





## Table of Contents

Acknowledgements.....	2
Introduction .....	3
Executive Summary .....	5
Key Findings and Our Recommendations.....	6
Our recommendations in full.....	7
Background .....	9
Methodology.....	14
Points to Note.....	15
Results index .....	19
Organisation and individuals' perspectives .....	19
Case studies .....	19
Survey responses.....	19
Results .....	20
Findings .....	41
Sources .....	97
Appendix 1 - The survey.....	100
Appendix 2 - Full statistical breakdown.....	111
Appendix 3 - DLA and PIP rates.....	112
DLA rates.....	112
PIP rates .....	114



## Acknowledgements

This report was researched, written and compiled by Alice Gaudet as part of the Student Experience Internship from the University of Manchester.

The report has been edited and published by the Healthwatch Trafford team.

We would like to thank all those people who told their stories about their experiences.

*We would also like to thank all the people and organisations that helped in the creation of this report, including:*

Age UK Trafford

Citizens' Advice Trafford

Greater Manchester Coalition of Disabled People (GMCDP)

Jane Forrest, Autism Support Co-ordinator, Cheshire and Wirral Partnership NHS Foundation Trust

Jane Hobson, Team Leader, Trafford Council Welfare Rights

MS Society

Richard Jones, Executive Director, Manchester Deaf Centre

Rick Burgess, GMCDP Executive and 'Recovery in the Bin' Facilitator

Sam Mountney, Senior Policy and Campaigns Officer, Epilepsy Action

Trafford Carers

Trafford Deaf Community Network (Trafford Deaf Club)

Trafford Deaf Partnership

The University of Manchester



## Introduction

This report has been produced by Healthwatch Trafford. The Healthwatch network consists of 152 Healthwatch organisations across each of the local authority areas in England. It also has a national body called Healthwatch England based in London. We are all independent organisations who aim to help people get the best out of their local health and social care services; whether it's improving them today or helping to shape them for tomorrow.

Everything we say and do is informed by our connections to local people and our expertise is grounded in their experience. We are the only body looking solely at people's experience across all health and social care in Trafford. As a statutory watchdog, our role is to ensure that local decision makers put the experiences of people at the heart of their care so that those who buy (commissioners) and provide our services (NHS Trusts, GPs, the voluntary sector and independent providers) can benefit from what Trafford people tell us.

Personal Independence Payment (PIP) was introduced in April 2013 as a roll-out system to replace Disability Living Allowance (DLA). Both benefits are awarded by the Department for Work and Pensions (DWP).

The North West region has one of the largest numbers of reassessed DLA claimants, and this type of claim constitutes half of the overall PIP caseload<sup>1</sup> According to DWP data<sup>2</sup> up to July 2018, Trafford Metropolitan Borough had 12,494 PIP claim registrations, of which 11,702 had been cleared. These people may have been awarded financial support, disallowed it, or their claim may have been withdrawn. Just over half (54%) of those whose claims had been cleared were granted PIP (6,261 people).

Eligibility is not means tested, and claimants can be either in or out of employment, but must be of working age (16-64). The system is designed to provide financial support to people with a disability, condition or impairment with the extra costs associated with their condition(s). It is composed of two elements: the mobility component and the daily living component. The living award has replaced the care award under the DLA system. Both elements can be awarded at two levels: either at a standard rate or an enhanced rate. In contrast DLA was awarded at three different levels: low, middle, and high. One of the key differences between the two systems is that PIP aims to assess need not on the condition, but on the impact of the condition on the claimant's life. [See Appendix 3 for information on the award rates for DLA and PIP.](#)

DLA claimants have gradually been invited to apply for PIP. Claimants must phone the DWP to start the application process and are then sent forms to fill in concerning how their condition affects them. They can also supply evidence. Most claimants are asked to have a face-to-face assessment, although some people are assessed on their forms alone. Claimants can request a home visit assessment and the DWP decide whether to grant one. The majority of claimants are asked to attend an assessment centre. Assessments in the

---

<sup>1</sup> Department for Work and Pensions, 'Personal Independence Payment: Official Statistics to July 2018' << [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/739224/PIP-statistics-to-july-2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/739224/PIP-statistics-to-july-2018.pdf) >> (11 September 2018), p 7.

<sup>2</sup> Department for Work and Pensions, Stat-Xplore statistics << <https://stat-xplore.dwp.gov.uk/webapi/jsf/dataCatalogueExplorer.xhtml> >> (11 September 2018).



North West are conducted by Independent Assessment Services (IAS), who are overseen by Atos. They have a contract with the DWP to carry out assessments and provide reports to the DWP who ultimately make the decision regarding the award. The assessment determines how much a claimant's condition affects their ability to carry out daily living and mobility activities, including things like cooking a meal and planning and making a journey, and what help they may need to do so. Assessors use a list of descriptors to assign a number of points for each activity, and these are used to determine the level and length of award granted by the DWP decision maker.<sup>3</sup> If claimants are unhappy with the decision they can ask for a Mandatory Reconsideration within a month of receiving their result. If they are still not happy after this they can appeal the decision, which is considered by a tribunal. This can be re-appealed, but after this stage the claimant cannot pursue the claim any further.

Healthwatch Trafford had heard that PIP claimants had faced a number of problems, both with the award they were granted and the application and assessment process. We were concerned that the change from DLA to PIP, far from improving the lives of people with disabilities, could in fact be having a detrimental effect. We contacted local organisations who support potential PIP claimants, individuals who wanted to share their stories as case studies, and gathered the experiences of a wider pool of Trafford PIP claimants through the use of a survey.

We have produced numerous reports in the past covering many elements of health and social care in Trafford. These can be found on our website at <https://healthwatchtrafford.co.uk/our-reports/> or by contacting us directly using the details on the back cover.



<sup>3</sup> Department for Work and Pensions, 'PIP Assessment Guide Part Two - The Assessment Criteria' (16 July 2018) << [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/725533/PIP-assessment-guide-part-2-assessment-criteria.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/725533/PIP-assessment-guide-part-2-assessment-criteria.pdf) >>



## Executive Summary

In light of the national media coverage of problems people were reported as having with the transition from Disabled Living Allowance (DLA) to the Personal Independence Payment (PIP), Healthwatch Trafford decided to look into the matter in our borough. The project was created to find out how Trafford residents involved in the PIP system had experienced and been affected by these changes.

We found that 86% of survey respondents described their overall experience of the PIP process as 'poor' or 'very poor'. More than half (60%) chose the most negative response; 'very poor'.

There are two elements of PIP awards: a daily living award and a mobility allowance award. Of those who had received the result of their claim, nearly three in five respondents (59%) experienced a decrease in their mobility award, and more than two thirds (68%) felt their financial stability and independence had decreased as a result of this. Almost two thirds (64%) reported a reduced standard of living as a result of the change to their mobility award.

A similar trend is shown regarding the living award respondents were granted. Almost half received a lesser amount (49%), and almost two thirds felt less financially stable (65%). Three in five respondents said their standard of living had decreased as a result of the change in their living award (60%).

To handle feeling less financially stable:

- 63% reported cutting back spending on bills including rent and heating
- 61% reported cutting back spending on food
- 49% reported cutting back spending on treatments or activities like counselling used to manage the symptoms of their condition
- 61% reported cutting back spending on social activities

Respondents reported that the level of award granted had an effect on their health. Two per cent who had received the result of their claim felt their physical health had improved because of their new award, and four per cent their mental health, but just over half (52%) reported a deterioration in their physical health, and more than three in five felt their mental health had suffered (62%).

The PIP application process itself had an even greater reported effect on respondents' health, with an average of 59% reporting a decline. A very small proportion (two per cent) felt their physical health had improved as a result of the process, and the same proportion felt it had had the same impact on their mental health. Over half (53%) said their physical health had deteriorated, and just under two thirds (66%) reported a decrease in the level of their mental health due to the PIP process.



## Key Findings and Our Recommendations

- We found that respondents overwhelmingly had a negative experience of the process.

**‘I’m just numb, I’ve resigned myself to not leaving the house, not having a life. I’ve cancelled my life from the autumn’**

**‘How much more can you put on one person? PIP’s just another thing to worry about. We should not be putting anybody or their carers through this’**

- We found that the majority of respondents felt their mental health had deteriorated, both as a result of their award, and of the application process. On average a third of respondents felt their physical health had also suffered.

- The proportion of applicable respondents reporting that they felt ‘very worried’ at different stages of the process ranged from more than a third (38%) to just over half (54%).

### Our Recommendations - in brief

- We recommend that local organisations who work with PIP claimants come together to share information and produce a comprehensive guide to the process.
- We recommend that Trafford Council review current council tax relief measures and consider what further support could be made available for PIP claimants, particularly if they receive no award while awaiting the result of a mandatory reconsideration or appeal.
- We recommend the Salford and Trafford Local Medical Committee and Trafford Clinical Commissioning Group review and change their policies on providing medical evidence.
- We recommend that Trafford Council and Transport for Greater Manchester review the provision of accessible community transport.
- We recommend Trafford MPs continue to speak up for their constituents who have faced difficulties under the PIP system.

“The PIP system definitely affected my mental health. I felt that I had to give my worst ever symptoms on the forms (my friend had to write it for me as I couldn’t bear the stress of having to describe my worst days), I had to share deeply personal and horrible information with a complete stranger at the interview who wasn’t properly qualified and doesn’t know me- only gets a glimpse of me in 1 hr to determine my life, despite other evidence from healthcare professionals. Surely testimonies from professionals that work with you should be enough rather than going through harrowing interviews. I felt dehumanised, degraded and disbelieved through the whole process, including on the phone. I am highly educated and yet they made me feel like an imbecile - I dread to think how people with learning disabilities and illiterate people are made to feel.”





## **Our recommendations in full**

### Working together

We recommend greater cohesion between organisations who support PIP claimants. We recommend opening a dialogue, potentially in the form of a regular forum. Attendees should include Trafford Council Welfare Rights, housing trust Welfare Rights Officers, Greater Manchester Law Centre, Greater Manchester Coalition of Disabled People, Advocacy Focus, Trafford CAB, local organisations like Trafford Carers, High Functioning Trafford, and other organisations and support groups in the Trafford area. By inviting conversation between those with different perspectives on the process, parties can be better informed, enabling them to better support claimants.

### Availability of information

We recommend a guide to the PIP process - including a flowchart showing what happens, complete with relevant contact numbers, timeframes, and advice - should be produced by those attending the forum. Details like the booking process for Ring and Ride, and phone numbers for local accessible taxi services should be included to help people get to assessments and to see their doctor for evidence. Welfare Rights drop-in sessions should be listed, and information on how to find condition-specific advice should be given. This would ease claimants' concerns at the start of the process, ensure they are fully informed of their rights and what to expect, and help them best prepare for each stage of the process. It would also improve signposting of services to boost efficiency. This should be distributed by Trafford Council to potential claimants and should be made available in GP surgeries and hospitals.

### Financial support

We recommend that Trafford Council introduce a form of council tax relief for people going through the mandatory reconsideration or appeal stage of the PIP process. This would ease the financial pressure while they receive a lesser amount of support than they feel they need and in turn prevent their health and wellbeing deteriorating further during this stressful time. We also recommend that Trafford Council review the list of persons exempt from Council Tax Support restrictions. The inclusion of PIP claimants receiving the enhanced living rate potentially doesn't take into account the needs and difficulties faced by claimants receiving other levels of award under PIP.

### Medical evidence

We recommend a review of the system for obtaining medical evidence by the Salford and Trafford Local Medical Committee and Trafford Clinical Commissioning Group. They should review the costs involved, and consider implementing a reduction or payment scheme for people in financial difficulty. The turnaround time for providing evidence should also be considered in light of the tight PIP deadlines. We believe that difficulties in obtaining evidence early on in the process affect claimants' feeling towards the process, and a stressful experience at this stage could impact on how they handle subsequent stages. A robust range of evidence provided should put the claimant in the best possible position at this stage of the process.





## Transport

We recommend that Trafford Council, in conjunction with Transport for Greater Manchester, review the provision of accessible transport in the Trafford area. This includes the availability and booking system for Ring and Ride, the number of taxis which are accessible for power-wheelchair users, and the advertising and eligibility criteria of schemes including the Blue Badge Scheme, travel vouchers, and 'Safer Journey Cards'. This would help claimants access medical and advisory services, reach their assessment centre, and maintain independence. A transport system specifically designed to take people to the more-commonly-used assessment centres should also be implemented.

## MP support

We recommend that Trafford MPs continue to raise PIP-related concerns in the House of Commons and commit to pledges such as Epilepsy Action's PIP Pledge and the MS Society's 'Scrap the PIP 20 metre rule' campaign. Stretford and Urmston MP Kate Green has been vocal on this subject,<sup>4</sup> but we recommend the current MPs for Altrincham and Sale West (Sir Graham Brady) and Wythenshawe and Sale East (Mike Kane) ensure the voices of their constituents are being heard.

## General

On a national level, key actions we recommend: all DWP-issued information and advice concerning the PIP process be available in a full range of accessible formats; the initial application form be reviewed and tested to ensure all types of condition can be fully represented in people's answers; review the contracts with assessment providers, and at the very least require more extensive and rigorous training for assessors and more stringent quality auditing; implement the recording of all assessments and automatically send applicants a copy of the claim report; work to reduce waiting times; and further consult interested organisations when making decisions concerning the process.

---

<sup>4</sup> They Work For You, Advanced search in debates, speaker "Kate Green" includes "PIP" << <https://www.theyworkforyou.com/search/?q=section%3Adebates+section%3Awhall+section%3Alords+section%3Ani&pid=24896&phrase=PIP&exclude=&from=&to=&person=&section=&column=> >> and in speeches , speaker "Kate Green", includes "PIP" << <https://www.theyworkforyou.com/search/?q=PIP&pid=24896> >>



## Background

One of our board members, in light of the national coverage of problems with the Personal Independence Payment (PIP) process, felt Healthwatch should look into the matter on a Trafford level. The North West region has one of the highest numbers of reassessed DLA claimants<sup>5</sup> and the project looked at how Trafford residents involved in the PIP system had been affected by the change from DLA. Some research has already been completed by other local Healthwatch on this topic: Healthwatch Brighton and Hove<sup>6</sup> looked at the impact of PIP and ESA (Employment Support Allowance) on vulnerable people in their area, and Healthwatch Kirklees<sup>7</sup> successfully campaigned for an assessment centre to be opened in Kirklees to prevent local people having to travel farther afield. We hope that in conducting this study Trafford PIP claimants have the chance to share their experiences and concerns, and we will be able to identify the key issues and propose recommendations to address these. Our preliminary research, guided by what we were told by organisations like Trafford Carers and Trafford CAB, identified the following areas of concern. The MS Society was kind enough to provide us with the data gathered for their report, 'A step too far?'.<sup>8</sup>

### System transparency

- In the course of hearing about claimants' experiences, it became apparent that communication of people's rights varied widely. We have heard that many people who would be better assessed in their own homes - rather than at an assessment centre - were unaware they could request this. We have found that many did not know they were entitled to see a copy of the report made on their assessment.
- Transparency issues also exist within the assessment report itself. We have heard people have been unable to find out what evidence they have provided has been used, and why. The use of informal observations in the assessment is also not disclosed at the time, which some people feel is unfair. We have also heard that sometimes these informal observations are used without taking into account the reliability criteria which should be met for any part of the assessment: that the activity can be completed safely, to a reasonable standard, repeated, and in a reasonable time.<sup>9</sup>

### 'Reasonable Adjustments'

- People also felt the system does not do enough to accommodate their needs, or make it easier to navigate the progress. Despite people's conditions, for example deafness, forming a central part of their application, the onus is on the claimant to

---

<sup>5</sup> Department for Work and Pensions, 'Personal Independence Payment: Official Statistics to July 2018' << [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/739224/pip-statistics-to-july-2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/739224/pip-statistics-to-july-2018.pdf) >> (11 September 2018), p.7.

<sup>6</sup> 'Personal Independence Payments and Employment Support Allowance - Examining the impact of PIP and ESA assessments on vulnerable people in Brighton and Hove' (February 2018).

<sup>7</sup> <https://healthwatchkirklees.co.uk/personal-independence-payment-pip-claimants-accessing-atos-assessment-centre/>

<sup>8</sup> 'PIP: A step too far', MS Society (2018).

<sup>9</sup> 'What are the 'reliability' criteria that are used during the PIP Assessment?' << <https://www.mypipassessment.co.uk/news/what-are-the-reliability-criteria-that-are-used-during-the-pip-assessment/> >>.



request an interpreter at their face-to-face assessment. They are unable to bring someone they know and trust, and instead have to work with a stranger who may not be as qualified as they feel they should be.

- Claimants can only reschedule their face-to-face assessment once, and people frequently find the first slot offered unsuitable. We have found people have been offered appointments far away, or with very little notice. Due to the nature of their condition(s) some people are unable to attend the assessment on the day itself, and their claims are rejected. Though this is appealable, the failure rates associated with all stages of the PIP process, paired with the additional stress of an extra stage, make this an undesirable outcome.
- We have also heard that some people are more successful completely reapplying for PIP after being unsuccessful in their claim. This can be more likely to change their result than pursuing a Mandatory reconsideration or appeal.

### Timescales

- We are also aware of issues with meeting the deadlines imposed by the DWP, particularly with obtaining appropriate evidence in the required timeframe. This is particularly relevant for people with limited mobility, or whose conditions may make it difficult to visit their doctor or contact them via other methods. The one-month deadline for returning the initial application forms can only be extended once, unless the claimant is deemed unable to go through the assessment process due to their health. Applicants who miss this one month deadline find their claims terminated.
- The guidance provided by the DWP and the contracted assessment providers (in Trafford, the North West, and most of the UK the provider is Independent Assessment Services, which is a part of Atos) is not always available in a sufficiently-wide range of formats as claimants require. Many need support with completing forms, and some we have heard from have spoken about the necessity of using specific language and phrasing in order to meet the criteria; something which many are unaware of or unable to do.

### The face-to-face assessment

- There is much in the media regarding the background of assessors, and many criticise the use of people including paramedics and occupational therapists, especially when assessing people with mental health or neurological conditions. There is much debate over whether assessors are adequately trained, and how much their assessment is taken into account over the evidence provided by the claimant like consultants' letters.
- Many feel that the lack of recording of assessments prevents a sufficient level of accountability on the part of the assessor. The company behind the assessment provider in the North West, Atos, says that claimants can record their assessment if they inform the provider beforehand and use equipment that can produce two identical copies of the assessment. This doesn't include the use of PCs, laptops, tablets, smartphones and MP3 players, but requires specific equipment which can be expensive.<sup>10</sup> The DWP (Department for Work and Pensions) has accepted that customers can ask the company conducting Work Capability Assessments for

---

<sup>10</sup> Scope, 'Is it possible to record my assessment?' << <https://www.scope.org.uk/support/disabled-people/money/PIP/faqs> >>



Employment Support Allowance (ESA) to make a recording, if they ask in advance, but this is not available yet for PIP assessments.

### Inconsistencies in the system

- Media coverage and issues raised in parliament have led to a number of legal cases and reviews of the PIP system. For example, in December 2017 the High Court ruled that the DWP's system was 'blatantly discriminatory'<sup>11</sup> towards people with mental health conditions in limiting support awarded to people who experienced psychological distress in relation to making journeys. Changes to the process since its implementation in 2013 mean that thousands of people's cases will need to be reviewed, putting them through the anguish of the process again.

### Condition-specific issues

- Problems specifically faced by people with certain conditions, often leading to disproportionate award refusal rates, have been the subject of numerous organisation reports and campaigns. For example, the Multiple Sclerosis Society's report, 'A step too far?'<sup>12</sup> focusses on the unsuitability of the 20 metre mobility rule for someone with the potentially-fluctuating and progressive condition. Rethink's 'It's broken her'<sup>13</sup> concerns those with mental health conditions, and Epilepsy Action's 'PIP Pledge' campaign<sup>14</sup> aims to make the process fairer for people with epilepsy. We have found that local people had concerns with the way claimants with certain conditions were assessed. Autism Spectrum Disorder was one such condition, or range of conditions, as it is hard to measure social interaction and communication in an artificial environment, and thus difficult to determine their effect on people's ability to do everyday tasks. As the conditions coming under this diagnosis are broad, even assessors with some specific training could potentially be unfamiliar with a claimant's condition. The assessment of 'intangible' or 'hidden' symptoms was also a cause for concern, particularly with regards to mental health conditions. Stigma surrounding mental health conditions and lack of insight into their impact on a person's life are common concerns regarding the way people with mental health conditions are treated within health and social care systems. We had been told about some of the problems faced by the Deaf community in Trafford, with repeated issues with the accessibility of the PIP system and availability of interpreters. This largely stems from a lack of understanding of Deaf people's day-to-day lives, and the ways in which they are able to access information and services.

### The impact of the PIP system and application process on claimants' condition(s)

- We have heard that repeated assessments for claimants whose condition is unlikely to change impose an unnecessary burden. People have told us about how difficult and upsetting it is to need to focus on their 'worst day possible' in order to maximise the chance of success. They say the system discourages them to think positively about their condition and its effect on their lives. Awareness of the high

<sup>11</sup> Greater Manchester Law Centre, 'Blatantly discriminatory' PIP criteria cost £3.6bn and 2.5 years of unnecessary suffering for claimants' << <https://www.gmlaw.org.uk/2018/07/16/blatantly-discriminatory/> >>

<sup>12</sup> 'PIP: A step too far', MS Society (2018).

<sup>13</sup> 'It's broken her', Rethink Mental Illness (2017).

<sup>14</sup> <https://www.epilepsy.org.uk/involved/campaigns/pip-pledge>



rate of cases going to appeal, and reports in the media that some assessments have recorded incorrect information may increase applicants' mistrust and anxiety.

- In some cases the MS Society report suggests the process has caused deterioration or relapse in people with Multiple Sclerosis<sup>15</sup> and the organisation Epilepsy Action told us the stress of the process can be a seizure trigger for people with epilepsy. The Rethink report 'It's broken her'<sup>16</sup> focusses on the negative impact of disability benefit assessments on applicants' mental health. People whose condition is fluctuating or progressive may see their needs increase, and so a decrease in their award can have a greater impact as time goes on. In fact, the MS Society found that, for people with MS, those with greater fluctuation in their condition had a greater likelihood of their award being reduced.<sup>17</sup> More than a quarter of those surveyed in the MS Society investigation also felt they were not given sufficient opportunity to explain the fluctuation of their condition.<sup>18</sup> In general we have heard that, despite the need for flexibility, many questions are closed, and yes/no answers provide little opportunity to elaborate.

What involvement does the local authority have?

- PIP decisions are made by the DWP, and are based on evidence submitted with the initial application form, the form itself, and the report made at the face-to-face assessment if one is required. The DWP have a contract with Independent Assessment Services who carry out face-to-face assessments. The local authority, Trafford Council, does not play any part in the PIP decision-making process.
- Local Medical Committees (LMC) advise Clinical Commissioning Groups (CCG) regarding their policing for providing medical evidence, but things like cost are decided on a surgery by surgery basis.
- Trafford Council currently offers some form of council tax relief for certain people.<sup>19</sup> If any member of a household is severely and permanently disabled, and the property has 'a room other than a bathroom, kitchen or toilet which the disabled person uses and needs, an extra bathroom or kitchen needed for the disabled person, or enough floor space indoors to allow the disabled person to use a wheelchair' the council tax will be reduced.<sup>20</sup> This form of relief is mainly applicable to people with physical impairments, and does not take into account other disabilities and conditions. For people aged 16-64 in receipt of the enhanced living rate under PIP most restrictions on Council Tax Support do not apply,<sup>21</sup> although awards are still not backdated. Guidance on this makes no mention of Trafford claimants receiving the standard living rate, or people receiving either level of mobility support. For Universal Credit (UC) recipients Trafford Council considers the start date of their UC claim as the start date for their eligibility for Council Tax Support. This is to 'ensure that vulnerable customers will not be placed into hardship and arrears with a liability for Council

---

<sup>15</sup> 'PIP: A step too far', MS Society (2018), p. 18.

<sup>16</sup> 'It's broken her', Rethink Mental Illness (2017).

<sup>17</sup> 'PIP: A step too far', MS Society (2018), p. 30.

<sup>18</sup> 'PIP: A step too far', MS Society (2018), p. 30.

<sup>19</sup> Trafford Council 'Reducing your bill' <http://www.trafford.gov.uk/residents/benefits-and-council-tax/council-tax/reducing-your-bill.aspx>

<sup>20</sup> Trafford Council 'Disabled Relief' <http://www.trafford.gov.uk/residents/benefits-and-council-tax/council-tax/reducing-your-bill.aspx>

<sup>21</sup> Trafford Council 'Council Tax Support - Protection' <http://www.trafford.gov.uk/residents/benefits-and-council-tax/benefits/welfare-reform-changes/council-tax-support.aspx>



Tax before Council Tax Support is claimed and credited to their account'.<sup>22</sup> No such provision currently exists for all PIP claimants, nor is there a system in place for people whose award may have been stopped while they pursue their claim to the Mandatory Reconsideration stage or appeal. Discretionary payments may be awarded to people of working age who struggle to pay their council tax, but this is the only form of council tax relief that could be applicable to all PIP claimants.

