financial value of PIP</li> <li>• lack of knowledge around PIP</li> <li>• capability of progressing a PIP application (e.g. due to condition or challenge of process)</li> <li>• stigma attached to benefits</li> </ul>

	<p>21. Are there any circumstances under which you would consider starting a PIP application (again)?</p>
70-85 minutes	<p><b>PIP assumptions (15 mins)</b></p> <p><b>Objective: this section looks to check on views/acceptance of common views expressed by PIP applicants in past research to understand extent to which influences their own perceptions.</b></p> <p>22. I wanted to get your reflections on some examples of feedback from PIP applicants about their experience claiming for PIP. [MODERATOR TO SHARE <a href="#">STIMULUS 1</a> ON SCREEN OR READ OUT]</p> <p><i>Group 1</i></p> <ul style="list-style-type: none"> <li>• 'In assessing you for PIP, DWP will look at what other disability benefits you are on.'</li> <li>• 'PIP is the same as DLA. If you've had DLA you should get PIP.'</li> </ul> <p><i>Group 2</i></p> <ul style="list-style-type: none"> <li>• 'Working is fine as long as you can still prove the difficulties exist, regardless of what job you do. Just be careful not to contradict yourself.'</li> <li>• 'You need as much medical evidence as possible to back up your claims.'</li> </ul> <p><i>Group 3</i></p> <ul style="list-style-type: none"> <li>• 'Certain health conditions automatically qualify you for PIP.'</li> <li>• 'The difficulty with anxiety and depression is that it fluctuates so much. I don't think PIP takes that into account.'</li> </ul> <p><i>For each of the above, probe extent to which they have heard these before and, if so, whether these have influenced the way they are progressing their own application.</i></p>
85-90 minutes	<p><b>CLOSE</b></p> <p>That is all my questions. Is there anything else you would like to add?</p> <p>Thank you very much for your time. This has been very helpful and will be used to inform the way in which PIP information is provided to people in the future.</p> <p>If you have any questions please do get in touch with us by email or phone. [NOTE THEY WILL HAVE RECEIVED THESE DETAILS ON THE INFORMATION AND CONSENT FORM – PROVIDED BELOW FOR REFERENCE]</p> <ul style="list-style-type: none"> <li>• Email: <a href="mailto:dwp.PIP@basisresearch.com">dwp.PIP@basisresearch.com</a></li> <li>• Phone: 08000 489 375</li> </ul> <p>There is a £50 shopping voucher to thank you for your participation. This will be processed in the coming week.</p>

# Appendix E: Bibliography

DWP (2018), 'Personal Independence Payment Claimant Research – Final Report', available [online](#)

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