## State Obligations

- The aims and requirements of the Department for Work and Pension's provision of support for people with disabilities should be borne in mind. The Personal Independence Payment system replaced Disability Living Allowance on the premise that it would better take into account the effect of claimants' conditions on their day-to-day lives. People with disabilities should be protected from discrimination by the 1998 Human Rights Act,<sup>23</sup> and the Equality Act 2010 names disability as a protected characteristic.<sup>24</sup> This protection is strengthened by the UK's commitment to the United Nations Convention on the Rights of Persons with Disabilities.<sup>25</sup> The treaty is concerned with ensuring people with disabilities experience full enjoyment of their human rights, and parties to it commit to taking steps to promote, protect and enforce this. Article 19 regards the rights of people with disabilities to live independently and be included in the community. Article 20 requires parties to take measures related to personal mobility to ensure the greatest possible independence for people with disabilities. Article 21 concerns the freedom of expression and opinion, and access to information through all forms of communication of their choice.
- Concerns that the changes brought about by PIP are limiting disabled people's independence, impacting on their health and wellbeing, and generally reducing their standard of living suggest that the system does not promote, protect and enforce disabled people's rights. We have heard of specific examples where this does not seem to be the case, for example with information and guidance not being made available in a full range of accessible formats.

---

<sup>22</sup> Trafford Council 'Council Tax Support - Universal Credit (UC)' <http://www.trafford.gov.uk/residents/benefits-and-council-tax/benefits/welfare-reform-changes/council-tax-support.aspx>

<sup>23</sup> Article 14 - Prohibition of discrimination, Human Rights Act 1998.

<sup>24</sup> Chapter 1. (4), Part 2, Equality Act 2010.

<sup>25</sup> UN Convention on the Rights of Persons with Disabilities, which came into force in 2008 and was signed by the UK in 2009.





## Methodology

### Survey

We designed an online survey consisting of 40 questions. The first part determined who was answering the survey in relation to the claimant, the nature of the claimant's condition(s), and the stage of the process they had reached. This aimed to provide context to their following responses. The next few questions asked how they found the form-filling stage, face-to-face assessment, and how aware they were about their rights concerning home visit assessments and requesting a copy of their report. Respondents were asked to choose a descriptor for how they felt at specified stages of the process. The next section concerned whether respondents had experienced a change in either their mobility or living award, and the implications of this in terms of their financial stability and standard of living. Surveyees were then asked whether they felt their physical or mental health had been affected by either the change in award or the application process. After an opportunity to share any further information the survey closed with four questions to gather demographic information on the sample.

The survey was designed to balance closed questions, which are more easily analysed, with opportunities for respondents to share their views. Qualitative scales, such as 'very good' to 'very poor' were frequently used.

The survey was promoted on the Healthwatch Trafford website and using social media (sharing links on the Healthwatch Trafford Facebook page, tweeting, asking relevant local organisations to retweet, and relevant local organisations kindly circulating the survey to their mailing list and/or anyone they knew may be interested in responding).

### Case studies

In the course of the project we asked the organisations and individuals we contacted whether they knew of anyone who would be interested in providing an anonymous case study. Prior to this, Healthwatch Trafford attended the Trafford Carers Tea Party and Pampering event at Cresta Court Hotel in July 2018 and invited anyone with an interest in PIP to leave their contact details.

### Organisation perspectives

We approached a number of local organisations including Trafford Carers, Age UK Trafford and Trafford CAB to find out what their biggest concerns were. They helped us identify the key issues and provided some context for the report. We were aware of some organisations whose perspectives would be valuable to the project and in the course of conversations were recommended others. Several other organisations were approached but could not be contacted within their timeframe of the project.

This was an eight-week project partnered with an internship from the University of Manchester. This project took place between 16th July 2018 and 7th September 2018, with an 18-day data collection period.





## Points to Note

The online survey was completed, either fully or partially, by a total of 60 people, 54 of whom (90.0%) are Trafford residents. While this is enough to get a flavour of the experiences of Trafford residents' experiences of the PIP process, a larger sample size would paint a more comprehensive picture of the situation.

It should also be noted that there may be a response bias. PIP claimants who are unhappy with the support they were awarded, or who had problems with the application process may be more interested in sharing their experiences than people who are satisfied with the system. Conversely, it is possible that some who have been through the process may have had such a negative experience they do not want to 'go through it again' by sharing their experience. The claimant in Case Study 2 reportedly cannot bear hearing about PIP after their distressing experience.

Because the survey was aimed at people who have conditions, disabilities or impairments which affect their everyday lives, accessibility and capacity issues will restrict the respondent group. For example, in the timescale of the project it was not possible to produce the survey in Easy Read format, or Braille, nor provide it in a format using British Sign Language. This meant that people who would need the survey in a format other than written English or plain English were unable to share their experiences unless someone was able to help them or answer on their behalf. Accessibility limitations may also have affected these people's awareness of the survey in the first place.

Disabled people often experience some degree of isolation, particularly if they don't have a network or family and friends, and this isolation increases as people's health and wellbeing deteriorate. Mobility issues, caused by either physical or psychological difficulties, can also make some groups harder to reach. We heard in some conversations with organisations that some groups are less likely to access services regularly, and therefore are more disengaged with parts of the community, including the disabled community.

Our research shows that 73% of claimants, almost three quarters, felt they were less financially stable (Question 25) as a result of their PIP award, and 63% of these dealt with this by cutting spending on bills, which could include things like broadband. 61% cut spending on social activities, which could include attending groups where the survey was discussed. As a result of this some people may have been rendered more inaccessible as a result of PIP, and therefore less likely to respond to the survey. The survey shows that 66% of applicable respondents reported their mental health had deteriorated as a result of the PIP application process, and 62% due to the change in award. Again, this trend, if applicable to the wider Trafford PIP-claimant-population, may have prevented potential respondents from answering the survey.

### i. Manual adjustments

In a few instances responses were manually changed after collection where mistakes had clearly been made. For example, one respondent answered question 8, 'Which assessment centre did you attend?' by choosing the 'Other' option, and then specifying 'Home'. This response was moved from the 'Other' category to the 'I had a home visit' assessment, increasing the original number of responses from 11 to 12. Another respondent also selected 'Other', before specifying 'Manchester Central Office' which is an alternative



name for Trinity Way, Salford, which was an option. This response was also manually altered to fall into the total for 'Trinity Way, Salford', to accurately reflect respondents' experiences. An explanation is given below if necessary. Where there were inconsistencies, as opposed to clear mistakes, the correct answer could often not be determined. See below for more details on inconsistencies.

#### ii. Inconsistencies

During analysis it was noted that there are a number of inconsistencies in respondents' answers. For example, 11 out of 60 respondents answered question 7, 'Where did you have the PIP face-to-face assessment?' saying 'I had a home visit', but after the manual adjustment explained in (i). the total number of respondents who answered question 8, 'Which assessment centre did you attend?' was 12 out of 60. Where the 'mistake' is obvious, manual adjustments have been made as per (i). In the timescale of the project it is not possible to identify all inconsistencies. For example, 13 respondents out of the 54 who responded to question 4, 'At what stage of the PIP assessment process are you?' said they had not yet received a result for their claim. However, despite all 60 surveyees responding to question 18, 'Choose the best description of how you were feeling: when you received the result', only eight respondents reported not having reached the results stage. Five people who said they had not yet received their results in question 4 must therefore have answered some later questions related to their results. The numbers of respondents reporting they had reached specific stages of the process varies throughout the survey. We cannot therefore be sure at which point inaccurate information was given. This makes it difficult to accurately determine how many respondents have reached the relevant stage for each question for their responses to be applicable.

#### iii. Applicability

As respondents had reached a range of stages of the PIP process not all survey questions were universally applicable. While many concerned general experiences and information on the claimant themselves, some were specific to certain stages of the process. For this reason they were not applicable to all surveyees, who could either skip the question or preferably respond by selecting the 'I haven't got this far yet' response, which generally people did. Some questions were appropriate to the stage a respondent had reached, but still didn't apply. For example, in question 8 regarding assessment centre locations someone who had reached the assessment stage of the process, but was granted a paper-only assessment would be a broadly applicable respondent, in that they had reached the relevant stage, but where the location of their assessment centre was asked they would not be within the 'specifically applicable respondent' group, owing to the fact they didn't attend an assessment centre. Because different parts of the survey are relevant for different respondents, results tables show the proportion of applicable respondents giving each response, if necessary.

#### iv. Proportionality

One of the main ways in which survey responses were analysed was with respect to the type of condition respondents have. Pre-existing material discusses the difficulties faced by people with particular conditions, and we felt it was important to see whether responses varied based on the respondents' condition(s). To assess how representative the survey data is in this regard it would be necessary to compare the condition or impairment



breakdown of the sample with that of Trafford<sup>26</sup>. However, several significant issues prevent this.

Firstly, the earliest - and only - point of the PIP process at which type of disability is available as a claimant characteristic breakdown is at the 'PIP Claims in Payment' stage. This therefore does not include the details of claimants who, as of July 2018, had not finished the PIP claim process, nor those who had been disallowed the award or withdrawn from the process. Consequently, people with conditions which are disproportionately disallowed PIP will be particularly underrepresented.

Secondly, the DWP only refers to claimants' 'main disability'. In contrast, our survey asked respondents to categorise all their conditions, with no provision made for indicating their 'main' condition. Furthermore, from hearing from people during this project it is clear that many do not feel that, if they have numerous conditions, one necessarily has a greater effect on their lives, or if they do, then they are often unable to specify the impact of each individual condition.

In addition to these basic problems comparing the data would be problematic. The survey categorised conditions into five broad categories or types, giving a few examples of each, and had an option for 'other' conditions in cases when the categories are not applicable. They were:

- (1) Physical impairment (eg. Paraplegia, Multiple Sclerosis, Osteoarthritis)
- (2) Mental health condition (eg. Schizophrenia, Agoraphobia, Bipolar Disorder, Anxiety)
- (3) Learning or cognitive disability, or have experienced brain injury (eg. Down's Syndrome, Epilepsy, Stroke)
- (4) Sensory impairment (eg. hearing impairment, visual impairment)
- (5) Chronic illness or condition (eg. Cystic Fibrosis, Chronic Fatigue Syndrome)
- (6) Condition, disability, or impairment not falling within the above categories

These categories, hereafter referred to as 'survey categories', were designed to be easily understood, straightforward to answer, and were based on general information available on types of disability. However, the DWP data<sup>27</sup> lists conditions at three levels: 'Disability Category', 'Disability Subgroup', and 'Disability'. While, for example, the disability category 'Psychiatric Disorders' contains many conditions that would be comparable with those falling within the survey option 'mental health condition', some are potentially problematic or controversial. One instance is the inclusion of the subgroup 'cognitive disorders', which aligns better with survey category (3). Epilepsy is in a similar position regarding classification. The survey suggests it as an example in the 'learning or cognitive disability, or have experienced brain injury' category, but to improve clarity the term 'or neurological condition' could have been included in the survey category. This would ensure respondents answered in a more defined way which would aid categorisation. The subgroup 'learning disability global', including the disability 'Down's syndrome' in the DWP's categorisation falls into their disability category of 'Psychiatric Disorders', which again doesn't correlate to survey category (2), but rather survey category (3). Further issues arise regarding chronic illnesses. While in the survey these would generally fall into survey category (5), the DWP disability categories do not make any indication of duration.

<sup>26</sup> Department for Work and Pension, Stat-Xplore Official Statistics.

<sup>27</sup> Department for Work and Pensions, Stat-Xplore 'Field: Disability Category / Disability Sub Group' << [https://stat-xplore.dwp.gov.uk/webapi/metadata/PIP\\_Monthly/Disability.html](https://stat-xplore.dwp.gov.uk/webapi/metadata/PIP_Monthly/Disability.html) >>



For example, ‘whiplash injury’ is generally temporary, whereas conditions like Cystic Fibrosis are life-long. This makes it very difficult to divide the categories, subcategories, or even disabilities listed in the DWP’s system between survey categories (5) and (6) in order to make comparisons. Further issues arise as understanding and classification by the general public may differ from that of those who define the data analysis fields. An example of this is Muscular Dystrophy being classed by the DWP as a neurological disease, whereas in common understanding many would consider it to be a physical disability.

Because respondents could, and often did, have more than one condition, when subsequent responses are analysed in respect of the conditions of the respondent this presents problems with proportionality. For example, someone who is both blind and has a schizophrenia might say they found the overall experience of the process ‘very poor’. We therefore could consider their response as that of someone with a sensory impairment, or of someone with a mental health condition. Because it is unlikely the respondent can definitively say which condition is more responsible for their experience, and it is not possible to accurately determine from their survey responses, both conditions are taken into account. Their answers are therefore analysed as coming from someone with a sensory impairment and from someone with a mental health condition, as their response is no less valid than someone with a single condition because they have multiple conditions.

When looking at the breakdown of answers by condition, for example the proportion of people saying their assessor was knowledgeable and supportive (Question 9), it was necessary to consider the number of conditions experienced by the people giving the responses, rather than the absolute number of responses (‘response count’). For this reason some data tables may appear to show more respondents than the 60 people surveyed. Some variation occurs in the number of conditions ‘behind’ the respondents where different respondents chose to skip questions.

#### v. Anonymity

To protect surveyees’ identities their names were not asked and if they chose to provide contact information to receive updates this was separated from their responses. In some cases, for example in case studies, details such as age have been omitted, and changes may have been made to the gender and relationship of individuals within a scenario.



## Results index

### Organisation and individuals' perspectives

- [Richard Jones, Executive Director, Manchester Deaf Centre](#)
- [Sam Mountney, Senior Policy and Campaigns Officer, Epilepsy Action](#)
- [Trafford Deaf Community Network \(Trafford Deaf Club\)](#)
- [Jane Forrest, Autism Support Co-ordinator, Cheshire and Wirral Partnership NHS Foundation Trust](#)
- [Rick Burgess, Greater Manchester Coalition of Disabled People Executive and 'Recovery in the Bin' Facilitator](#)
- [Jane Hobson, Team Leader, Trafford Council Welfare Rights](#)

### Case studies

- [Case study 1](#) : Complex health problems, including osteoarthritis which affects, full body, heart disease, and diabetes.
- [Case study 2](#) : Family member who has a several mental health conditions including a severe long-term mental health condition.
- [Case study 3](#) : Partner has impaired mobility due to spinal injury & has been diagnosed with cancer so health is expected to deteriorate & needs increase.
- [Case study 4](#) : The legal appointee for niece who is profoundly disabled and has amongst other conditions severe learning disabilities and sensory impairments.
- [Case study 5](#) : The appointee for son, who has low IQ, moderate learning disabilities, and congenital heart disease.
- [Case study 6](#) : Cares for son, a young person who has autism.
- [Case study 7](#) : Helped her child, a young person with autism, with the PIP process.

### Survey responses

Due to the size and complexity of the results, it is provided in full in a separate document. <https://healthwatchtrafford.co.uk/wp-content/uploads/2018/10/HW-PIP-project-report-Appendix-2-Survey-Results.pdf>.



## Results

In addition to gathering the wider experiences of Trafford PIP claimants through survey responses, we also spoke to individuals. We asked a range of local people or organisations involved in working with or supporting PIP applicants about their experience of the system. We asked them what they felt were the issues faced by claimants, and how both the changes to award and assessment process itself can have an impact on people. We also spoke to some PIP claimants or their families about their personal experiences. We are very grateful to them for sharing their stories.

---

We met **Richard Jones, Executive Director, Manchester Deaf Centre** in August 2018. A qualified British Sign Language interpreter facilitated communication.

Richard said that, to start with, government-issued information surrounding PIP is not accessible. Completing the initial stage of the application process is challenging. Written English is not the first language of most Deaf people, and other formats including Video Relay carry their own problems. Manchester Deaf Centre's (MDC) Sensory Service Team can help claimants filling out forms by prior appointment.

**'The assessment is the problem, it seems to be a backwards process. The assessors decide what is written'**

Richard had believed the assessment would be a follow-up to the already-completed paper forms, but in reality it seemed as though the information already supplied hadn't been considered. He criticised the fact Deaf people are assessed by hearing people, as they haven't been through the same experiences, attitudes, perception, and barriers. Although Deaf people can describe their situation and their day-to-day lives, a hearing person will never fully understand, let alone be able to capture in a short conversation facilitated by an unfamiliar interpreter. He also said **'a Deaf person is more disengaged'**. To assess a Deaf person based on their interaction with others within the assessment room is not a fair representation of their everyday lives, as their experience of engaging with others in the outside world is very different.

He also said he wasn't surprised that mental health conditions worsen in people going through the PIP assessment process, but that for many Deaf people are used to such difficulties.

**'They have to be resilient, they expect it to be tough as that's how it's been all their life.'**

Richard said confidence was an issue for many Deaf people during the assessment process, as they were **'frightened to say something in case it was 'wrong''** or could damage their claim. He said it was hardest for those with no condition other than a hearing impairment as their impairment is invisible, and those with other additional disabilities can come



across as a more obviously deserving claimant, or can at least rely somewhat on the assessment of their other conditions.

He highlighted the difficulties the Deaf community already face. 20% of Deaf people are unemployed compared with the national average of 4%, meaning that many are dependent on welfare support. He said a third of Deaf people have mental health problems, compared to one quarter nationally, and so added stress and worry can have a big impact on people's health.

Of the tribunal cases he's aware of, only 2 out of 30 cases were not overturned, but in order to reach the appeal stage people face many issues in a drawn-out process.

**'The horror stories are continuing.'**

Manchester Deaf Centre works in partnership with the University of Manchester Free Legal Advice service to provide simple legal advice, and Network Circle of Deafness, an advocacy service.

---

We spoke to **Sam Mountney, Senior Policy and Campaigns Officer, Epilepsy Action.**

Epilepsy Action saw a spike in calls to their helpline regarding PIP in mid-2017. The organisation reports that people with epilepsy are disproportionately losing out - 60% of those transferring from DLA received a lower amount or had their award taken away, which is greater than the level for any other condition. In July 2018 a written question<sup>28</sup> to the Minister of State, Department for Work and Pensions, revealed that of 7,690 PIP claimants with epilepsy, 5,150 (67%) were granted no award. Of these only 630 appealed to a tribunal (12% of claimants granted no award, 8% of all PIP claimants with the condition). Epilepsy Action suggest that people who have less support through the process are the ones who drop off at this stage. Two thirds of those who appealed were successful in having the verdict overturned.

He described the process as 'stressful' and 'very demoralising', and said it can be a very protracted process, with long waits for appeal dates. This can have an impact on claimants' mental health, with stress being a seizure trigger for some people. The organisation is aware of increased seizure rates during the PIP process - **'the process can be a very thankless task'**. He suggested this put people off continuing with the process and going on to appeal, particularly with the lack of interim support available.

**'The waiting time is completely unacceptable - there needs to be some kind of support for people going through the process.'**

A landmark ruling in March 2017, called the 'RJ' ruling, changed how the DWP assesses whether claimants can carry out activities safely and need supervision to do so. This court case made assessors consider not only the frequency of the risk of harm, but also the

---

<sup>28</sup> 'Personal Independence Payment: Epilepsy: Written question - 162167'  
<https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2018-07-09/162167/>





severity. This is particularly important for people with conditions like epilepsy, as though people may experience seizures on less than 50% of days, when they do experience them the consequences can be very severe. Although the ruling has made people with epilepsy feel more positive about the PIP assessment process, it is still too early to tell if the change has made a marked improvement, and potentially there is concern that the RJ case, as the first focussed on this point, may have made a rushed judgement. Another area which concerns them is claimants not being awarded points even when they need assistance administering rescue medications during seizures.

Epilepsy Action launched a PIP pledge campaign, urging MPs to fight for fairer PIP process for people with epilepsy, and this was included as evidence in the second independent review of the PIP assessment.<sup>29</sup>

He felt the assessment was geared towards physical disabilities not neurological conditions or mental health conditions. Although he appreciates that PIP focusses on the impact of the claimant's condition, rather than the condition itself, he said the assessors carrying out the work capability assessment of ESA were generally more knowledgeable about conditions - **'the assessment is not suited to capturing and reflecting what life is like'**.

**'PIP is a bit of a perfect storm for people with epilepsy.'**

---

We attended a social meeting of **Trafford Deaf Club** on Thursday 16<sup>th</sup> August 2018 at Sale Excelsior Club. Roughly 20 members were present, and a qualified British Sign Language interpreter facilitated communication.

Nine people present had been through, or were going through, the PIP application process. They were unable to complete the survey as written English is not an accessible form of communication for many members of the Deaf community, but through group discussion and some individual conversations the following points were raised.

**"I'm really disappointed with this country and the way they treat Deaf people."**

Several people said they were 'very worried' about applying for PIP. They feel that the DWP don't listen to the British Deaf Association, or campaigns for improvements to the treatment of the Deaf community. From the very start of the process people face barriers. **"No-one is willing to explain and help with the form."** Several people had problems with the use of minicom, which relies on people's ability to read written English very quickly. As English is not most Deaf people's first language this is very difficult and can be impossible to use. Issues with the new Video Relay service were also reported. Others told of difficulties understanding the signed videos the DWP has produced explaining the PIP process. One lady said that it took her four weeks just to gather all the information and evidence required. A member of the group had received support from Trafford Council Welfare Rights with completing the forms, and having an advocate go with them to the assessment. Another said that Kate Green, MP for Stretford and Urmston, had been involved with the Trafford Deaf partnership.

---

<sup>29</sup> Paul Gray, 'Personal Independence Payment (PIP) assessment: second independent review', (March 2017).



**“You definitely need an advocate as the interpreter can’t help.”**

**“There’s no social worker for the Deaf. You get signposted to loads of different places because no-one knows what to do, it’s a joke.”**

- Issues with interpreters were almost universal, both in terms of concern over their qualification level, and their unreliable attendance.

People in the Deaf community often have varying levels of familiarity with BSL, lip reading, and written English. Communication and accessibility are frequent problems. While some variation between interpreters is inevitable, assessment providers only require BSL/English interpreter to be a Level 2, whereas the National Registers of Communication Professionals working with Deaf and Deafblind People requires a Level 6 qualification to be considered for their approved register. Registered interpreters carry a yellow ID card. Trainee sign language interpreters are not permitted to work in the legal domain, and yet it has been reported that they are being used by assessment providers for PIP assessments. This can cause problems not only with claimants’ confidence in the interpretation and in fully communicating, particularly with details like medical terms, medication dosages, and jargon. Different hospitals in the area tend to use certain interpreter agencies, and some are known to be better than others, and this seems to also be the case with interpreters involved in PIP assessments. Claimants reported this leads to a lack of confidence in the interpretation they received, which in turn adds to the stress of the process. An unqualified (below Level 6) interpreter could be an unfair disadvantage to claimants.

**“I feel Deaf people should be able to pick their interpreter - we don’t get offered the choice.”**

One lady received a phone call at 8pm but was busy, and as it was evening didn’t try to answer. When she arrived at her face-to-face assessment the interpreter was there but the assessor was not. She followed this up and discovered the phone call had been to inform her that the assessment had been cancelled, and the assessor, presumably not reading the claimant’s notes, had left her a voicemail message. She also experienced a correspondence letter related to her application being lost, and this combined with the rescheduled assessment and wait made the process last several months. Another lady’s face-to-face assessment was rescheduled over and over again due to cancellations - the location of the first assessment she was offered was unsuitable for her to get to; the next she arrived at the centre and found the assessor and interpreter had been booked for different times; and the next time no interpreter turned up. People reported similar situations with medical appointments - one person had three appointments in a row where no interpreter showed up, and at the last one found out an interpreter hadn’t even been booked for that appointment. Others reported similar experiences with accessing general health and care services - with one person arriving for a hospital appointment in good time, checking an interpreter would be attending, and then having to wait for 1 hour 40 minutes after their scheduled appointment for an interpreter to show up. When they did they said the hospital had only booked them an hour earlier. People repeatedly described cancelled appointments as ‘a waste of time’, particularly in light of the distance many had to travel.

**“It makes me sick the way some people fob me off.”**



- Physical accessibility was also a problem for many.

The majority of those in attendance who had applied for PIP had their face-to-face assessments in Stockport, which is awkward to get to by public transport, and difficult to park close to for those travelling by car. **“I didn’t feel comfortable at all, if you don’t know the area it’s really hard.”** One person reported being asked to go to an assessment in Liverpool, and one in Newcastle. Generally getting to assessment centres was a common problem: **“It was a joke, I had to get up really early to get there, the traffic was awful, and it was a rough place, I didn’t feel comfortable.”**

- The general impact of PIP on people’s health and wellbeing was also discussed.

It has been suggested<sup>30</sup> that mental health conditions are more prevalent amongst Deaf people. The comments below demonstrate the effect of the process on the group’s wellbeing, and their feelings towards PIP.

**“It really affects your mental health, I want to sue them!”**

**“I was knocked in confidence, really down, grumpy, angry, it really affects your mood”**

**“We came out, minds worrying about whether we were going to be successful or not”**

**“I felt very emotional”**

**“It’s very cruel”**

In light of these problems, some of which are specific to the Deaf community, someone suggested the DWP panel which makes decisions on whether to award PIP should contain a Deaf person. They also felt that organisations supporting Deaf people were not sufficiently consulted during the planning of the PIP system, or that their views were taken into account.

There was also an opportunity to hear from an interpreter who supports Deaf people in a range of situations, and has been involved in interpreting PIP face-to-face assessments. They reported that the key issue and reason why interpreters don’t show up is service providers leave it until very late to book an interpreter. This mirrors one man’s complaint that he arrived for a hospital appointment in good time, checked an interpreter would be attending, and then had to wait for 1 hour 40 minutes after the scheduled appointment time for an interpreter to show up. When one did they said the hospital had only booked them an hour earlier. The interpreter present at the social says that in their experience Independent Assessment Services (IAS, delivered by Atos) often tries to book interpreters

---

<sup>30</sup> SignHealth, ‘Mental Health’ << <https://www.signhealth.org.uk/about-deafness/mental-health/> >>



3-4 days ahead of the assessment date. This frequently means that interpreters aren't available for the required time, or potentially that less-qualified interpreters are used. They also said that PIP assessors and interpreters don't always realise the importance of body language to a Deaf person. They themselves interpret tone of voice as part of their interpretation, and says that sometimes during PIP assessments this means conveying when the assessor speaks harshly. They also reported that Deaf claimants were often very stressed during the assessment, mainly because they were worried about losing out on money they rely on, and this could affect the way in which they responded to questions.

---

We spoke to Jane Forrest, Autism Support Co-ordinator, Cheshire and Wirral Partnership NHS Trust, in August 2018.

Trafford Autism Partnership Board meet quarterly to discuss the Autism strategy in Trafford. A representative from DWP, who is a decision maker in the PIP process, attended their last meeting in June 2018. They generally come across people with Autism who are facing issues with applying for PIP at their bi-monthly post-diagnostic drop in sessions. They find a lot of the people who attend are those who do not engage with many other services, but panic when they receive the letter inviting them to apply for PIP. Many don't have anyone to support them with applying, and they can help with filling in the form and obtaining evidence, and sometimes can provide someone to accompany claimants to their face-to-face assessment. They often work in conjunction with Trafford Carers and Trafford Council Welfare Rights, and they sometimes refer people to Welfare Rights, particularly with appeals.

The key issue they experience is the 'really poor understanding' of Autism across the range of people involved in the PIP process. The assessors used by Independent Assessment Services (which comes under the wider body Atos) can be nurses, occupational therapists, paramedics or physiotherapists. The board has heard from many claimants they support that, without specialist training in Autism and experience of developmental disorders, these professionals don't understand their condition and the difficulties they face. In one instance, they supported a claimant with completing the form and providing evidence, and provided them with a companion to accompany them, and the result awarded the individual zero points, meaning he would receive no support under PIP. When they requested to see the report that had led to this result, it took over a month to arrive, which surpassed the one-month deadline set for requests for Mandatory reconsideration. As a result of this they had to call repeatedly, often being kept on the line for long periods of time, to ask for an extension. They found that call logs had not been properly kept which caused difficulties tracking the progress of the request. This in turn added to the claimant's stress. The report, when it arrived, was not representative of the conversation that had happened.

**'The sticking point is assessors who don't properly understand what people present, both in terms of evidence and what's in front of them. People often don't have regular specialist therapeutic support, and it seems that family members' evidence isn't considered as valuable. The problem is in interpretation of the information we provide.'**



One of the issues that occurs with providing evidence for people with autism is that many haven't engaged with services since their diagnosis, and as that may have been some time ago the only paperwork they can provide is their diagnosis letter. This is written from a different perspective and as such doesn't specifically address the indicators looked for in PIP, which has sometimes, erroneously, led to suggestions of conflict with other evidence provided.

Both those working to support claimants with autism, and claimants themselves are aware of some of the other problems faced. Questions asked during the assessment which lead to observations can 'catch people out', for example asking how they travelled there. Not everybody is aware of this, and may not answer accurately, for example failing to explain any difficulties they faced. Awareness that there may also be targets in place for the assessors to meet also causes concern. Time pressures are also challenging. For many people with autism, seeing a long form is stressful; they don't know how to break it down and so struggle to fill it out.

**'The form is really intimidating, so people put it off for a long time which makes things even harder.'**

The elongated-nature of the process can also add to anxiety. A claimant they supported recently was offered a face-to-face assessment in Wigan, and although this caused travel difficulties, she 'couldn't bear to wait for another appointment.' Mobility difficulties associated with autism often are not considered, with little focus on how stressful travelling and getting out can be for people. The board reports that in their experience, people's health and wellbeing deteriorate going through the PIP application process, which is often intimidating and leads to added anxiety.

For one claimant who had had a lifetime award under DLA - meaning they was not required to be assessed again under the old benefit - the change to PIP has been very distressing.

**'This person feels as if they're having money that was promised to them taken away. They cannot get their head around the fact that, to them, they're losing out. This claimant is currently going through the Mandatory Reconsideration stage and, until this point, has only had support from their family. For people going through any part of the appeal process there is no financial support provided at this stage, and lack of compensation increases financial worries. They say to us, "I can't afford to pay for food, or to pay my bills".'**

Someone raised the point at a recent board meeting: if there's a GP and a diagnostic team who know the person well, and these professionals have said what they think the person is entitled to, why bring in third parties who don't have any specialist knowledge? Why employ autism experts in the first place?

**'Why have a lengthy, bureaucratic process, which causes a huge amount of stress for people, when they have a formal diagnosis?'**



We spoke to Rick Burgess, Greater Manchester Coalition of Disabled People Executive and ‘Recovery in the Bin’<sup>31</sup> Facilitator in late July 2018 about his experiences and perspective on the PIP system and process. Rick has identified as disabled for roughly 15 years, and started blogging about disabled people’s rights in the early 2000s, around the time of many welfare reforms.

### PIP: Aims

Rick believes that by making cuts to welfare and legal aid in close succession, it can be inferred that the government did not act in good faith.

**“It’s an assessment for people who cannot apply without assistance, and they’ve cut the assistance. It’s blatant discrimination.”**

He is also critical of the extent to which the government consulted organisations and charities that support people with disabilities. For example, in a consultation<sup>32</sup> on the ‘Moving Around’ part of the assessment and the 20m rule he said they failed to take into account their more informed views. 95% of responding organisations<sup>33</sup> and 78% of individuals<sup>34</sup> thought this element of the assessment should be changed.

**“Instead of taking away barriers it creates them.”**

He also said that the proportion of Mandatory Reconsiderations (MR) which don’t result in change, paired with reputedly discarded<sup>35</sup> targets<sup>36</sup> aiming to uphold 80% of decisions make the MR stage pointless.

**“It’s putting people through the process for no point, hoping they’ll drop out of the process.”**

### The system

**“The system can work if you put in the right effort, but many don’t know how - and some don’t have the capacity to.”**

He said it was difficult to assess the process as ‘it’s dynamic at every stage’, with people entering and dropping out all the time. He also suggested that potentially Trafford has a number of ‘hidden people’ - potential claimants who could afford to not be a part of the system, and therefore do not appear in statistics. Rick felt the DWP PIP admin system is

<sup>31</sup> << <https://recoveryinthebin.org/> >>

<sup>32</sup> Department for Work and Pensions, ‘The Government’s response to the consultation on the PIP assessment Moving around activity’ (October 2013) <<

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/251631/pip-mobility-consultation-government-response.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/251631/pip-mobility-consultation-government-response.pdf) >> at 3.2, p 11.

<sup>33</sup> 122 of 129 organisations consulted in the government’s consultation on the moving around activity in the PIP assessment, as recorded in the report referenced the previous footnote, at 3.2.

<sup>34</sup> 792 of 1013 individuals consulted in the same report, at 3.2.

<sup>35</sup> Work and Pensions Committee, ‘Victory for claimants as Government agrees to drop MR measure’ (December 2017) << <https://www.parliament.uk/business/committees/committees-a-z/commons-select/work-and-pensions-committee/news-parliament-2017/reform-pip-esa-process-statement/> >>

<sup>36</sup> Department for Work and Pensions, Freedom of Information request (May 2017) <<

<https://www.whatdotheyknow.com/request/402400/response/978248/attach/2/FOI%201740%20response.pdf> >>





intentionally difficult to navigate to deter people or set them up to fail. He said it doesn't make it clear that there is an email address that can be used to request reasonable adjustments, leaving people to try to use the poorly managed phone helpline.

**“When they do make mitigations they are really grudging and try to change as little as possible.”**

He said it's very difficult for claimants to have a paper-only assessment, (ie. not requiring a face-to-face assessment,) even for those for whom a face-to-face appointment would not be productive, or would be very distressing. He believes cost and target rates influence whether people are granted a home visit. Assessment providers are obstructive, and home assessments are very difficult to obtain in order to meet time targets and reduce costs. Many believe this situation is maintained because the assessment providers are satisfied with the results this system produces, which make significantly greater savings than was originally planned. Another common issue is with providing evidence, and particularly with obtaining it in the tight timeframe. Whether surgeries charge for evidence letters is decided on a surgery-by-surgery basis, and therefore is down to the decisions of Clinical Commission Groups (CCGs). Local Medical Committees (LMCs) give advice regarding healthcare providers providing evidence for things like welfare support claims, and Rick has heard that some committees have reportedly been told in presentations by assessment providers that medical evidence letters are not used in the assessment.

**‘No matter how strong a case you present, if you meet a brick wall it's a brick wall.’**

### The impact of PIP

**‘It's traumatic for people because you have to face your impairments and the barriers you face.’**

**‘When it's your life on the line it's paralysing’**

Rick said that in his experience people find it easier to support others than deal with their own case. In one case he's supported someone with, the claimant had had physical and mental impairments from a young age. The PIP process triggered post-traumatic stress disorder (PTSD), leading to them having to engage with crisis mental health services. The only way they were able to get through the assessment process was to have a purely paper-based assessment, and even then this was by no means straightforward, and required weeks of gathering information. In another situation he witnessed a 'strong person with a stable support network' go through the process and end up 'on suicide watch - it almost destroyed them. The process completely floored them.' Rick also reports increased cases of self-harm and suicide or suicidal thoughts amongst claimants, and said there is a need to increase the capacity of the community mental health team. Some people he knew of had ended up in crisis needing emergency intervention, having not previously been mental health system users. The process can trigger flashbacks and PTSD for anyone who has faced trauma, and this can result in risk-taking behaviours and substance abuse. Some assessments involve a physical examination, and Rick reports that people have been left injured after this. As people's financial situation worsens, they are likely to stop opening important mail concerning their benefits.

**“It becomes a perfect storm and they shut down.”**





If a claimant fails at re-appeal their only option is to reapply and go through the whole process again.

**‘Even for those who aren’t struggling as much financially, it’s the difference between surviving and thriving.’**

### Knock-on effect

He talked about the financial implications of the changes - though the DWP are cutting costs, in reality local councils have to make a greater social care contribution, particularly as people’s conditions worsen going through the assessment, which further increases the strain. More generally higher demand is being placed on crisis intervention, welfare checks, therapy, policing, and so on, and without further support targeted at PIP claimants the increased demand on these services will only increase. Early intervention is financially sustainable and ethical, rather than having to ‘pick up the pieces’. Withdrawing support can have a further ‘domino effect’ on the disabled community: disabled people without British citizenship, including asylum seekers, who often cannot apply for PIP, are often extremely isolated, and disabled members of the community who would usually support people in more marginalised groups can no longer do so if their independence is reduced.

### Sources of support

There are a number of organisations and support groups that could potentially help in the Trafford area, often aimed at supporting people with specific conditions. However, sometimes these organisations are no better placed to navigate the system and lack in-depth understanding. Rick is an executive of Greater Manchester Coalition of Disabled People (GMCDP), who ran a successful ‘Benefits Self-Defence’ two-day workshop in June this year. This was aimed at helping claimants navigate benefits systems, including that of PIP. He said GMCDP creates a much-needed peer-support network and understands the difficulties that other support systems face. For example, services where you need to book ahead create barriers, both practically, as many disabled people face mobility and travel issues in addition to varying health levels, and for people who are harder to reach in the community. GMCDP instead offers drop in sessions which better accommodate ‘hard to reach’ people. GMCDP is potentially applying for funding from the Building Connections Fund, distributed by the Big Lottery Fund for a project tackling loneliness and isolation. For those appealing unfavourable decisions, both council welfare rights teams, advocacy services like Fightback4Justice, a paid service in the North West, and Greater Manchester Law Centre can help, although due to oversubscription some can only deal with deal with certain stages of the process.

### Recommendations

Ideally the development of a specific advice service would greatly help people. Current general-advice providers (like council welfare teams, and the CAB) have insufficient capacity, and because advice is needed within a strict timeframe, streamlining the approach would make the process more efficient. He also says better signposting to other



services is needed, particularly as many claimants are likely to experience isolation. For people still going through, or are yet to go through the process, Rick highly recommends recording face-to-face assessments, or having someone there to take notes. He personally has created a recording kit which meets the DWP's requirements, and potentially other organisations and support groups could follow suit. Although a commitment to record all assessments has been made, he is concerned it will not be fully rolled out for some time, and until it is assessment fraud will continue. For organisations involved in supporting claimants in any way, he suggested a flowchart guiding claimants through the application and assessment process, and another for the appeal process would be useful, with timescales and tips included. He also suggested a policy where councils 'ease off' payments like council tax while a claimant is going through the appeals process, as they are likely to be struggling financially.

**“To be honest at the moment it’s firefighting, there isn’t going to be change any time soon”**

**“It’s the disability benefit which disables you.”**

---

We spoke to **Jane Hobson, Team Leader, Trafford Council Welfare Rights** in early August 2018.

Just over 30% of calls Trafford Council Welfare Rights (TCWR) receive on their advice line are regarding PIP, and many of the calls and emails they receive are the result of referrals from other services and organisations, including Community Mental Health Teams and social workers. They hold appointment sessions once a week at six locations across the borough, and can arrange home visits if necessary. They can help people fill in their PIP forms, in addition to forms relating to other benefits including Employment and Support Allowance and Universal Credit Work Capability Assessment, and can support people to legally challenge unfavourable decisions.

**‘People are full of trepidation before it’s even started, having heard all the horror stories.’**

The forms are long and challenging, especially considering the fact that many claimants potentially have reduced capacity. The way in which people have to explain their condition and its impact on their lives is also difficult to achieve successfully: **‘The majority don’t know how to channel it.’**

Most people need to have a face-to-face assessment as part of the PIP decision making process, and this stage is the source of many complaints. In many cases, particularly when the claimant has a mental health condition or learning difficulties, a face-to-face conversation is not a good way to assess them, and can be a risk to a claimant’s success. TCWR advise people to give as much extra evidence as possible with the form. In their experience people have been asked to attend assessments the following day in Warrington or Liverpool, not with the 7 days’ notice, in writing, as is required. If they were unable to attend this, they were put on their second and final chance to attend an assessment. This meant they had to go to the next appointment offered, or be referred back to DWP,



recorded as ‘failing to engage/attend’, which could potentially terminate their claim. For one claimant, the companion they needed to accompany them was unable to attend on the rescheduled date. Frequently, the first assessment appointment offered is far away, and potentially more at the IAS’ convenience than the claimant’s. In many cases vulnerable claimants miss appointments because they are unable to get there; don’t have a companion to attend with them; are not feeling well enough on the day; or haven’t been opening letters, particularly as a result of mental health conditions.

**‘Whatever happens at the assessment, people feel totally undermined.’**

The majority of tribunal appeals they are involved in concern PIP cases, and over the last year they have been aware of more appeals, in line with national figures. They believe Trafford’s figures are fairly representative of Greater Manchester and the UK as a whole. Many appeals they come across are for cases where the claimant is transferring from DLA to PIP, as it’s more difficult for those who have been reliant on DLA. They find the timescale between first filling in an appeal form and receiving the verdict is often over nine months. The TCWR team write a submission outlining the relevant facts, and refer to law and case law, using evidence that they have often obtained for the appeal specifically. When they compare this to the DWP report it is generally clear what the decision should be. In several cases this year they have arrived at the tribunal venue to find that the tribunal has already made the decision to allow the appeal. In a few such cases no further evidence was provided: these cases were failed by DWP, but passed on exactly the same evidence at tribunal. In the copies of reports TCWR see there is no consistency, and comments seem to be totally subjective and misrepresentative of what was said during the assessment. At a Bar Council event in 2017 Sir Ernest Ryder, Senior President of Tribunals, said that the quality of evidence provided by the DWP was so poor it would be ‘wholly inadmissible’ in any other court,<sup>37</sup> and suggested around 60% of appeals were ‘no-brainer’ cases. The fact that in so many appeals the verdict is overturned so quickly suggests there is something seriously problematic about the process. Few lodge complaints with the DWP or the assessment service provider IAS.

**‘It takes all of the claimant’s efforts to apply, the tribunal appeal is very traumatic, and so they don’t challenge the DWP.’**

The fact that such a high proportion are unsuccessful at the Mandatory Reconsideration (MR) stage, but then have their result overturned at tribunal suggests strict refusal targets may still exist, and that the MR stage is designed or used to deter people from challenging the decision.

**‘People find the whole process demeaning.’**

Stress caused by the process can only impact on claimants’ health, especially for people with mental health conditions, and this is why care coordinators need to work so closely with Welfare Rights teams. Jane said Greater Manchester Mental Health Team (GMMHT) is overstretched and currently fully occupied with helping people claim benefits, because without that stability they are not going to get better. PIP review forms are often sent 12 months ahead of review assessment, with the warning that if they’re not returned by the

---

<sup>37</sup> Disability Rights UK, ‘Senior Judge says DWP evidence to tribunals so poor it would be wholly inadmissible in any other court’ (November 2017) << <https://www.disabilityrightsuk.org/news/2017/november/senior-judge-says-dwp-evidence-tribunals-so-poor-it-would-be-wholly-inadmissible> >>



deadline PIP will stop. In many cases the claimant has not long finished their previous assessment process which makes it even more stressful.

Under Universal Credit discretionary payments may be awarded to ease the financial burden when benefit support is insufficient. On some situations services like social support can also potentially negotiate with landlords etc. Jane said there were few sources of support in the Trafford area, and that if people have no family to help them, they are at a huge disadvantage. More support needs to be available regarding the claim procedure, particularly providing informed companions to accompany claimants to assessments.

IAS gave a presentation at a forum TCWR attended, and the representative answered people's questions and concerns, but the TCWR team felt the version of the situation they were talking about didn't correspond with the situation in reality.

**'The process isn't made to fit the needs of the claimant who is, by definition, disabled, and as such may have access and capacity issues.'**

---

The following accounts were captured between July and September 2018. To protect case studies' identities some details have been omitted or altered without changing the nature or impact of their stories. Their letters used may not bear any relation to their names, their gender and relationship of individuals within a scenario may have been altered and some details, such as their conditions, may be referred to in a more general way. This is to give them an opportunity to speak anonymously and to prevent them from being identified.

**Case study 1 - W has complex health problems, including osteoarthritis which affects his full body, heart disease, and diabetes. Under DLA he received the higher rate of mobility support, enabling him to have a specially adapted car under the Motability scheme, and low-level care support.**

W uses a transit propelled wheelchair as he is unable to use a self-propelled one, and is cared for by a family member and a carer. Since he was first awarded DLA the progressive nature of his conditions have meant that his needs had changed, but he was unable to be reassessed for DLA and had to wait two years to be invited to apply for PIP. **'I'd be in a home if not for carers'**

He wasn't worried about the assessment process as a tribunal had found him unable to work during a Jobseekers' Allowance appeal. He found the expense of providing evidence to be prohibitive, but gave full disclosure for his health records to be accessed. He didn't feel there was enough information and support available **'I trusted the government site to inform me, to do what's right'** and thinks the process isn't transparent enough **'you think you know what's going on but you don't'** - and sought support from Manchester Law Centre to help complete the forms. He felt this applied to other forms of support available, for example Carers Allowance, which he had only found out about through friends.



W hadn't been told he could request a home visit assessment, which would have solved issues with reaching the assessment centre and allowed the assessor to see the adaptations made to his home. He had to rearrange his face-to-face assessment as he couldn't get transport or a companion for the first date given, and was aware that if he couldn't attend on the rearranged date his DLA payments would be stopped. After the phone call he was so shaken he had to go to bed. **'It was basically a threat'** This led to him being very anxious about the assessment.

The assessor didn't seem to understand W's medical conditions, and he later found out that informal observations had been made during the assessment which he was not informed about and were used to reach a verdict on his award. When W received the result of his assessment, and saw the report which had been made, he believed these informal observations had been given more weight than the medical and anecdotal evidence he provided. Some of the observations made incorrect assumptions regarding his mental health, and the report included numerous other inaccuracies. One such inaccuracy was that, having told the assessor he had been attending counselling for stress and anxiety, it had been recorded that he had no mental health problems.

Although the result he was awarded is not significantly different to the amount of DLA he had been receiving, his needs are increasing as his conditions progress. An increase to the living element is in line with what he felt he would have been awarded had he been able to be reassessed under DLA, but being granted the standard level of mobility support has meant he is not eligible for the Motability scheme and must return his car this autumn. He was very upset on receiving the result of his assessment, and losing his car after relying on it for 17 years to give him independence was a particularly hard blow. He is unable to use public transport, and because of his wheelchair taxis are not accessible. W lives in a fairly isolated area where specially adapted taxis are difficult to get. Before he got his Motability car he says he spent 7 years barely leaving his home. **'They're taking away the only lifeline I had'** He says that after receiving the result **'I went into my shell'**, and had to be made to eat and leave the house - **'I had to be pushed out the door'**.

Without his car, W says he will have to have GP appointments over the phone, and call for an ambulance when he needs to attend hospital appointments. His weekly outings to a social group and counselling will cease, and this is bound to affect his mental health. **'I'm just numb, I've resigned myself to not leaving the house, not having a life. I've cancelled my life from the autumn'** He asked for a Mandatory Reconsideration but the verdict didn't change, and is being supported by Greater Manchester Law Centre to appeal to a tribunal. He hopes to be awarded the enhanced rate of living in addition to the enhanced rate of mobility, which would reinstate his Motability car. **'The stress of the process is immense'**



**Case study 2** - L takes on a lot of the care of her family member, N, who has a several mental health conditions including a severe long-term mental health condition. N had originally been on low-level care and mobility under DLA, but their care award was raised during a particularly difficult time.

L completed the PIP application forms for N and accompanied them to the assessment. **'They need someone to keep an eye on them 24/7, their mind wanders'** and they need help, reminding and encouragement with things like eating, going out, and paying bills, particularly through periods where their condition worsens. When the PIP application forms arrived L reports that N found the experience **'traumatic'**. Because of their conditions, N finds dealing with authority, such as official forms, difficult to handle. **'They found it very challenging'** L struggled herself to help fill them out - finding them poorly explained, and in many cases not digging deep enough to properly explain the challenges N faces in daily life. **'If someone without mental health issues can't fill them out, what's someone with mental health issues supposed to do?'** When N was unable to complete the forms L says they were **'left in tears'**, and **'got very shirty'**. The knowledge that it was an important document caused N to panic, and L believes this is intended: **'that's what they want you to do'** When she was unable to help her relative fill out the forms alone she sought help, as a housing trust tenant, from the housing trust's welfare rights officer. They guided her through the process for over 6 months. **'It made a massive difference, I wouldn't have been able to go through it without that help'**

L didn't think the assessor seemed as if they had any medical background, and certainly didn't come across as understanding mental health conditions. The assessor wouldn't listen to her account of how N's condition affects their life, and N struggled to answer the questions, often giving monosyllabic answers. **'The assessor put too much trust in a mental health patient who can't always understand or remember things, N had no idea it was important to answer the questions properly'** L also thinks the fluctuating nature of N's conditions wasn't taken into account, and sums up the whole assessment as **'awful'**. The wait to hear the result was a worrying time **'you're absolutely threadbare'** **'they were so frightened they would have their money taken away'**. L reports that N wanted to take their own life.

When they received the verdict, N had been awarded no award under PIP. They asked for a Mandatory Reconsideration, and when that didn't overturn the result they appealed to a tribunal. **'N was crying at the trial [sic]. They were a broken person, they'd lost everything'** The tribunal overturned the original verdict and awarded N the enhanced rate of both living and mobility support, but the whole process including the trail took around 12 months. L says her relative can't handle hearing about it, and leaves the room - **'as soon as you mention PIP they're off'**.

L feels the process is there **'to break you'** **'It's a test, and I felt as though they didn't want you to pass the exam'**. Her biggest concern is that patients with mental health issues or learning disabilities are increasingly facing financial hardship. **'How on earth can**





you expect them to handle money?’ Although she has sought support from a local carers support organisation ‘there is only so much they can do’.

---

**Case study 3 - D’s partner F has impaired mobility, largely due to spinal injury, and has recently been diagnosed with a form of cancer and so his health is expected to deteriorate and his needs increase. He uses a mobility aid, and under DLA received middle level mobility support and low-level care support.**

F has problems writing legibly and so D helped him fill out the forms. They found the 20-page form a huge undertaking and had complete a draft version first to practice, and then had to fill it out in half-hour sections. At the assessment centre there was only one accessible parking space, and it was occupied, so F had to be dropped at the entrance while D parked a distance away. There was no-one available at the entrance to help F inside and once inside the centre there was a long walk to the room, and D reports feeling ‘**watched**’ during this unavoidable journey.

The person who assessed F came across as cold, and ‘**very unempathetic**’. ‘**It was like they were just ticking boxes**’ They didn’t know you could request a copy of the report and were very concerned that he might lose his Motability car which enabled him independence. They were left waiting for the verdict over Christmas and said the wait was ‘**dreadful**’. D described it as a ‘**very nervous time, we were on tenterhooks with worry**’. F received the enhanced rate for both mobility and living and was extremely relieved when he received the award.

Despite the positive outcome, D described the assessment process as ‘**absolutely horrendous**’ ‘**It was a nightmare**’ D felt that had her partner lost out completely, or received a lower award, F would have become depressed.

---

**Case study 4 - T is the legal appointee for her niece, H, who is profoundly disabled, and has amongst other conditions severe learning disabilities and sensory impairments. Under DLA H had received the higher rates of both care and mobility award.**

H lives in a supported tenancy and has 24-hour care one-on-one care. T expected H to be invited to apply for PIP soon after it was rolled out, having been told as such, but in reality it was several years before the transfer from DLA was complete. ‘**Every gut instinct said she should remain on the highest levels**’ H’s conditions are permanent, and T finds it frustrating and an additional source of stress that H will have to go through the assessment process again in a few years as the award is not indefinite, despite the fact any improvement to her conditions would be minimal. T had to take two days off work in order to complete the forms given the amount of information and evidence required, the





difficulties acquiring it, and the tight deadline. T expressed in the form that a face-to-face assessment would not be suitable for H as nothing would be gained. **‘She’s got no idea, she can’t participate meaningfully in anything. She has no meaningful understanding of the world.’** T recognises that because of their profession they are in a better position to articulate the effect of H’s disabilities on her day-to-day life.

T was most concerned that H wouldn’t be awarded the enhanced mobility rate as this would mean they weren’t eligible for the Motability scheme. When the result and accompanying report arrived T had mixed feelings. They were relieved the enhanced rate had been awarded for both living and mobility, and felt some aspects of the report were fair and accurate, but also identified incorrect or unrepresentative content. **‘It was such a drawn out process, and as she’d got the award I didn’t have the energy to pursue it further’**

**‘How much more can you put on one person? PIP’s just another thing to worry about. We should not be putting anybody or their carers through this’** T knows some carers who have gone into meltdown over PIP, and calls the process **‘crackers, crazy’**. T thinks one of the greatest challenges is that healthcare assistants and carers try to be positive, and focus on what people are able to do, but the process is set up differently. Overestimating a claimant’s capability can threaten their success, and instead you need to consider their life on their worst day. **‘It really is by guess or by God’**

---

**Case study 5 - B is the appointee for her son, F, who has low IQ, moderate learning disabilities, and congenital heart disease. F had received medium-level care support and low-level mobility support under DLA.**

B prefers the fact that PIP takes into account the claimant’s vulnerability better than DLA did, but faced a number of problems going through the assessment process. Just months before she had had to go through the process of applying for ESA for F, and the timing of the PIP application invitation was **‘devastating’**. B is highly educated, but still found the forms very challenging and had to take time off work to complete them. **‘What about people who aren’t as educated?’** She sought support from Trafford Council Welfare Rights **‘The Welfare Rights officer was the most amazing person, I wouldn’t have been able to do it without their help, but it’s bad that I need that when I have a degree’** **‘They’re so strict about deadlines, but their timescales are moveable which just isn’t acceptable’**

B didn’t know they could request a home assessment, and the face-to-face assessment took 3 hours from the time they arrived at the centre to the time they left. **‘The length of the wait and assessment were completely unacceptable for someone with learning disabilities’** While the assessor had a good level of English, it was not her first language and F had problems understanding some of the questions. **‘It felt like we were being**



**interviewed by the police, it felt like they were going down a checklist'** She felt the assessor hadn't read any of the information she had provided on the forms. B reports that she was **'so on edge'** throughout the assessment, and F was left exhausted and really upset. **'He went to pieces after, broke down'**

Initially F was awarded the enhanced living rate and the standard mobility rate under PIP. **'The results were a bit of a joke, there were lots of discrepancies'** B could see from the accompanying report that F had been very close to the threshold for the higher mobility award, and the indicator used to justify the points given **'just didn't make sense'**. She asked for a Mandatory Reconsideration, and received the same result but with a different, irrelevant indicator used to justify the same score. B appealed to a tribunal which awarded the enhanced level of both living and mobility. Even after this verdict they did not receive the Motability car for five months. **'The whole process is so negative, it's not supportive'**

**'It felt like I was being fobbed off, like they were trying to catch you out'** With all the general care she gives her son, in addition to a recent operation and recovery period, and applying for ESA, B reports **'feeling anxious all the time'** She says she tries to protect her child by taking on the stress herself, but it's left her having counselling. **'I've had the year from hell'** This isn't the first time she's struggled to get support for F; she's had to pursue and push for other help, **'it didn't just magically fall into my lap'** **'Sometimes I get to a medium sized fence, and I just don't have the energy to jump'**

**'I really feel for those people who don't know what to do, where to go, who don't have that support'**

---

**Case study 6 - M cares for her son, S, a young person who has autism. S received medium-level support under DLA.**

M was called upon to apply for PIP when S turned 16. She said she thought the focus of PIP is better than that of DLA, but is still not suitable for conditions which are not purely physical. Straight away M felt that the application forms weren't asking the right questions in order to assess how her son's condition affected his day-to-day life.

When it came to the face-to-face assessment, M didn't know she could request a home visit for S, who may have found it less upsetting to be in a familiar setting. **'I had to prepare him. I didn't want him getting in a state. He was a bit frightened about the assessment'** During the conversation M felt the assessor didn't understand autism at all. They also didn't let M speak, and when she tried to, they didn't seem to listen to her or try to understand the impact on S's life. **'They really twisted it and twisted it'** **'S was**



**spoken to like an adult, he needs to be spoken to like a child'** She wanted to explain about an incident where he was hurt by strangers, to demonstrate how vulnerable he is, but couldn't do so in front of him and wasn't able to speak to the assessor privately. **'He's so so vulnerable'** She tries to give S some independence with things like cooking and getting the bus, but always has to be there to supervise, and this wasn't taken into account despite her efforts to explain this. **'The assessment wasn't a review of the questions on the form at all'**

**'It was worrying not knowing what the result would be, it means a lot to his world'** S was awarded nothing, and when the Mandatory Reconsideration didn't change the verdict, M appealed. She describes the appeal as **'an absolute joke'**; her son was awarded the higher rate of living and no mobility element. On re-appeal this was overturned to award no living element, but the lower rate of mobility. The DLA payments stopped when the first decision was made, and they are unable to seek a further appeal. She said there was no consistency with what was said as the justification for the award, and what was actually awarded.

**'In some ways he's treated as if he's an adult, but in others as if he's a child; whichever is cheaper for the system. The whole process was absolutely terrible, disgusting'** She also felt that in general there was not enough information and guidance available - **'I didn't even know about DLA until he was 11'**.

---

#### **Case study 7 - L helped her child A, a young person with autism, with the PIP process. A had been on DLA.**

L anticipated that PIP would be straightforward as A's condition is diagnosed and permanent. She found the questions on the application form more relevant to Autism than those asked during the DLA assessment, but they were still **'very difficult'**. **'It's very emotional when you're writing about your child'** L is aware that she is highly educated and is used to completing complicated paperwork and phrasing things in a particular way as a result of her career. She thinks that to be successful in the initial application you need to fill it in in a certain way, for example using technical language and buzzwords which many people would be unfamiliar with. **'The forms must be so off-putting, most people don't understand them - even quite educated people. It's so unfair'** L works 4 days a week and on top of this spends time helping others navigate the system, providing support with filling out the application forms.

When it came to arrange the face-to-face assessment, L says it wasn't made obvious that a home visit assessment could be requested, and says it was **'tricky to sort a time'** - spending more than half an hour waiting on the phone. L was concerned ahead of the assessment. **'It was very stressful going in. I'd heard the assessors could be very difficult, and they had targets to reach'** L described the assessor who saw A as **'aloof, and distant'**, and said she didn't say very much but seemed, at the time, to be listening



and making lots of notes. **'A suffered a nosebleed because of the stress, it was incredibly stressful'** They weren't made aware that they could request a copy of the report made at the time, but L, though concerned in light of stories about assessors' harshness, felt A's condition and its effect on their everyday life had been made clear. Her biggest concern was that A would just miss a threshold points value, in which case she was prepared to fight for it to be looked at again.

**'At the time I felt like they listened to me, but it's such a subjective process'** The result they received left L **'shocked'**. A had been awarded zero points, meaning she did not receive any award under PIP. The letter was very brief, and the time limit to request a Mandatory Reconsideration was one month, in spite of the fact the letter had taken two weeks to arrive. L spent 40 minutes waiting on the phone just to get through to somebody. **'A was terribly terribly upset and frightened'**. L spoke to others going through the process, and contacted the National Autistic Society who sent her a guide detailing how to relate the questions asked to autism specifically. L was able to discover that the assessor had a nursing background but had not had specific training on conditions like autism. She also learnt that none of the evidence she had initially provided had been looked at in reaching a decision. L secured an extension, and took three weeks off work, unpaid, in order to re-provide evidence that they had ignored, gather further evidence, and explain the inaccuracies she felt had been made in the initial report. **'It was appallingly stressful'**

The letter she wrote was 28 pages long and addressed the mistakes, including assumptions made based on treatments and therapies chosen for A's mental health conditions, and details which were totally, factually, incorrect. L says she can only assume the assessor had a target to meet for such an unrepresentative report to have been created. L knows another family in a similar position, but when their child received zero points they **'couldn't face appealing'**. For A, their DLA support had paid for trips with the Autistic Society for the Greater Manchester Area, but without this money they would not be able to afford these valuable outings. **'For us it's the difference between coping and being able to do things, and enjoy things in life'**

A's result was changed on reconsideration and they were awarded the enhanced rate of care and standard rate of mobility, but this was only awarded for 4-5 years, despite the fact A's condition and how it affects their life is unlikely to change for the better. After the experience the first time round, A doesn't want to have a face-to-face assessment again and L will have to fight again. **'It's ridiculous. It's exhausting filling out forms. You can't get a diagnosis of autism if you don't have it'** She said that there is a particular lack of support for adults with conditions like autism, and when it comes to support with things like PIP the only help available is from charities or people volunteering out of goodwill. L has supported someone else through the process, and says they **'got the result they wanted but only because of me. It makes me so angry.'**

**'I know how to deal with professionals, I'm not afraid to approach them. I know how to work with the system. But many don't. It's fortunate for my child but I fear for others'**





## Findings

Findings should be considered in light of the aims of the PIP system and the requirements of UK and international legislation on the rights of people with disabilities, as discussed in 'Background - State Obligations'.

The organisations and individuals we spoke to voiced a number of concerns. They echoed issues we were already aware of, summarised in 'Background', but also highlighted some specific situations, particularly in or around Trafford. The case studies conducted captured individuals' experiences of the PIP assessment process. These largely mirror the results gathered in our survey, and touch on problems raised in our conversations with organisations and individuals working with PIP claimants.

The perspective of organisations, individuals and case study participants on the PIP system and how it affects claimants' health and wellbeing was, in general, very negative.

### Survey

60 people submitted responses to the survey. Some questions were universally applicable, for example those regarding demographics, and those focused on the initial stages of the process. Some were only applicable to those who had reached a certain stage of the process, for example having received their result. Some had multiple criteria for applicability, for example requiring the respondent have reached the assessment stage and to have require a face-to-face assessment and to be asked to have it at an assessment centre. For these reasons the number of surveyees to whom each question applied varied. Some surveyees chose to skip some questions.

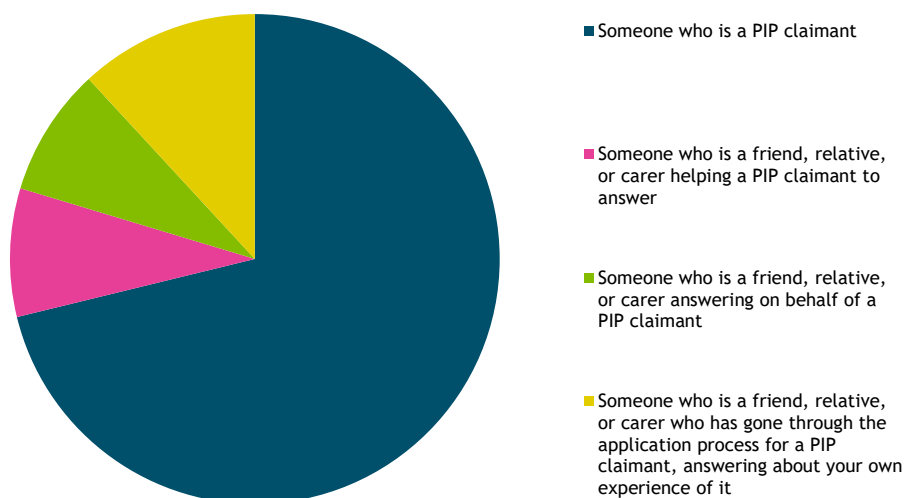
Q1. - Ascertaining who the respondent was in relation to the PIP claimant

98.3% of surveyees responded to this question (59 respondents).

More than two thirds (71.2%) of respondents were answering about their own experience as a claimant, and more than one in ten were answering about their own experience of another person going through the process (11.9%).



## Q1. Are you:



### Q2. - Ascertaining the conditions, disabilities or impairments of the claimant

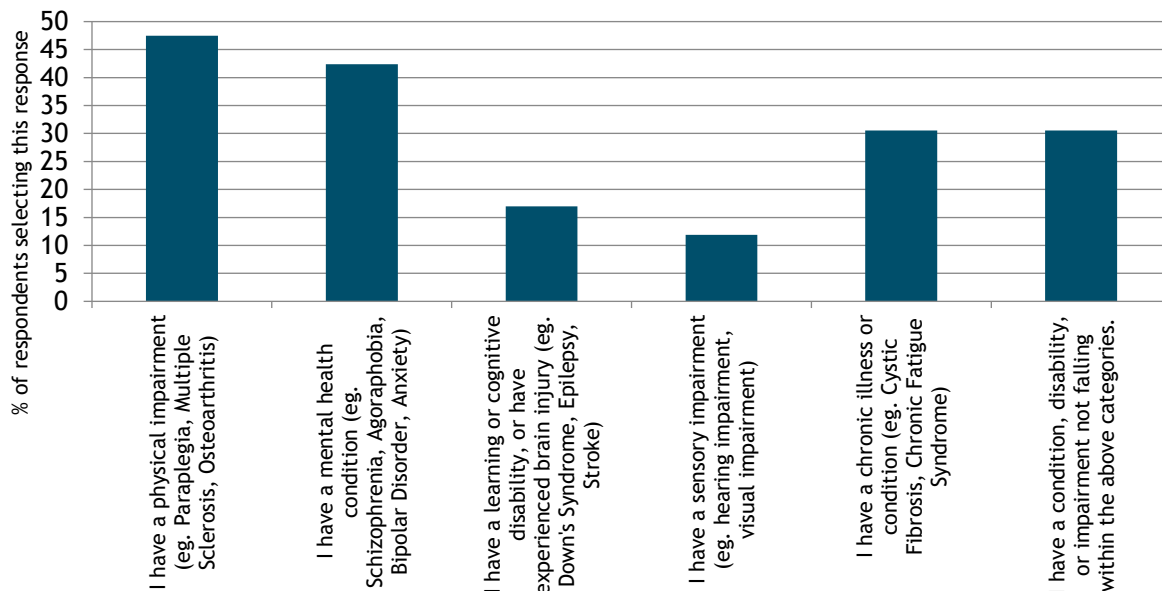
98.3% of surveyees responded to this question (59 respondents).

Almost half of respondents (45.8%) said the person the claim concerned has one condition, disability or impairment, over a third said they have two (33.9%), one in six (16.9%) said they have three, and 1.7% reported four conditions, with the same proportion reporting five. In total the 59 respondents gave 106 responses, but within the categories of condition selected it is possible they may have more than one condition, for example multiple mental health conditions, or visual and hearing impairments. In reality the number of conditions affecting the respondents is therefore likely to exceed 106. Of the types of conditions respondents reported, the most common both in terms of frequency and proportion of all responses were physical impairments. Just under half (47.5%) of all respondents selected this answer, and it made up over a quarter (26.4%) of all responses. The second most prevalent category of condition was that of mental health conditions. 42.4% of respondents have a condition falling in this category, and these make up almost a quarter (23.6%) of all responses. 30.5% of respondents have a chronic illness or condition, equivalent to 17.0% of all responses. The same proportions reported 'a condition, disability or impairment not falling within the above categories'. It should be noted, however, that conditions falling within this category may have a greater degree of subjectivity attached to them. What is considered a condition, disability, or impairment outside the stated categories will vary from person to person. Some other conditions may also be classified differently by different people. Please see the section 'Points to note' for further discussion of this. Almost 10% of all responses represented learning or cognitive disabilities, or conditions related to brain injury (9.4%), and these affected 17.0% of respondents. Less common were sensory impairments, which affected 11.9% of respondents but constituted just 6.6% of all responses.

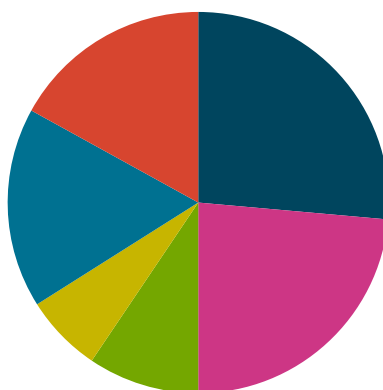




## Q2. Please select all which apply to the person the claim concerns - prevalence of conditions



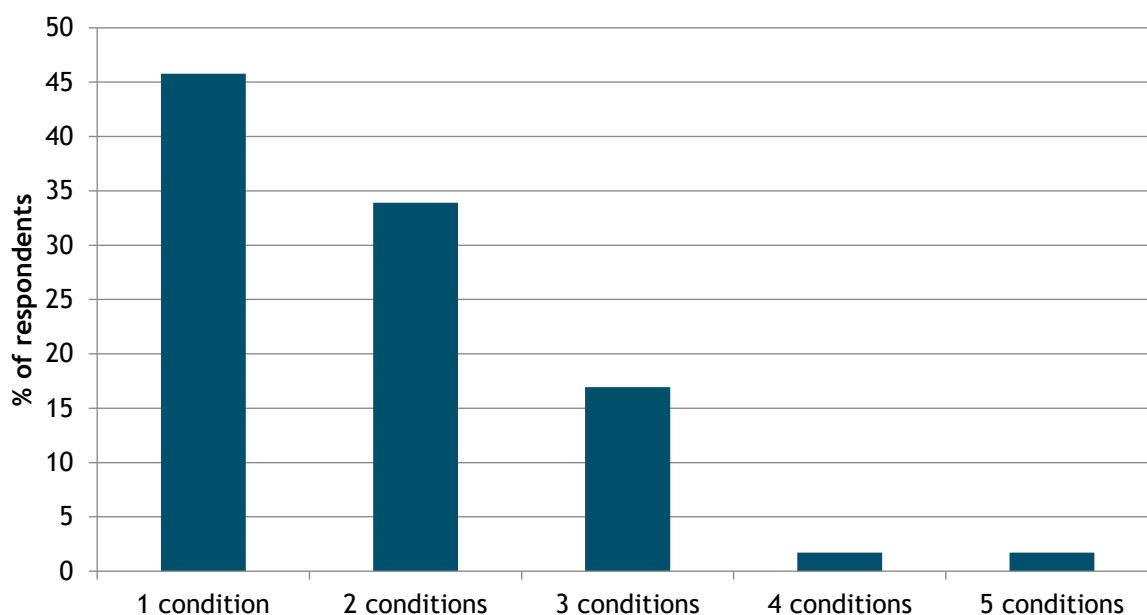
## Q2. Please select all which apply to the person the claim concerns - proportion of all conditions



- I have a physical impairment (eg. Paraplegia, Multiple Sclerosis, Osteoarthritis)
- I have a mental health condition (eg. Schizophrenia, Agoraphobia, Bipolar Disorder, Anxiety)
- I have a learning or cognitive disability, or have experienced brain injury (eg. Down's Syndrome, Epilepsy, Stroke)
- I have a sensory impairment (eg. hearing impairment, visual impairment)
- I have a chronic illness or condition (eg. Cystic Fibrosis, Chronic Fatigue Syndrome)
- I have a condition, disability, or impairment not falling within the above categories.



## Q2. Number of conditions reported by respondents



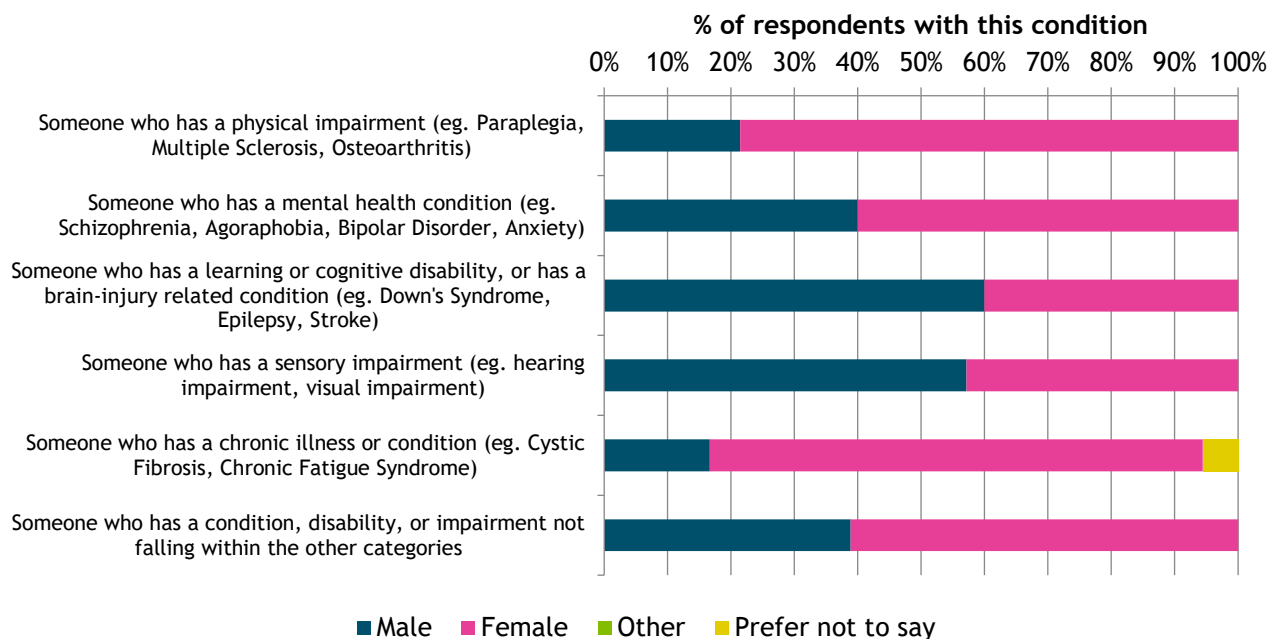
We also looked at the gender breakdown of different categories of condition. Question 38 asked respondents to say how they identify. A greater proportion of respondents identifying as female had physical impairments (59.5% vs. 28.6% in those identifying as male), which is as could be expected, as common conditions like arthritis are more prevalent in women.<sup>38</sup> A greater proportion of respondents identifying as male reported mental health conditions than women. A greater proportion also said they have a learning or cognitive disability, or a brain-injury related condition. Autism Spectrum Disorders, which respondents may class within this category, are another example of a condition which disproportionately affects one sex - in this case men.<sup>39</sup> Differences can be seen across all types of condition, but it should be noted that the 'male' group makes up a far smaller proportion of the sample than the 'female' group (36.7% vs. 61.7%), and so making comparisons between the two can only be speculative. The small sample size of only 22 people identifying as 'male' are unlikely to be representative of the population. The same applies to those identifying as 'female', although to a slightly lesser extent as the group size is greater.

<sup>38</sup> NHS, 'Arthritis' << <https://www.nhs.uk/conditions/arthritis/> >>

<sup>39</sup> National Autistic Society, 'Gender and Autism' << <https://www.autism.org.uk/about/what-is/gender.aspx> >>



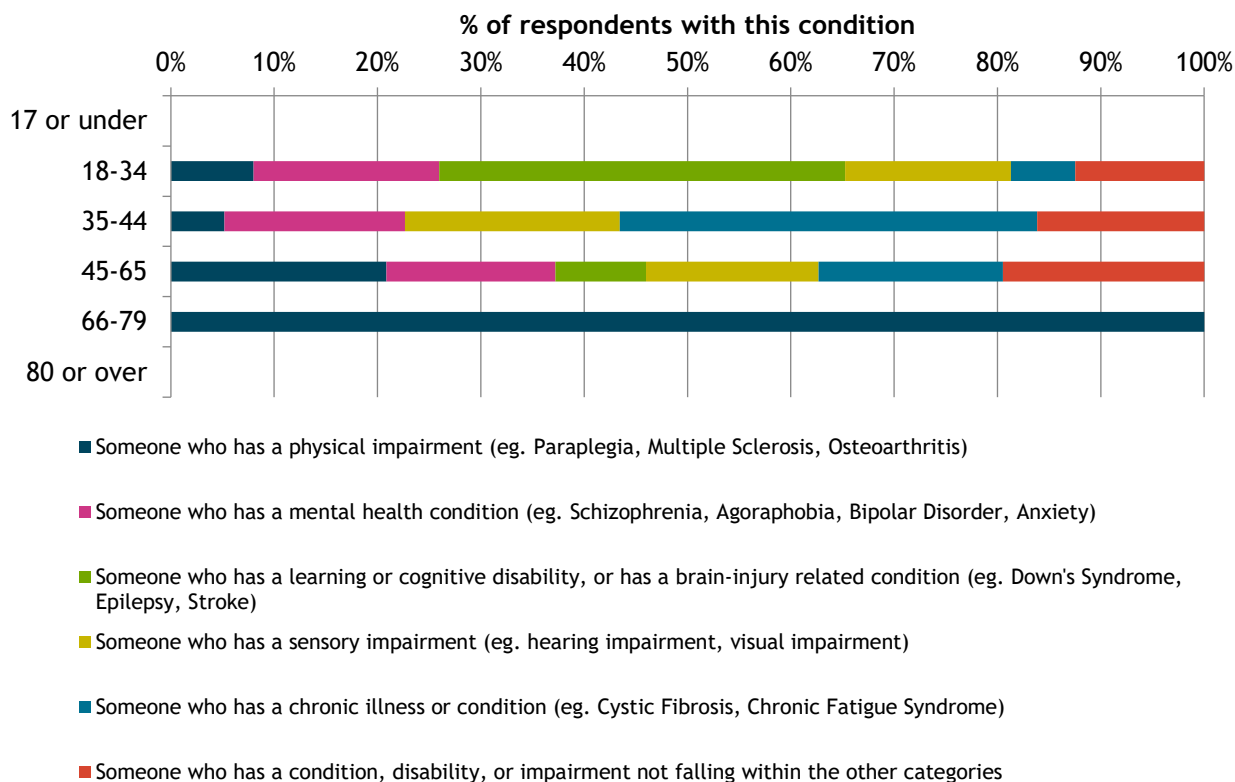
## Q2 & Q38. Gender breakdown



We also looked at the breakdown of responses in relation to the age of respondents. Unsurprisingly the type condition reported by people over 45 was physical impairments, which often develop or worsen with age. This was also the only type of condition reported by respondents over the age of 66. It should be noted however that when looking at data in respect of respondents' age the class intervals are unequal, and the 45-65 group covers the broadest range of ages, whereas the 35-44 group cover spans less than half as many ages. The category with the greatest proportion of younger people, or the youngest group who responded, had learning or cognitive disabilities, or brain-injury related conditions. Again the sample size is too small to make any conclusions, but this could be because several other types of condition often are later-onset, for example sensory impairments like macular degeneration, physical impairments like osteoarthritis, and chronic illnesses like heart disease.



## Q2 & Q 37. Age breakdown

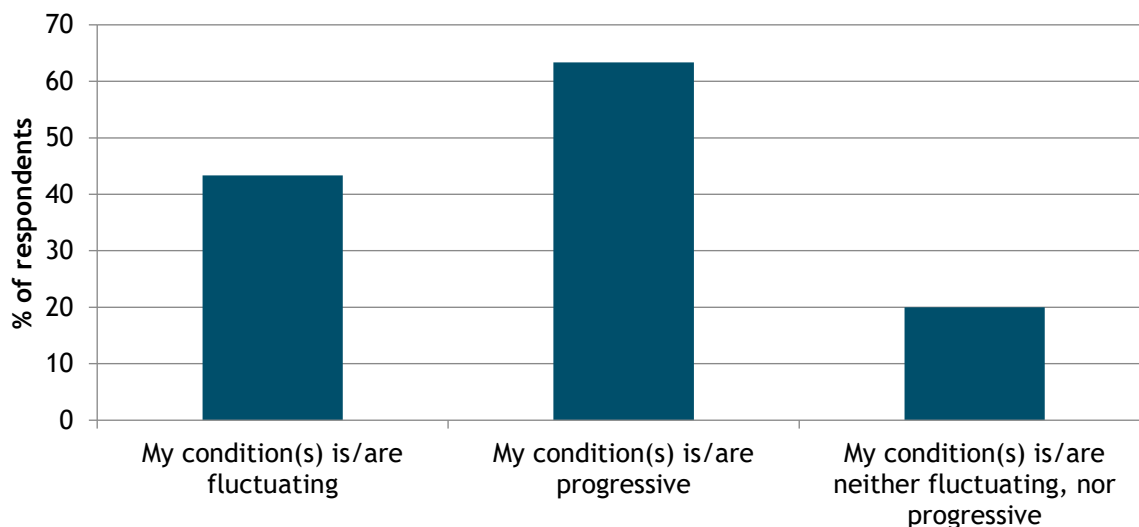


### Q3. - Ascertaining the nature of the conditions, disabilities or impairment of the claimant

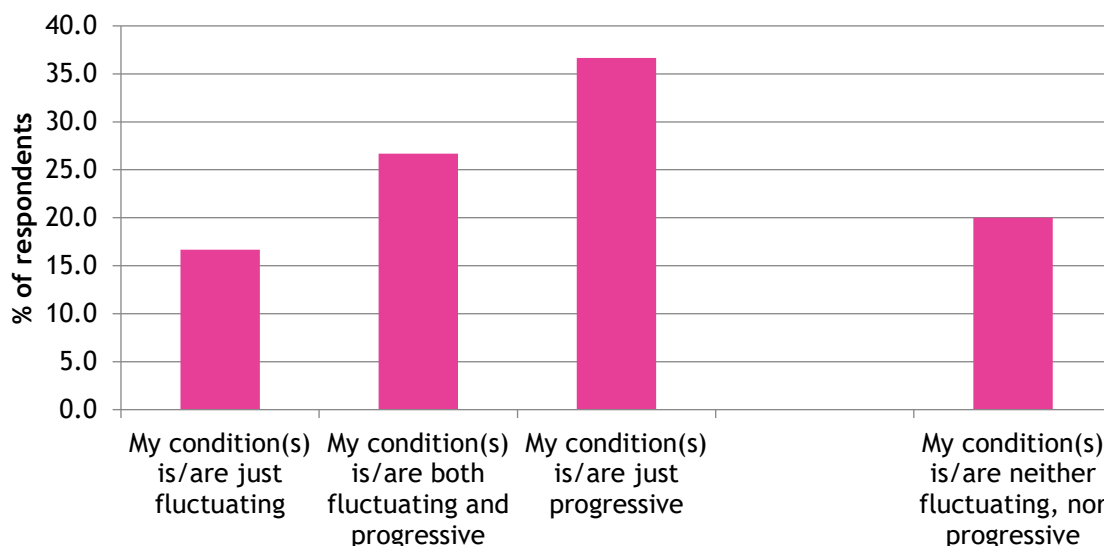
All surveyees responded to this question. Respondents could say their condition(s) is/are neither fluctuating nor progressive, fluctuating, progressive, or both fluctuating, and progressive. Almost two thirds of respondents answered that their condition(s) is/are progressive (63.3%), 43.3% have a condition or conditions which are fluctuating, and only 20.0% have a condition or conditions which are neither fluctuating nor progressive. Broken down further, more than a quarter of respondents (26.7%) answered both fluctuating and progressive, more than a third (36.7%) said just progressive, and 16.7% just fluctuating. Conditions which fluctuate are likely to be harder to assess. People whose conditions are progressive will see their needs increase and will face further difficulty as time goes on if they receive a reduced award or insufficient award.



### Q3. Please select all statements which apply to the person the claim concerns:



### Q3. Please select all statements which apply to the person the claim concerns - further breakdown



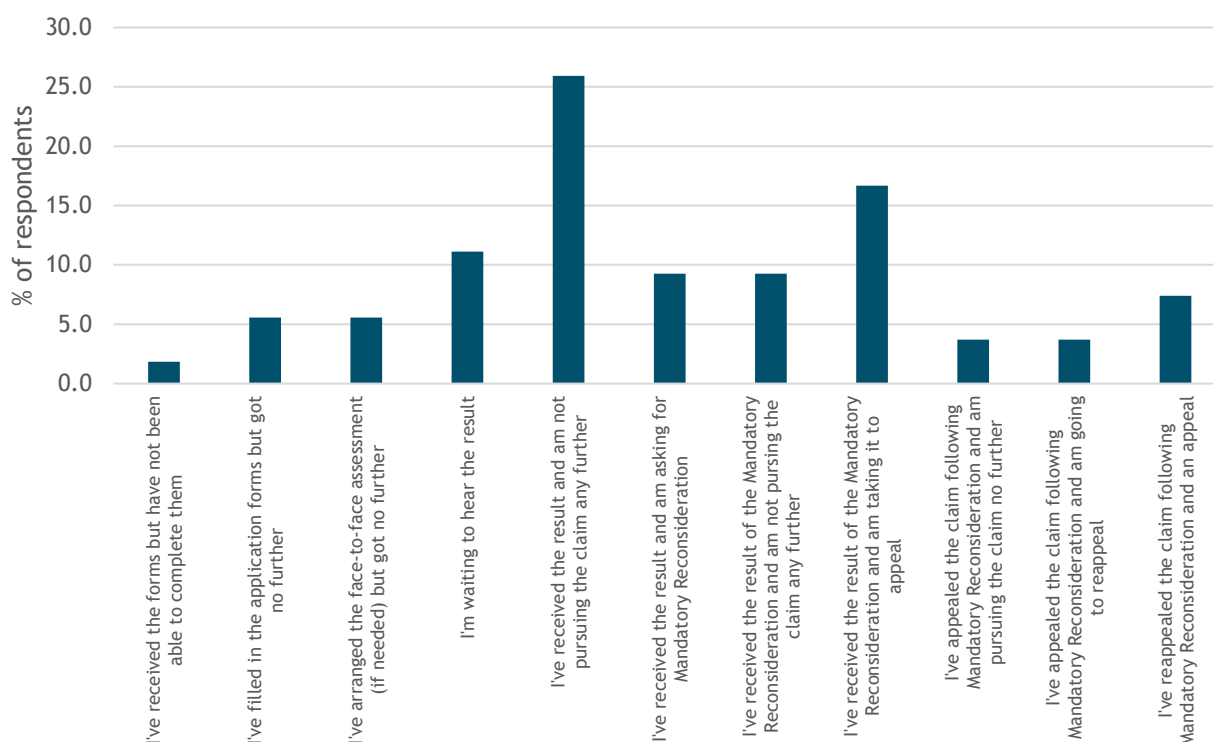
#### Q4. - Ascertaining the stage the claimant has reached in the PIP process

90.0% of surveyees responded to this question (54 respondents). There was a wide spread in the responses, with some respondents at each of the 11 stages mentioned. The most common stage for respondents to have reached was to have received the result and not be pursuing the claim any further. Just over a quarter of respondents (25.9%) were at this stage. Almost as many (24.1%) had not reached this stage, and exactly half (50.0%) of



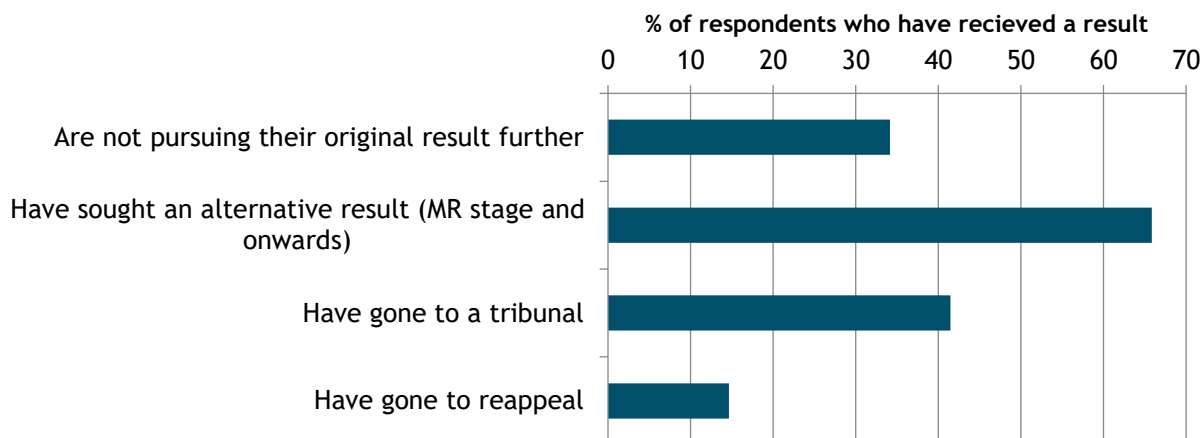
respondents had pursued their claim further than this. This means that in total over three quarters of respondents had received an original result from the DWP, and completed the initial application process. Of those in the earlier stages, 1.9% were unable to fill in the forms and continue, and 11.1% had been through the application process but were waiting to hear their result. Almost 10% of respondents dropped out of the process on receiving the result of their mandatory reconsideration, but 41.5% of those who had received an original decision and a reconsidered decision continued their claim, appealing at least once. 35.3% of appeals went to reappeal (14.6% of respondents who had received a result) and, whether happy with the result or not, 9.8% of respondents who have received a result have been given a decision by a tribunal at the reappeal stage and cannot pursue the claim any further.

#### Q4. At what stage of the PIP assessment process are you?





## Q4. At what stage of the PIP assessment process are you? - further breakdown



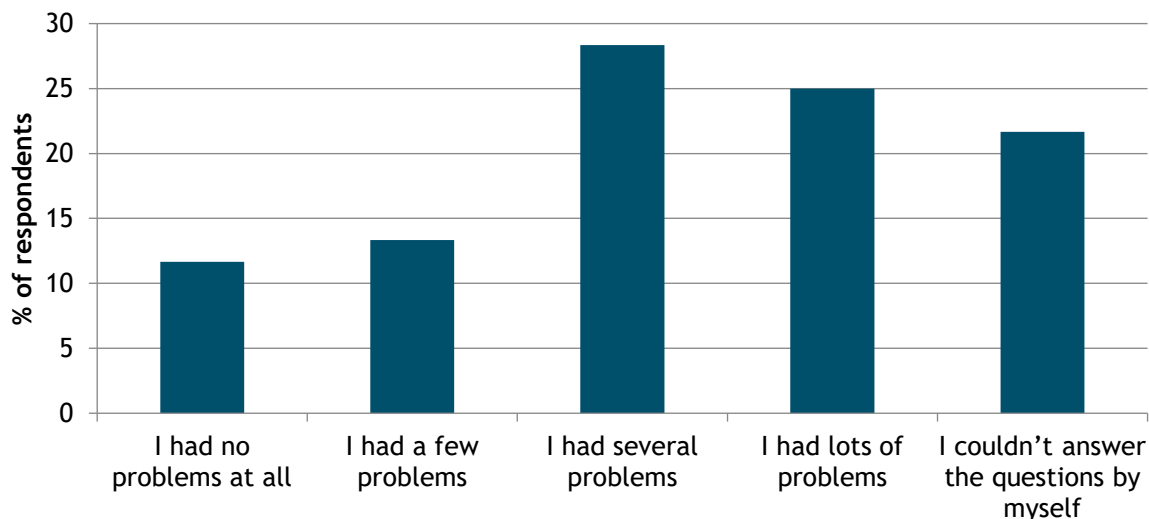
### Q5. - Looking at difficulty levels of the PIP application forms

All surveyees responded to this question. 11.7% had no problems filling out the application forms, but the huge majority (88.3%) had some level of difficulty. The most common response to the question was 'I had several problems' (28.3%), but a similar proportion answered saying they had 'lots of problems' (25.0%) and 'I couldn't answer the questions by myself' (21.7%). Over one in five (21.7%) experienced such a high level of difficulty that they were unable to complete the forms alone. Respondents with a learning or cognitive disability, or a brain-injury related condition were particularly likely to give this response. No respondents with this type of condition, or with a sensory impairment completed the forms problem-free. However, those with sensory impairments were the only group to all be able to answer the questions alone. The group who were most able to complete the forms without problems were those with physical impairments. This is in line with commonly-held views that the format of the PIP application process is aimed at physical impairments which are potentially more straightforward to assess and explain on paper.

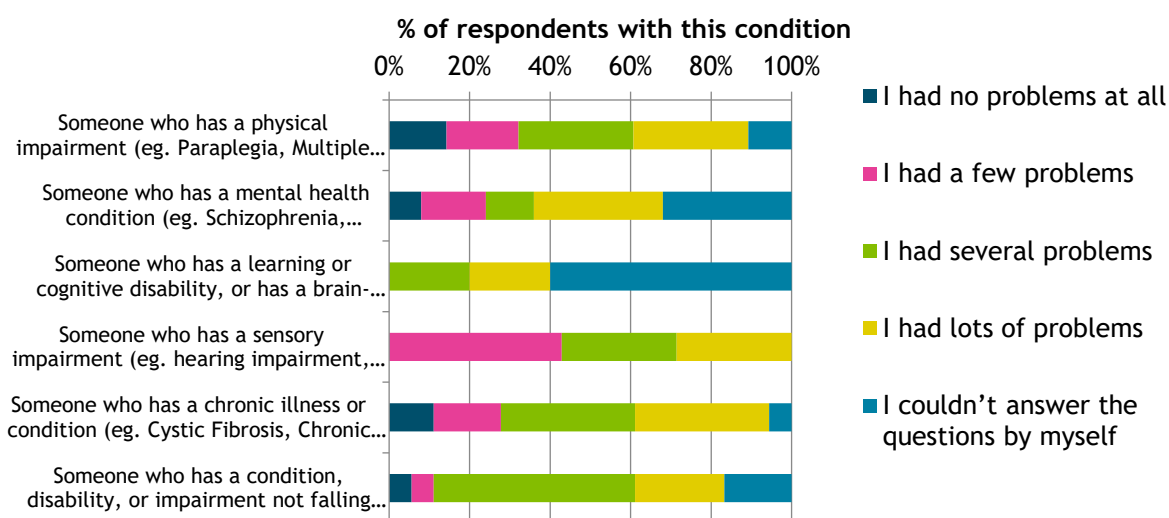




## Q5. Please choose the most appropriate descriptor for how you found filling out the PIP application forms



## Q5. Condition breakdown



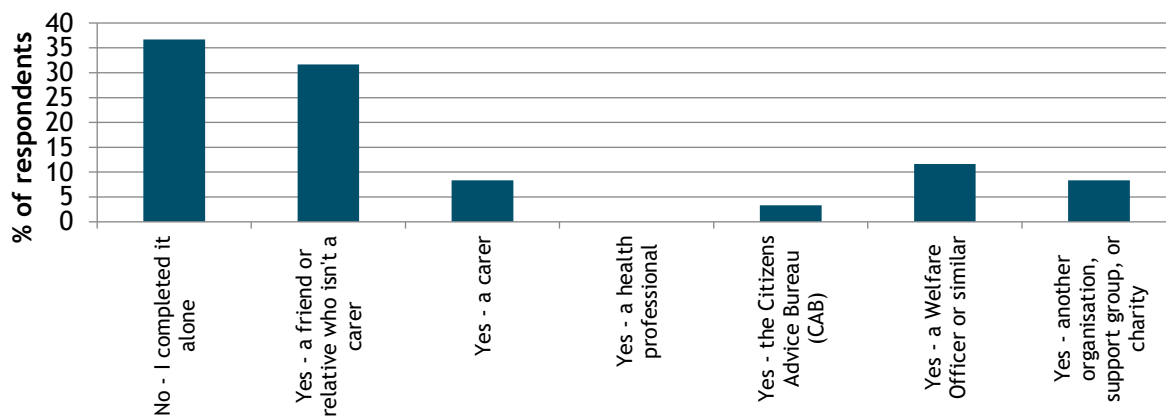
Q6. - Looking at whether respondents had been helped to fill out the forms, and if so by whom

All surveyees responded to this question. Over a third (36.7%) of surveyees filled out the forms alone. The next most common response (31.7%) was people who had received help and support from a friend or relative who isn't a carer, with 8.3% receiving help from a carer. Other sources of help and support used were the Citizens' Advice Bureau (3.3%), welfare officers or similar people (11.7%), and other organisations, groups or charities (8.3%), which included: the National Deaf Children's Society; High Functioning Trafford, a



local support group for children and young people with autism and their families; and a social worker, although the respondent commented that they had not been useful. One respondent answered that a welfare officer had helped and supported them with the tribunal stage. No respondents said they had received help and support from a health professional.

## Q6. Did you have any help and support to fill out the forms?

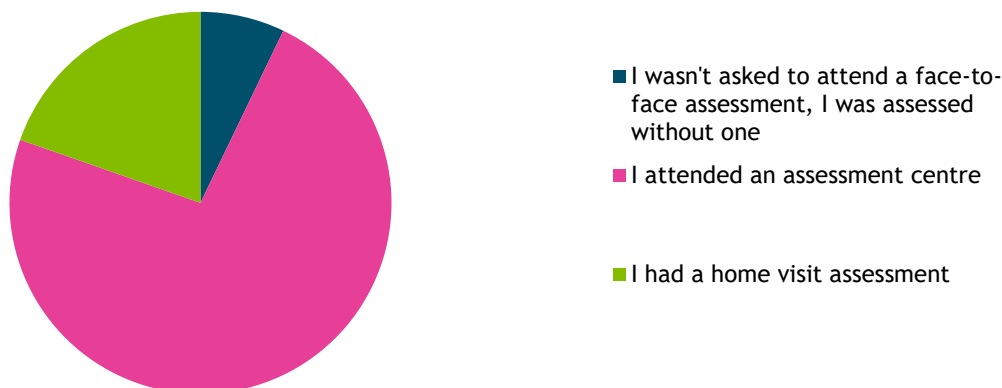


## Q7. - Looking at which type of face-to-face assessment claimants had

All surveyees responded to this question. The question was applicable to 93.3% of respondents (56), based on how far they had progressed through the PIP process according to their answer to this question. Of those who had reached this stage of the process, 7.1% were not asked to attend a face-to-face appointment, but 92.9% were required to have one. Overall, the most common type of assessment, with almost three quarters conducted this way, was at an assessment centre (73.2% of respondents at this stage). Almost one in five (19.6%) were home visit assessments, and 7.1% had a paper-only assessment.



## Q7. Where did you have the PIP face-to-face assessment? - applicable respondents



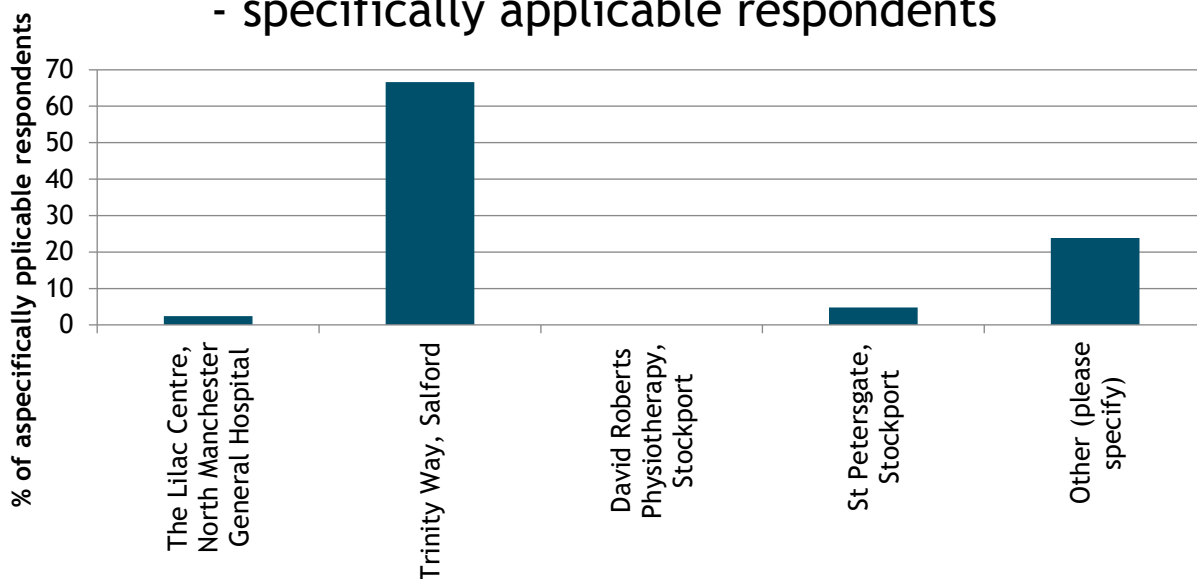
### Q8. - Looking at which assessment centres claimants were asked to attend

All surveyees responded to this question. The question was broadly applicable to 93.3% of respondents (56), based on how far they had progressed through the PIP process according to their answer to this question. When considering the assessment centres attended, 68.3% of respondents had reached this stage and had a face-to-face assessment at an assessment centre, rather than being assessed at home or solely on paper. The proportions of respondents attending each centre, as shown below, are therefore of these specifically applicable respondents. The answers given by those who answered 'Other' to this question were taken into account, and demonstrated that assessment centres besides the four located closest to Trafford were frequently used for respondents' face-to-face assessments.

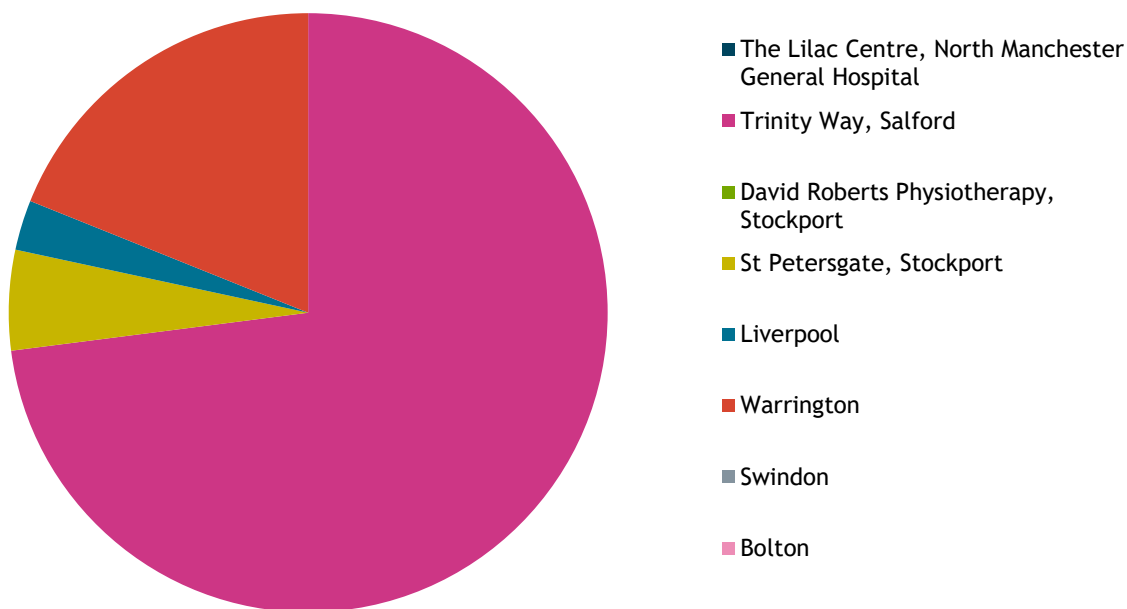
Over two thirds of those who had a face-to-face assessment at an assessment centre went to Trinity Way, Salford, also known as Manchester Central Office (68.3%). The second most common location was Warrington, where 17.1% of specifically applicable respondents attended. A small proportion attended St. Petersgate in Stockport (4.9%), The Lilac Centre at North Manchester General Hospital (2.4%), Bolton (2.4%), Liverpool (2.4%), and Swindon (2.4%), although it should be noted that this last respondent is not a Trafford resident. No respondents attended the assessment centre at David Roberts Physiotherapy, in Stockport, which is one of the centres closest to Trafford. Locality did not appear to affect the centre attended, which fits with the picture painted by claimants' comments that they had to go to centres far away.



### Q8. Which assessment centre did you attend? - specifically applicable respondents



### Q8. Which assessment centre did you attend? - specifically applicable Trafford respondents



### Q9. - Looking at the claimant's experience of their assessor

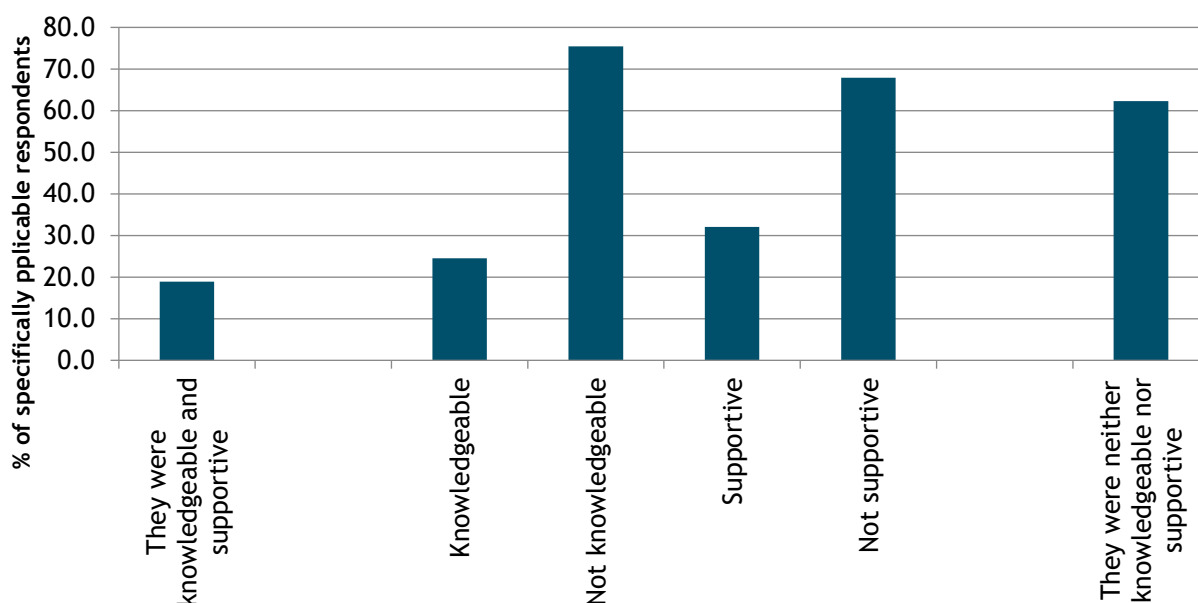
All surveyees responded to this question. The question was broadly applicable to 95.0% of respondents (57), based on how far they had progressed through the PIP process according to their answer. When considering people who had a face-to-face assessment with an



assessor, either at home or at a centre, the question was specifically applicable to 88.3% of respondents (53).

18.9% of respondents who had a face-to-face assessment felt their assessor was knowledgeable and supportive. Over 10% (13.2%) felt they were not knowledgeable, but were supportive. A small minority (5.7%) felt the assessor was knowledgeable but not supportive, and the majority, and almost two thirds, felt their assessor was neither knowledgeable, nor supportive. Overall just under a quarter of specifically applicable respondents felt their assessor was knowledgeable (24.5%), while just over three quarters felt they were not (75.5%). A greater minority of 32.1% felt their assessor was supportive, whilst over two thirds (67.9%) felt they had not been.

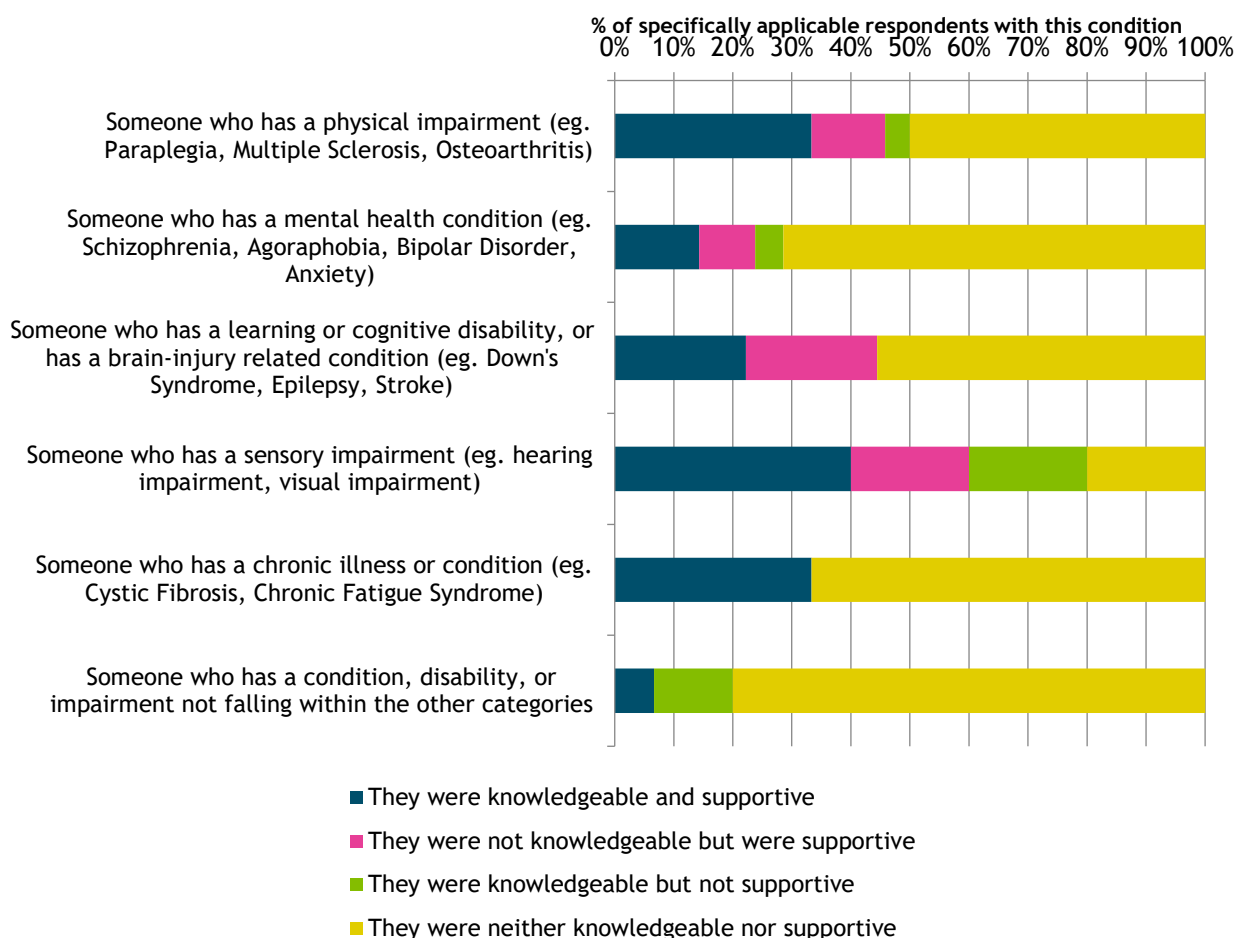
### Q9. Did you feel that the assessor understood your condition(s) and appreciated its impact on your daily life? - breakdown



The group who most felt their assessor was neither knowledgeable nor supportive were those with a condition falling outside the categories used in the survey, with two thirds (66.7%) giving this response. A similar proportion of respondents with a mental health condition felt the same. The groups most satisfied with their assessor's understanding were those with physical and sensory impairments, each with 28.6% saying they were both knowledgeable and supportive, with the 'chronic illness' (27.8%) close behind.



## Q9. Condition breakdown



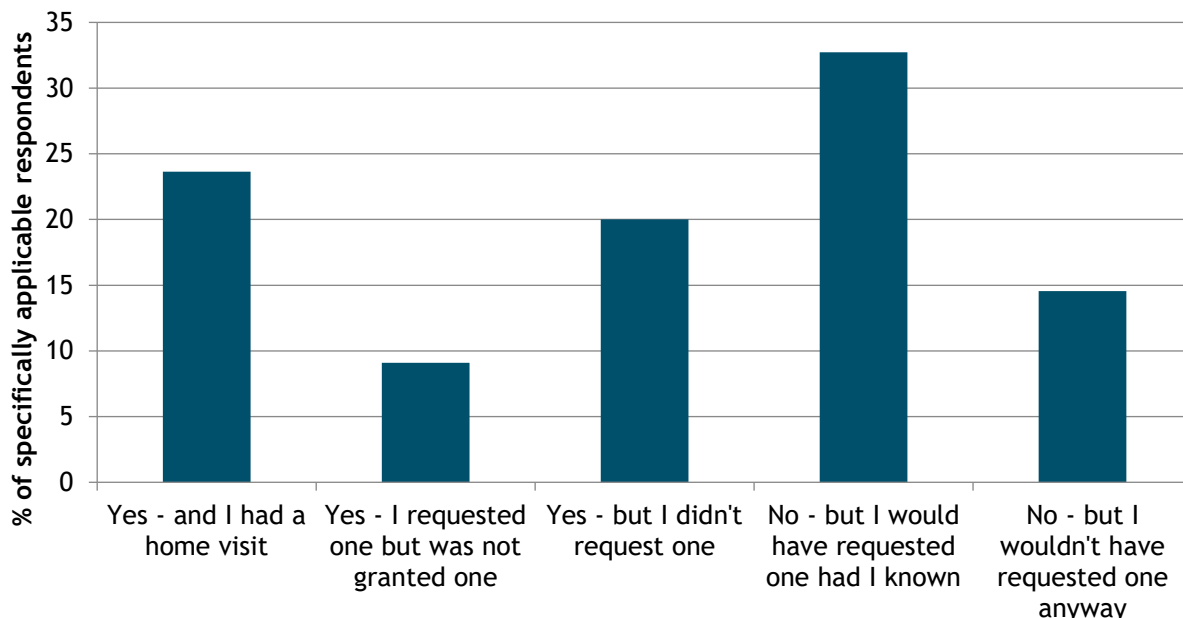
The location of surveyees' face-to-face assessment might affect their experience of their assessor if the same assessors are repeatedly used by certain centres. However, because respondents attended a number of different centres, with some accounting for more than half of all respondents' assessments and some being only visited by one respondents, it would not be illustrative to draw comparisons.

### Q10. - Looking at awareness of home visit assessments

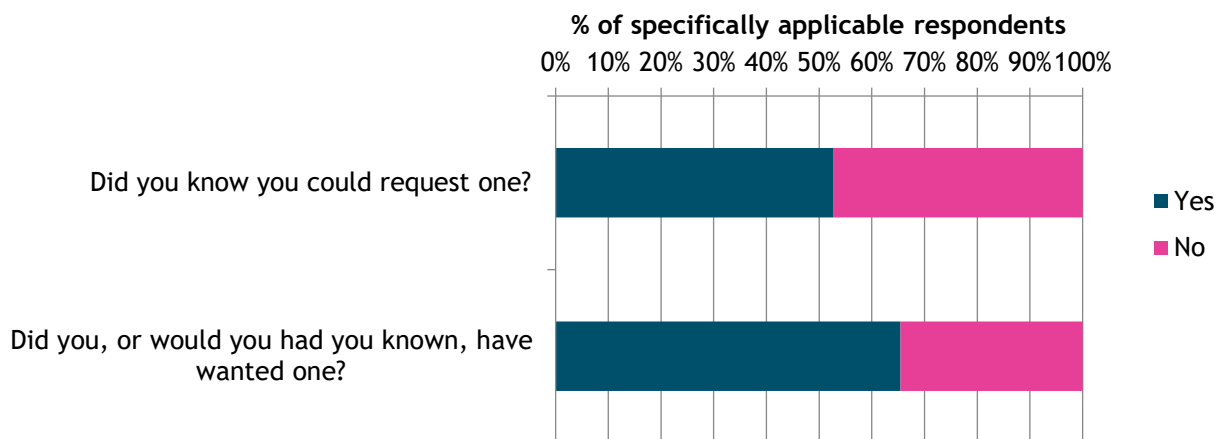
All surveyees responded to this question. The question was broadly applicable to 95.0% of respondents (57), based on how far they had progressed through the PIP process according to their answer. When considering people who were asked to have a face-to-face assessment at home or at a centre, rather than be assessed by paper forms only, the question was specifically applicable to 91.7% of respondents (55). Almost a quarter of applicable respondents were aware they could request a home visit, and had one (23.6%), but a large minority (32.7%) were not aware, but would have requested one had they known. Overall, slightly more than half (52.7%) of respondents knew they could request one, but almost two thirds (65.5%) wanted or would have wanted one.



**Q10. Were you aware you could request a home visit if you would have difficulties attending an assessment centre? - specifically applicable respondents**



**Q10. Further breakdown**



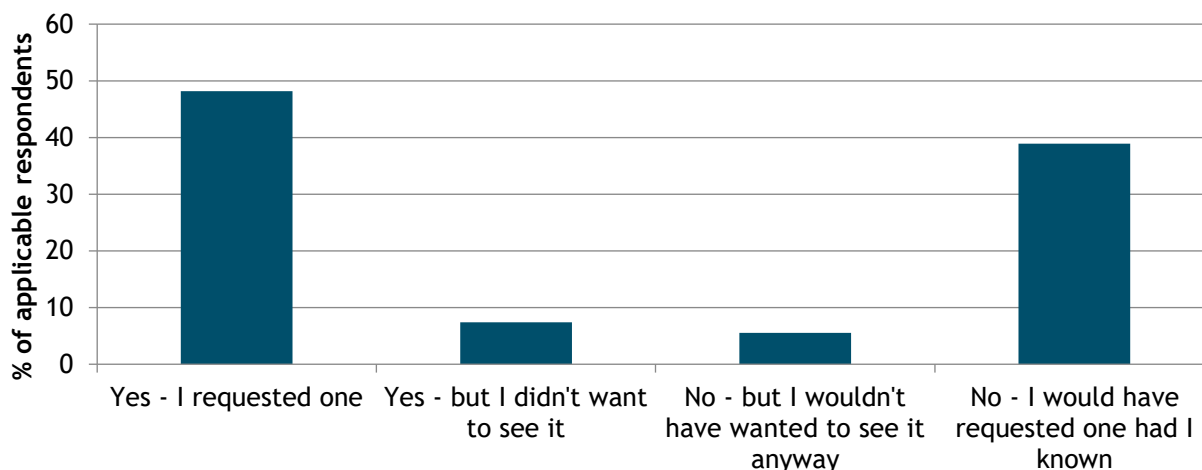
**Q11. - Looking at awareness of report requests**

98.3% of surveyees responded to this question (59 respondents). The question was applicable to 91.7% of respondents (55), based on how far they had progressed through the PIP process according to their answer. Almost half of the applicable respondents were aware they could request a copy of the report, and did so (48.1%), but a large minority (38.9%) were not aware, but would have requested one had they known. Overall, slightly more than half (55.6%) of respondents knew they could request one, but a huge majority (87.0%) wanted a copy, or would have wanted one had they known.

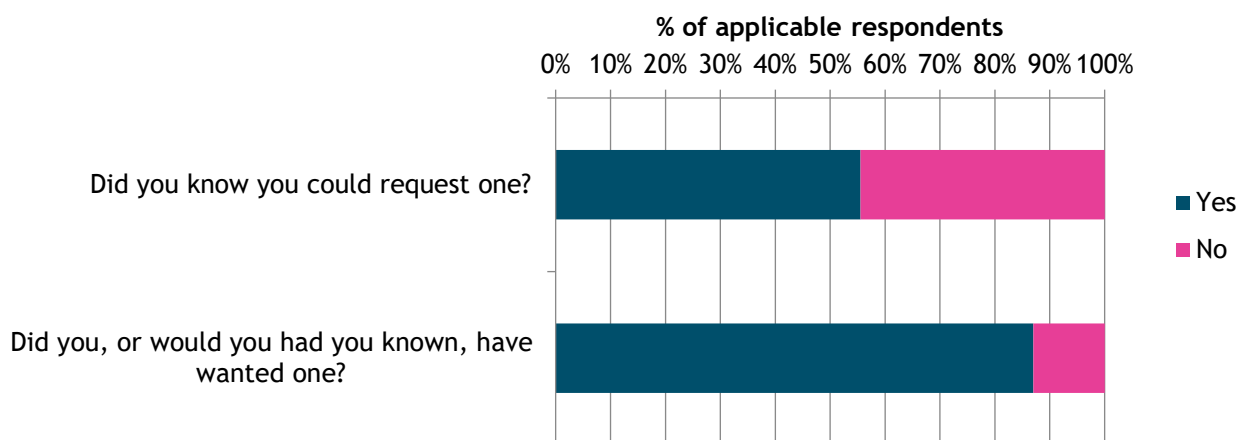




Q11. Were you aware you could request a copy of the report made by the assessor after the assessment? Or, if you didn't need a face-to-face assessment, the report made following submission of your application forms? - applicable respondents



### Q11. Further breakdown



Q12. - Looking at claimants' overall experience in their own words

98.3% of surveyees responded to this question (59 respondents), although several of these respondents answered using more than three words or used full sentences. In order to produce a 'wordcloud' showing the words' relative frequency some processing was necessary. Where respondents had used three words no processing was necessary. Where claimants had used more words but still described the process in some way processing was necessary. If, for example, a respondent had used more than one word to say something like 'too long' then their response was manually adjusted to 'overlong', in order to take into account their views but be comparable to the rest of the question's responses. This specific change occurred three times. Other changes included replacing 'couldn't travel by



taxi or public transport’ with ‘inaccessible’. If a respondent hadn’t described the process in their extended answer no adjectives could be extracted. If extended answers included several points describing the process then the main three points were used. The frequency table below shows the word used to create the wordcloud.



Frequency	Word	Notes
19	intimidating	
12	complicated	
10	scary	
9	long	
7	stressful	
7	negative	
6	painful	
4	*repetitive	Note 1. One instance of 'repetitive' was adapted in a situation where a respondent wrote an extended paragraph rather than three words, but 'repetitive' summarises one of their main points.
3	straightforward	
3	*difficult	See Note 1. This applies to one instance of 'difficult'.
3	degrading	
3	*overlong	See Note 1. This applies to all three instances of 'overlong'.
2	frustrating	
2	misleading	
2	confusing	
2	nightmare	Although these words have a lesser frequency, they are largely negative and several are synonyms for other words included in this table.
1	misunderstanding	
1	understanding	
1	heartbreaking	
1	disappointing	



1	horrendously		
1	demoralising		
1	*inaccessible	See Note 1. This applies to one instance of 'inaccessible'.	
1	embarrassing		
1	unsupportive		
1	judgemental		
1	competitive		
1	unnecessary		
1	long-winded		
1	interesting		
1	unrelatable		
1	unrealistic		
1	humiliating		
1	ridiculous		
1	terrifying		
1	disgusting		
1	*unsuitable	See Note 1. This applies to this instance of 'unsuitable'.	
1	exhausting		
1	impossible		
1	kafkaesque		
1	provoking		
1	gruelling		
1	drawn-out		
1	intrusive		
1	upsetting		
1	demeaning		
1	disabling		
1	twisting		
1	positive		
1	friendly		
1	bullying		
1	inhuman		
1	anxiety		
1	awkward		
1	formal		
1	unfair		
1	quick		
1	cruel		
1	hard		
1	easy		

We are aware that people with some specific conditions regularly face the same problems with the PIP system, and also that some conditions have a disproportionate 'fail' rate. We were interested to see whether a claimant's condition affected how they felt at different stages of the process. Questions 13-18 are therefore broken down by condition, and the proportion of people with each condition giving a particular answer is also shown. It should be noted that there are some issues with breaking down responses by condition, and these are explained in the section 'Points to note'.

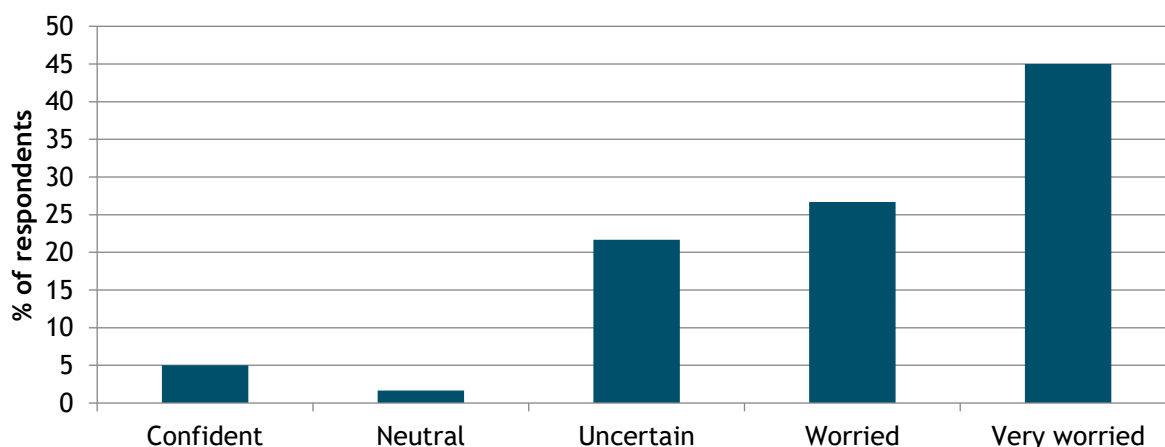
Q13. - Looking at claimants' feelings at the start of the process, based on previous understanding and awareness



All surveyees responded to this question. The question was applicable to all surveyees. A small proportion (5.0%) of surveyees felt 'confident' about the application process pre-application, based on what they knew about PIP. More than one in five (21.7%) felt 'uncertain', and overall almost three quarters (71.7%) were either 'worried' (26.7%) or 'very worried', the highest level of concern (45.0%)

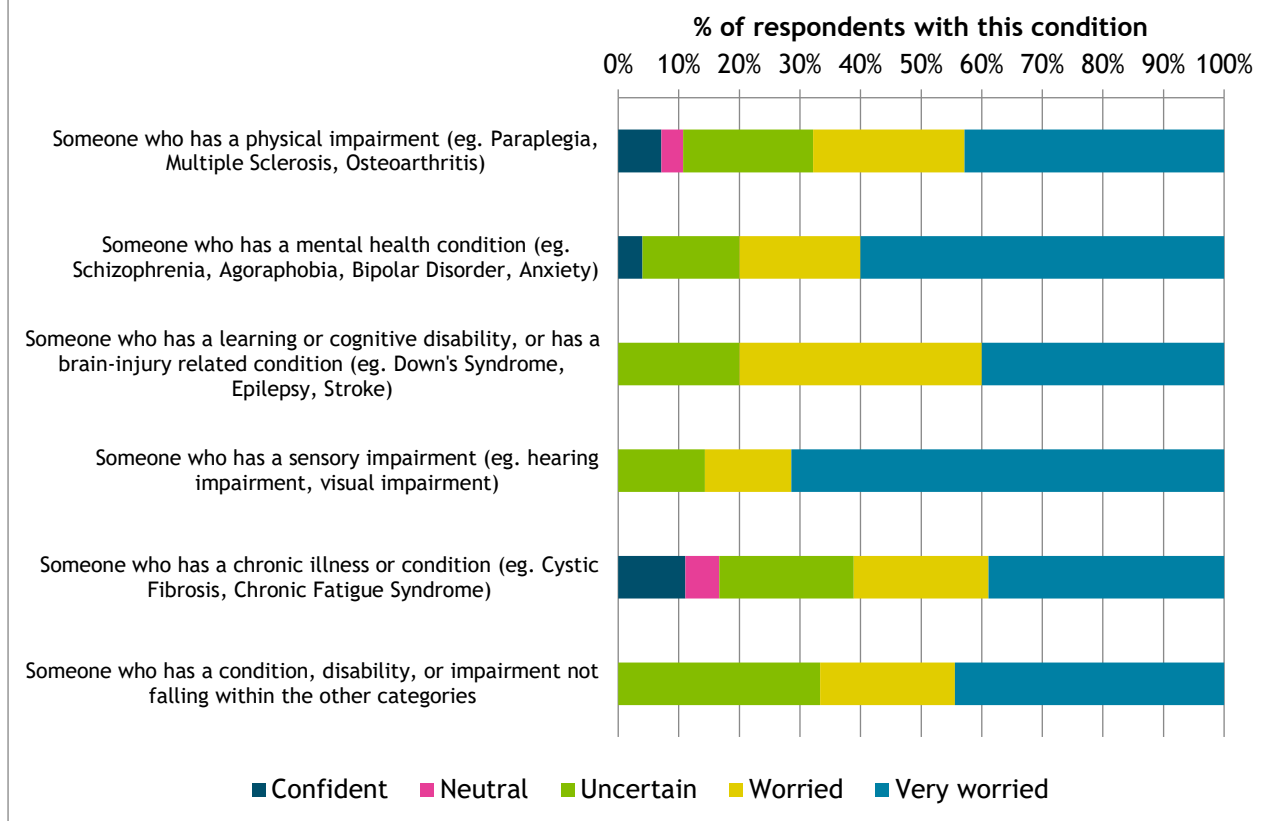
Broken down by condition, applicable respondents who had a chronic illness or condition were the most likely to feel 'confident' at this stage of the process (11.7% of those with this type of condition), whereas no-one with either a learning, cognitive or brain-injury related condition, a sensory impairment, or a condition outside of the categories reported feeling confident at this stage. Respondents with a sensory impairment reported the highest level of concern, with 85.3% answering either 'worried' or 'very worried'. People with learning, cognitive, or brain-injury related conditions answering similarly, with a large majority selecting either answer (80.5%). Those with a chronic illness or condition had the lowest proportion of 'worried' or 'very worried' responses, at 61.3%, though it should still be noted that this is nearing two thirds of respondents with that type of condition. The proportionally highest group answering 'very worried' to question 13 were people with a sensory impairment (68.7% of those with that category of condition).

### Q13. From what you already knew about PIP, choose the best description of how you were feeling about the application process: before you applied for PIP





## Q13. Condition breakdown



### Q14. - Looking at claimants' feelings at the application form stage

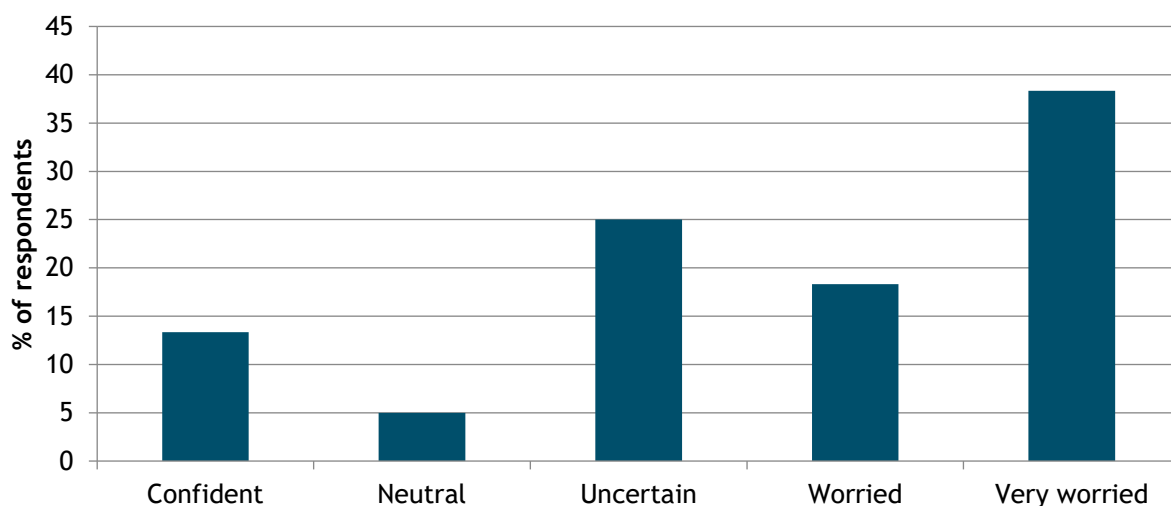
All surveyees responded to this question. The question was applicable to all surveyees, although if anyone had answered 'I've received the forms but have not been able to complete them' the question would not have been applicable to all respondents. A greater proportion of respondents felt either 'confident' (13.3%) or 'neutral' (5.0%) at this stage in comparison to that in Q13. In fact, almost three times as many people reported feeling more certain or neutral at the form-filling stage of the assessment (18.3%) than pre-assessment (6.7%). However, a quarter (25.0%) felt 'uncertain', and the majority (56.7%) answered either 'worried' (18.3%) or 'very worried' (38.3%).

Broken down by condition, applicable respondents who had a chronic illness or condition, or a physical impairment were the most likely to feel 'confident' at this stage of the process (21.1% and 21.8%, respectively, of those with this type of condition), whereas no-one with a sensory impairment reported feeling confident at this stage. Again, respondents with a sensory impairment reported the highest levels of concern, with 72.1% answering either 'worried' or 'very worried'. Those with a physical impairment had the lowest proportion of 'worried' or 'very worried' responses, at 43.8%, though it should still be noted that this is nearing half of respondents with that type of condition. The proportionally highest group answering 'very worried' to question 14 were people with a mental health condition, more than half (50.3%) of whom answered in this way. The

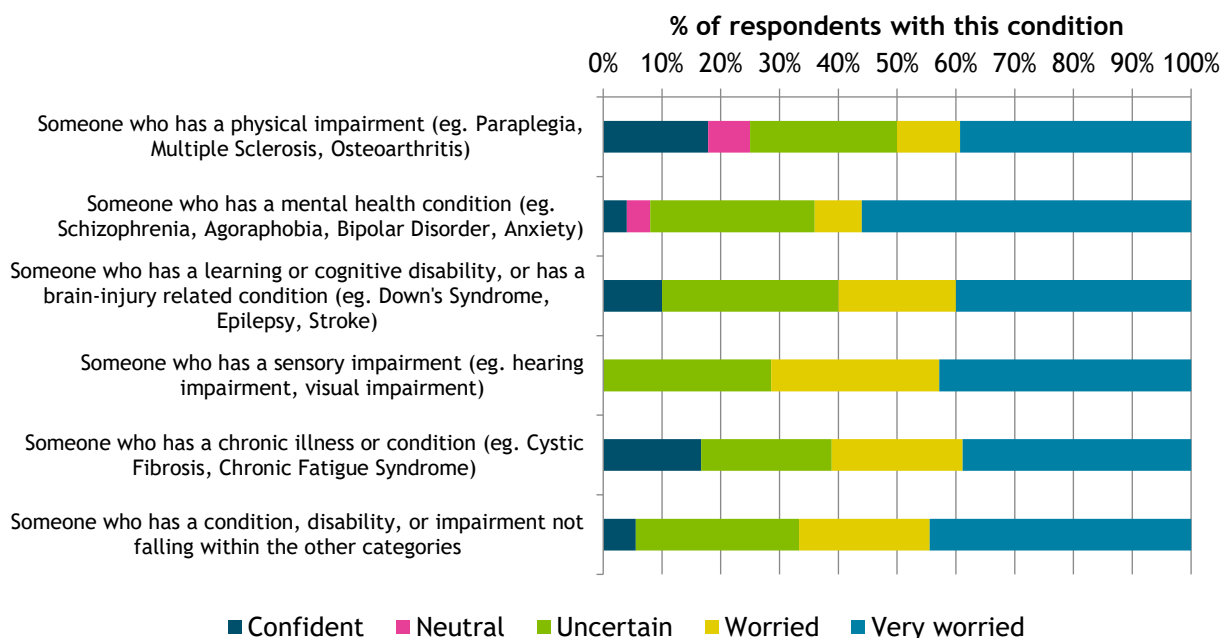


proportion of people with other types of condition who answered 'very worried' was roughly a third.

### Q14. Choose the best description of how you were feeling about answering the questions and providing evidence: when you were filling out the forms



### Q14. Condition breakdown



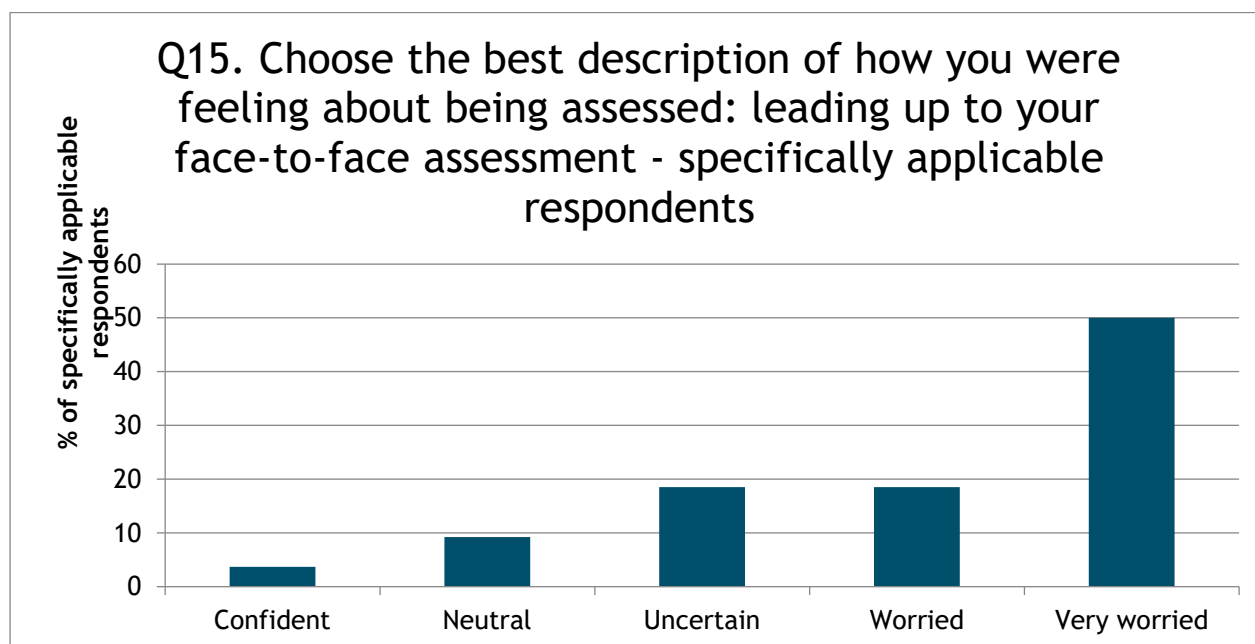




### Q15. - Looking at claimants' feelings pre-assessment

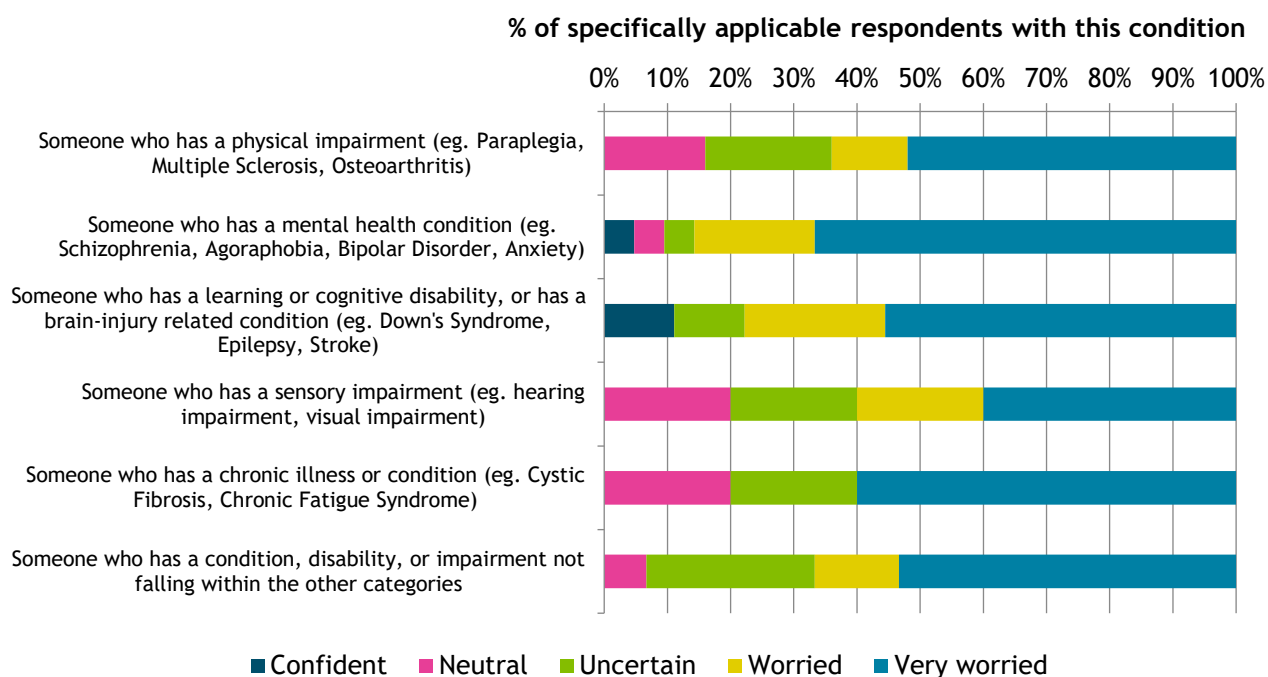
All surveyees responded to this question. The question was broadly applicable to 91.7% of respondents (55), based on how far they had progressed through the PIP process according to their answer. The question was specifically applicable to 88.3% of respondents (53) as the question was not applicable to those who didn't have a face-to-face assessment. Exactly half (50.0%) of applicable respondents reported feeling 'very worried' leading up to their face-to-face assessment, with a further 18.5% answering 'worried'. A small proportion (3.7%) felt 'confident' at this stage.

Broken down by condition, applicable respondents who had a learning or cognitive disability, or who had a brain-injury related condition were the most likely to feel 'confident' at this stage of the process (16.7%), whereas no-one with a physical impairment, sensory impairment, chronic illness or condition, or other uncategorizable condition reported feeling confident at this stage. Applicable respondents with a mental health condition reported the highest levels of concern, with 83.2% answering either 'worried' or 'very worried'. Those with a chronic illness or condition had the lowest proportion of 'worried' or 'very worried' responses, at 57.7%, though it should still be noted that this is more than half of respondents with that type of condition. The proportionally highest group answering 'very worried' to question 15 were again those with a chronic illness or condition (57.7%), as no-one from this group answered 'worried'. The lowest proportion giving this answer were those with a sensory impairment (34.6%).





## Q15. Condition breakdown - specifically applicable respondents



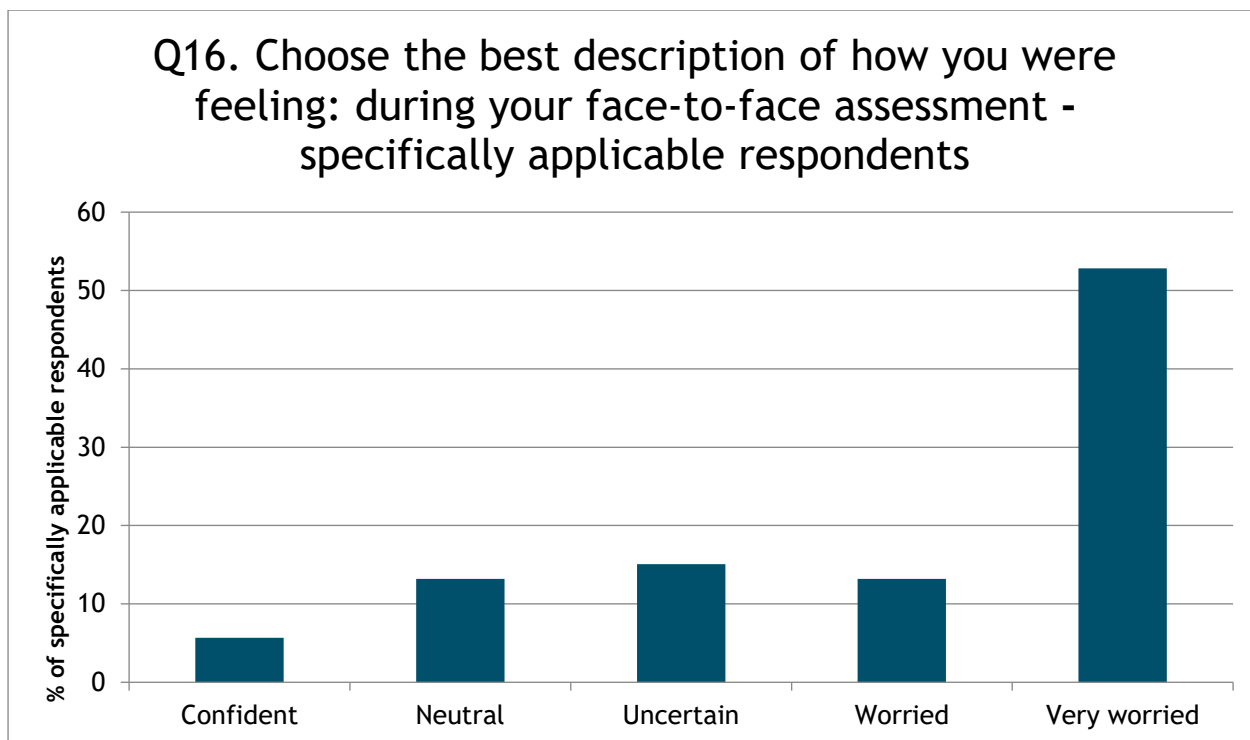
### Q16.- Looking at claimants' feelings during the assessment

All surveyees responded to this question. The question was broadly applicable to 93.3% of respondents (55), based on how far they had progressed through the PIP process according to their answer. The question was specifically applicable to 88.3% of respondents (53) as the question was not applicable to those who didn't have a face-to-face assessment. A low proportion (5.7%) reported feeling 'confident' during their assessment, with an even spread of applicable respondents saying they felt either 'neutral' (13.2%), 'uncertain' (15.1%), or 'worried' (13.2%). More than half were 'very worried' during the assessment (52.8%).

Broken down by condition, applicable respondents who had a learning or cognitive disability, or who had a brain-injury related condition were the most likely to feel 'confident' at this stage of the process (17.6%), whereas no-one with a mental health condition, sensory impairment, chronic illness or condition, or other uncategorizable condition reported feeling confident at this stage. Applicable respondents with a mental health condition reported the highest levels of concern, with 73.4% answering either 'worried' or 'very worried'. Those with a sensory impairment had the lowest proportion of 'worried' or 'very worried' responses, at just over a third (36.5%). The proportionally highest group answering 'very worried' to question 16 were those with a mental health condition (63.9%), making up almost two thirds of the group's answers. For five of the six condition categories (all except those with a sensory impairment) around half of applicable respondents said they were 'very worried' (lowest: 45.0% - physical impairment, highest: 63.9% - mental health condition).

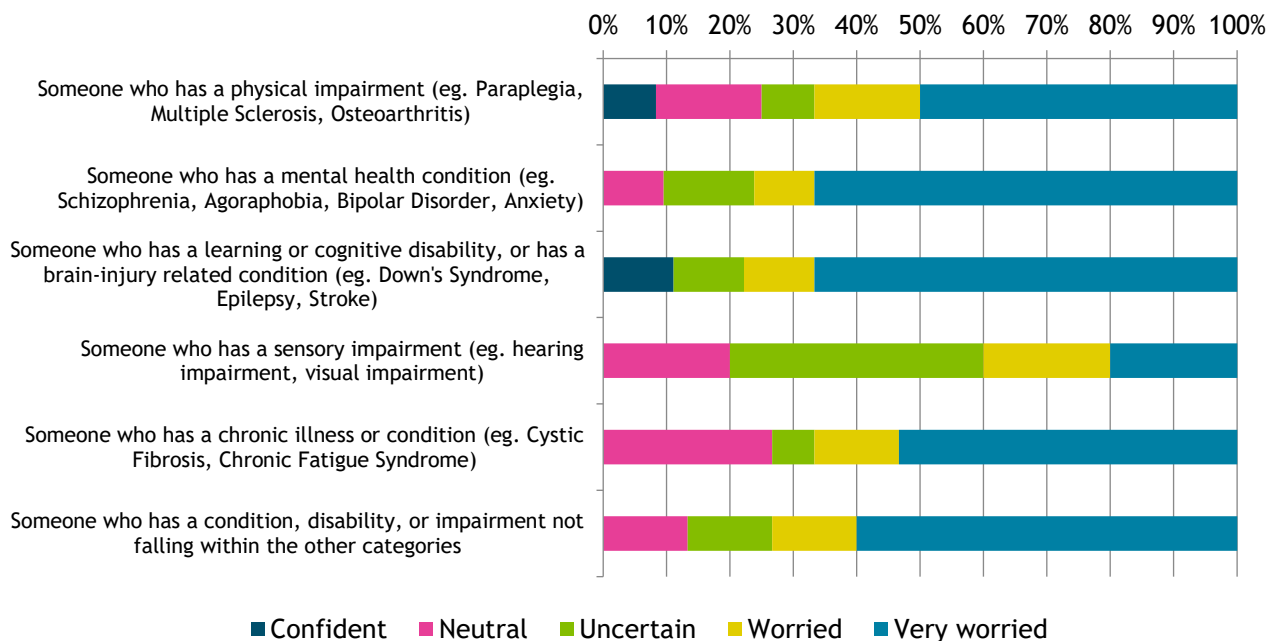


### Q16. Choose the best description of how you were feeling: during your face-to-face assessment - specifically applicable respondents



### Q16. Condition breakdown - specifically applicable respondents

% of specifically applicable respondents with this condition



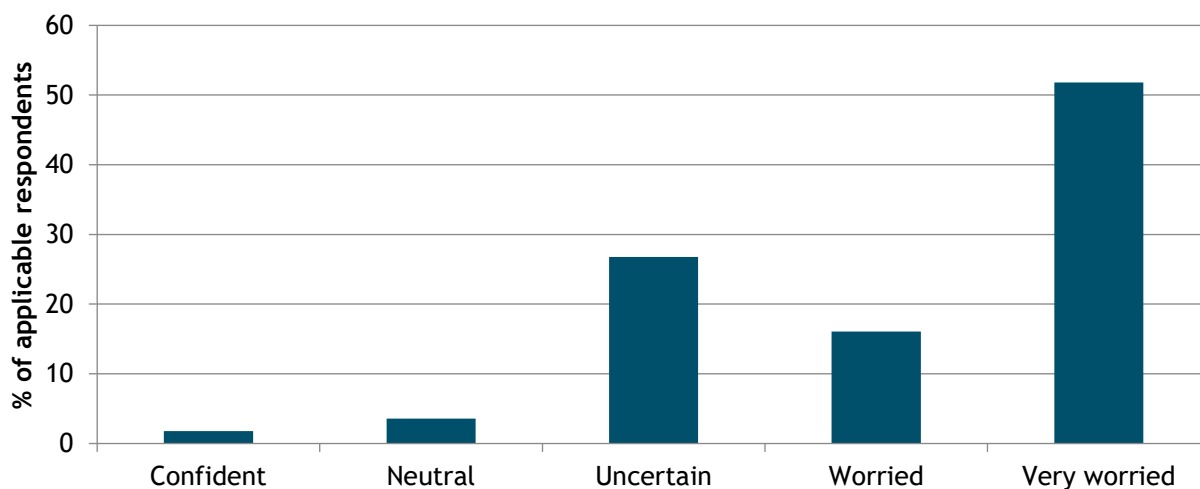


### Q17. - Looking at claimants' feelings post-assessment, pre-result

All surveyees responded to this question. The question was applicable to 93.3% of respondents (56), based on how far they had progressed through the PIP process according to their answer. Very few (1 applicable respondent) felt 'confident' while waiting for the result of their claim. The vast majority (94.7%) were either 'uncertain' (26.8%, over a quarter), 'worried' (16.1%), or 'very worried' (51.8%, over half).

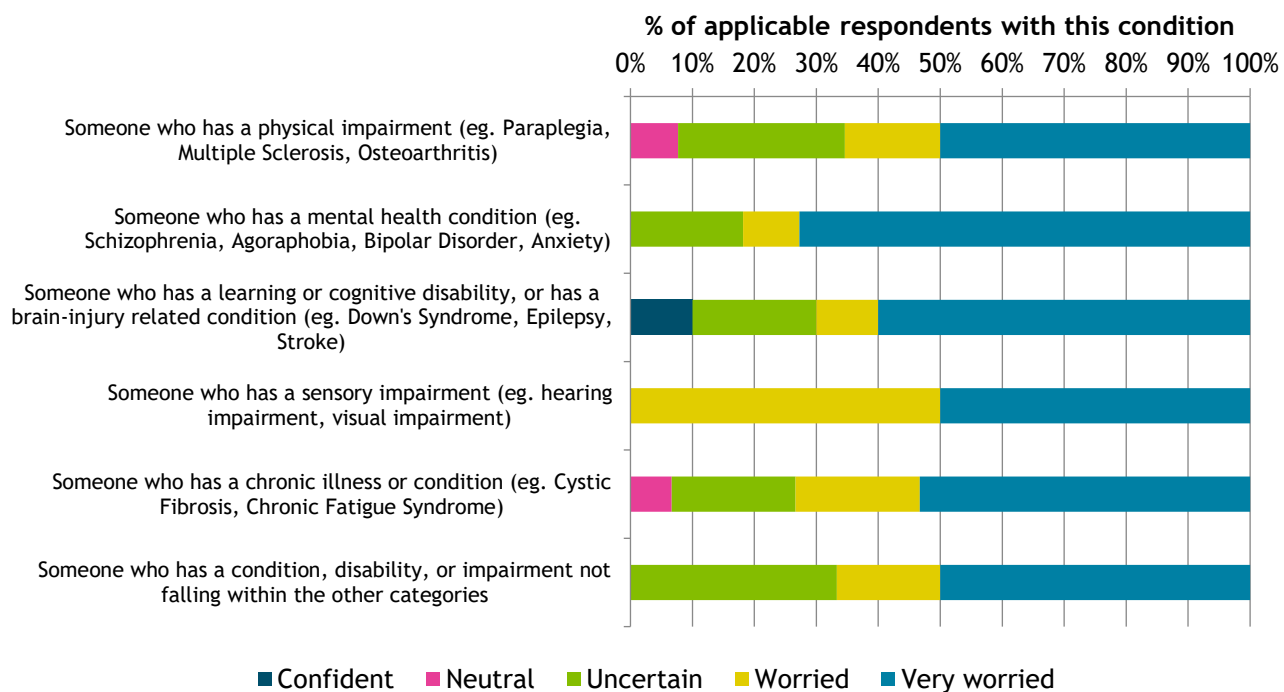
Broken down by condition, applicable respondents who had a learning or cognitive disability, or who had a brain-injury related condition were the only respondents who felt 'confident' at this stage of the process (16.4%). Those with a sensory impairment reported the highest levels of concern, with 100.0% answering either 'worried' or 'very worried'. Those with a physical impairment had the lowest proportion of 'worried' or 'very worried' responses, at 59.9%. The proportionally highest group answering 'very worried' to question 17 were those with a mental health condition (68.7%), making up more than two thirds of the group's answers. For five of the six condition categories (all except those with a sensory impairment) almost half of applicable respondents said they were 'very worried' (lowest: 45.1% - physical impairment, highest: 68.7% - mental health condition).

### Q17. Choose the best description of how you were feeling: while waiting to hear the result - applicable respondents





## Q17. Condition breakdown - applicable respondents



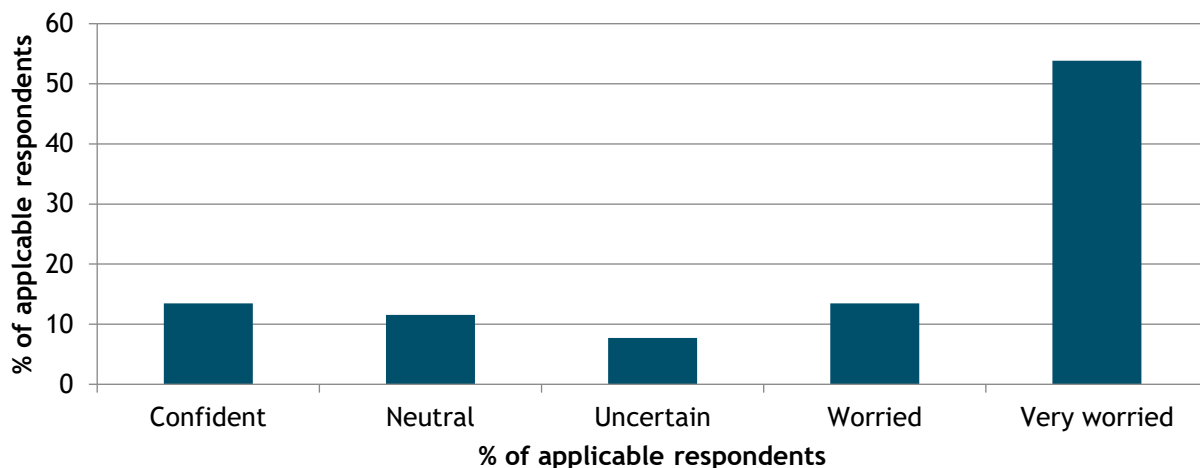
### Q18. - Looking at claimants' feelings on receiving their result

All surveyees responded to this question. The question was applicable to 86.7% of respondents (52), based on how far they had progressed through the PIP process according to their answer. 13.5% of applicable respondents felt 'confident' when they received their result, and almost the same proportion, 11.5%, were 'neutral'. More than two thirds (67.3%) reported a level of concern; either 'worried' (13.5%), or 'very worried' (53.8%). Over half of all applicable respondents (53.8%) said they were 'very worried' once they had got their result.

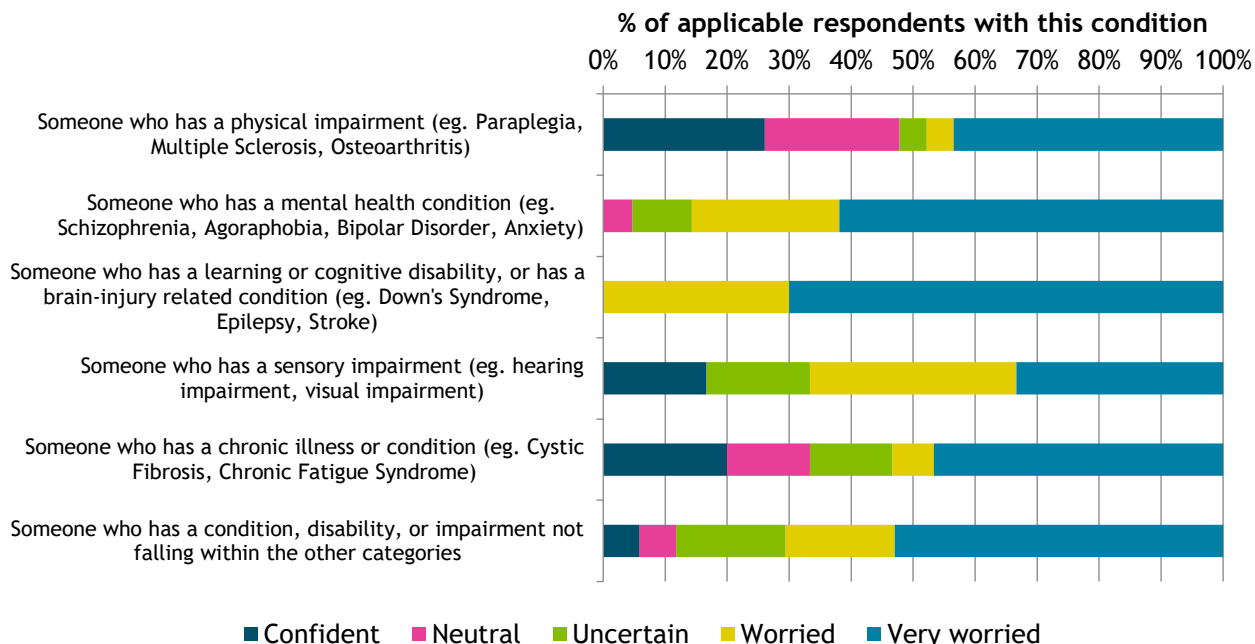
Broken down by condition, applicable respondents who had a physical impairment were the most likely to feel 'confident' at this stage of the process (27.5%), and one in five people with sensory impairments or chronic illnesses or conditions also answered in this way. Applicable respondents with a learning or cognitive disability, or a brain-injury related condition reported the highest levels of concern, with 100.0% answering either 'worried' or 'very worried'. Those with a physical impairment had the lowest proportion of 'worried' or 'very worried' responses, at under half (45.3%), though it should still be noted that this is a significant proportion of respondents with that type of condition. The proportionally highest group answering 'very worried' to question 18 were those with a brain-injury related condition (74.5%), making up almost three quarters of the group's answers. For all groups the proportion of applicable respondents reporting they felt 'worried' or 'very worried' was close to or over half.



## Q18. Choose the best description of how you were feeling: when you received the result - applicable respondents



## Q18. Condition breakdown - applicable respondents





### Q19. - Looking at change in the mobility element of awards

93.3% of surveyees responded to this question (56 respondents). The question was applicable to 78.6% of respondents (44), based on how far they had progressed through the PIP process according to their answer. A very small proportion of applicable respondents' mobility award increased (2.3%). A large minority (38.6%) stayed the same, and almost 60% (59.1%) received a lesser amount of mobility support. There didn't appear to be much of a difference in responses based on type of condition, possibly as many respondents had more than one condition.

### Q19. How did the mobility element of your award change in moving from DLA to PIP? - applicable respondents



### Q20. - Looking at the financial impact of change in the mobility element of awards

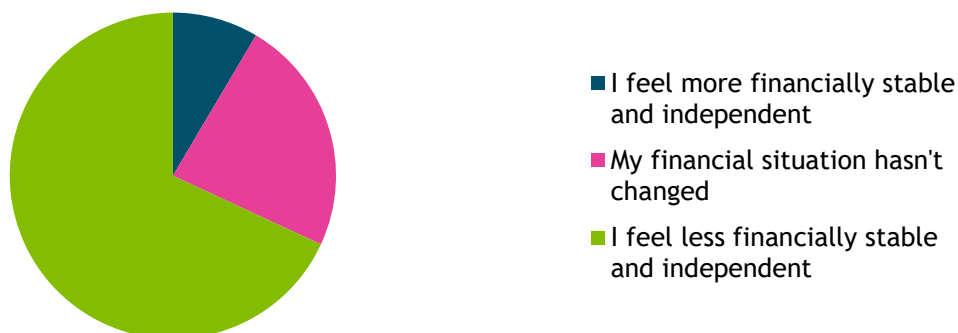
96.7% of surveyees responded to this question (58 respondents). The question was applicable to 81.0% of respondents (47), based on how far they had progressed through the PIP process according to their answer. Less than one in ten (8.5%) felt more financially stable as a result of the mobility support they were awarded. Just under a quarter (23.4%) felt their financial stability hadn't changed. More than two thirds (68.1%) reported feeling their financial stability and independence had decreased.

No-one with a condition outside of the specified categories said they felt more financially stable, whereas a low proportion of those from other groups answered in this way (for all other types of condition this was under 17%). The categories of people with an uncategorizable condition, a mental health condition, and those with a learning or cognitive disability or brain-injury related condition had very high proportions receiving a lesser award (84.6%, 83.3%, and 80.0% respectively). The type of condition with the lowest proportion of affected people losing out was physical disabilities, with just over half (52.2%) receiving a reduced award. This is what might be expected as those with physical disabilities may be more likely to have mobility needs, and for these to be more easily and obviously assessable.

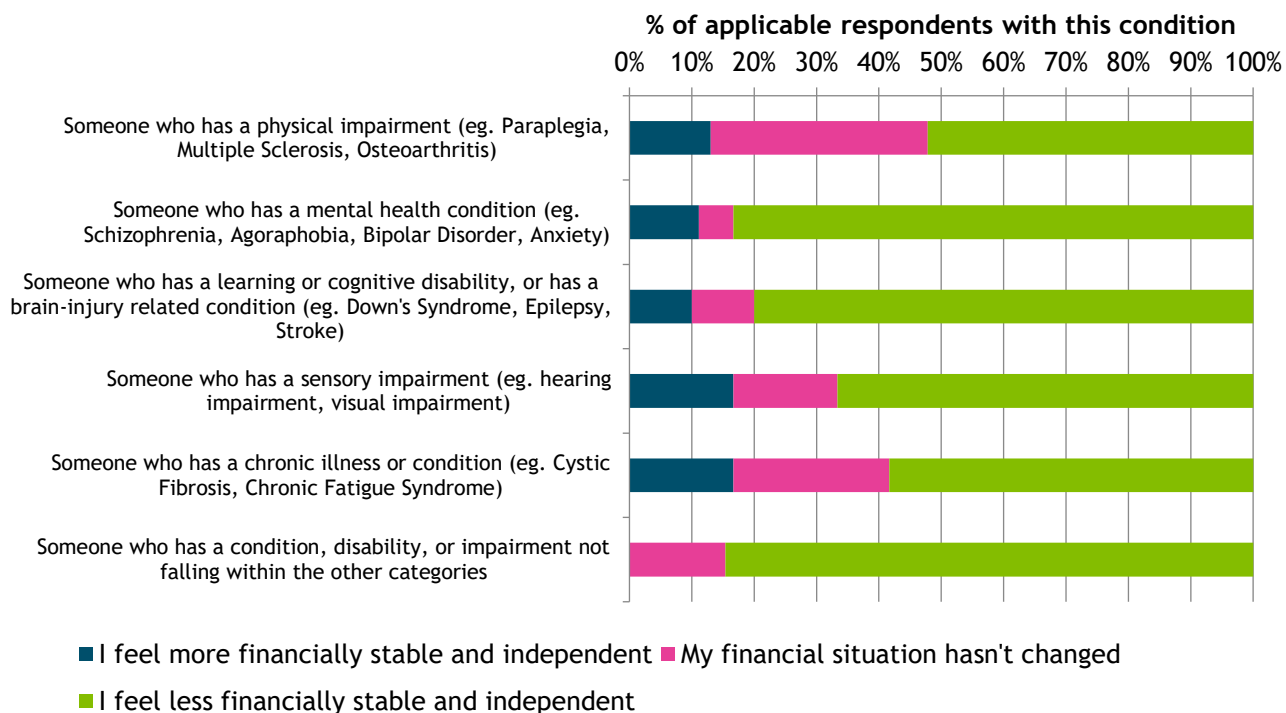




## Q20. What financial impact has the change to your mobility award had? - applicable respondents



## Q20. Condition breakdown - applicable respondents

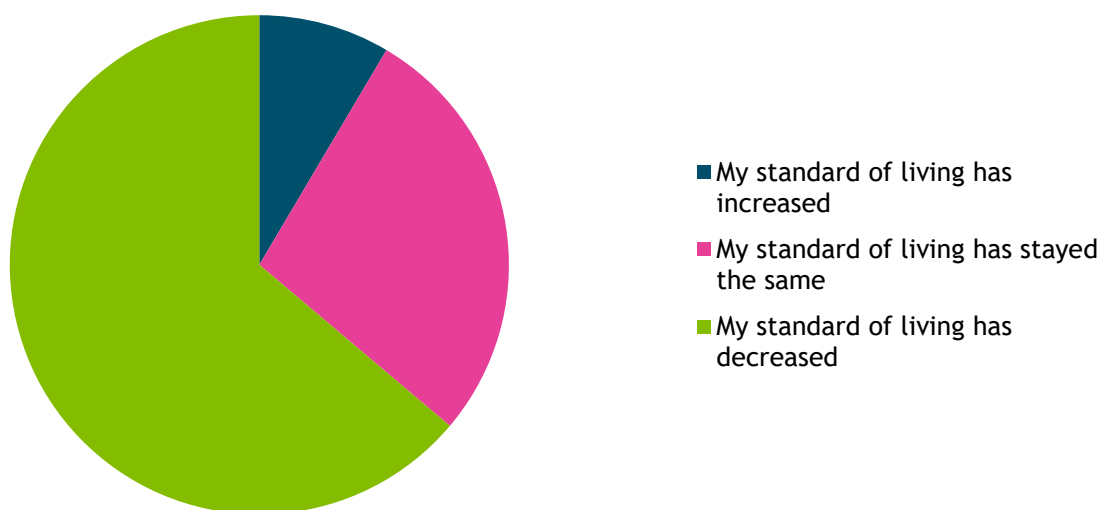




**Q21. - Looking at the impact on claimants' standard of living as a result of change in the mobility element of awards**

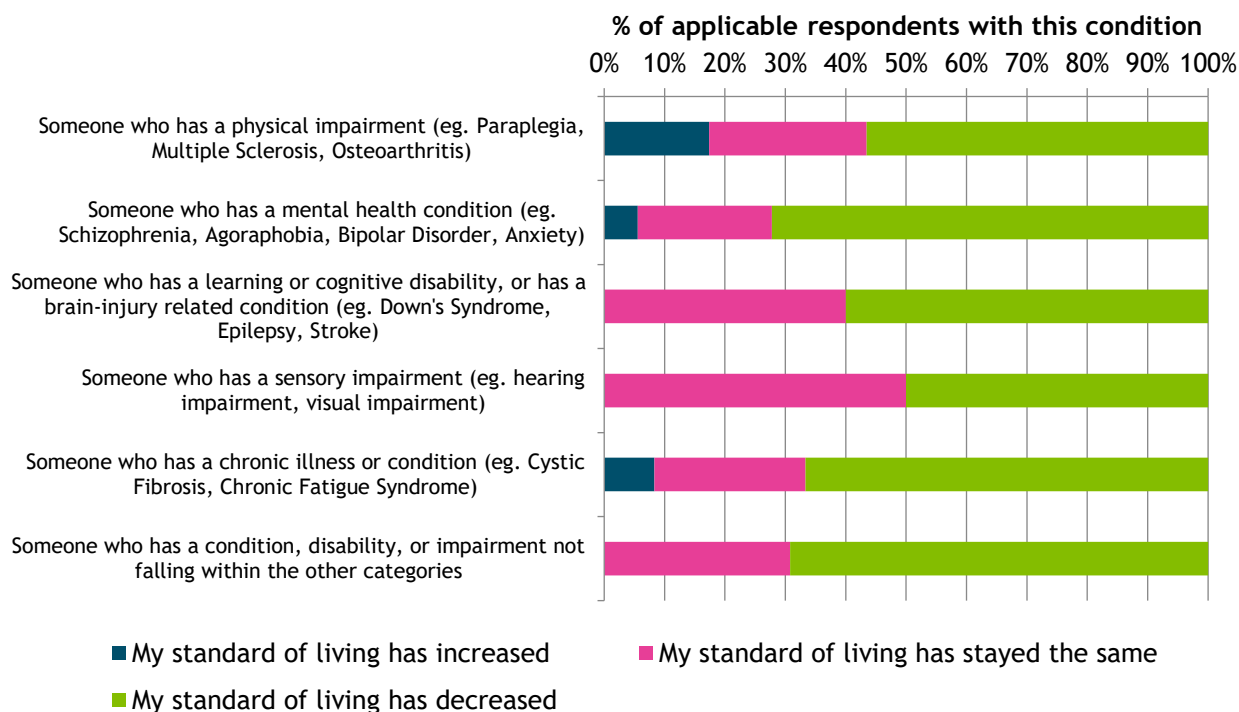
96.7% of surveyees responded to this question (58 respondents). The question was applicable to 81.0% of respondents (47), based on how far they had progressed through the PIP process according to their answer. Less than one in ten (8.5%) felt their standard of living had improved as a result of the mobility support they were awarded. Just over a quarter (27.7%) felt it hadn't changed. Just under two thirds (63.8%) reported a decrease in their standard of living. These figures are very close to the results of question 20, regarding the financial impact of a change in mobility award, suggesting the two consequences - financial stability and standard of living - are related, which logically follows. The group with the greatest proportion of people who said their standard of living had increased were those with a physical impairment, in line with this category of condition feeling more financially stable than other categories. Once again, however, the proportion of people with a physical impairment receiving a greater amount of mobility support did not differ very much from that of other categories of condition.

**Q21. What impact has the change to your mobility award had on your standard of living? (eg. taking into account your general health and wellbeing, social life, independence etc.) - applicable respondents**





## Q21. Condition breakdown - applicable respondents



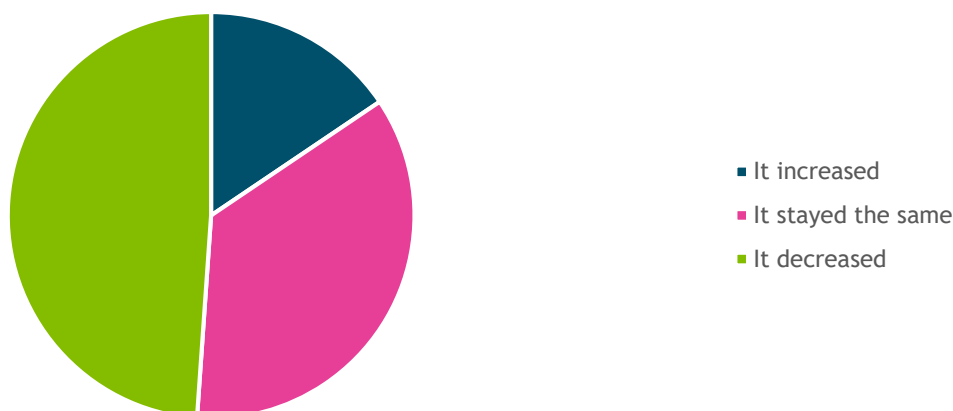
### Q22. - Looking at change in the living element of awards

95.0% of surveyees responded to this question (57 respondents). The question was applicable to 78.9% of respondents (45), based on how far they had progressed through the PIP process according to their answer. A greater proportion of applicable respondents received an increased amount of living support compared to mobility support (15.6% increased living, compared to 8.5% mobility). More than a third (35.6%) of applicable respondents received the same level of living support, and just under half (48.9%) were awarded a lesser amount than they received under DLA.

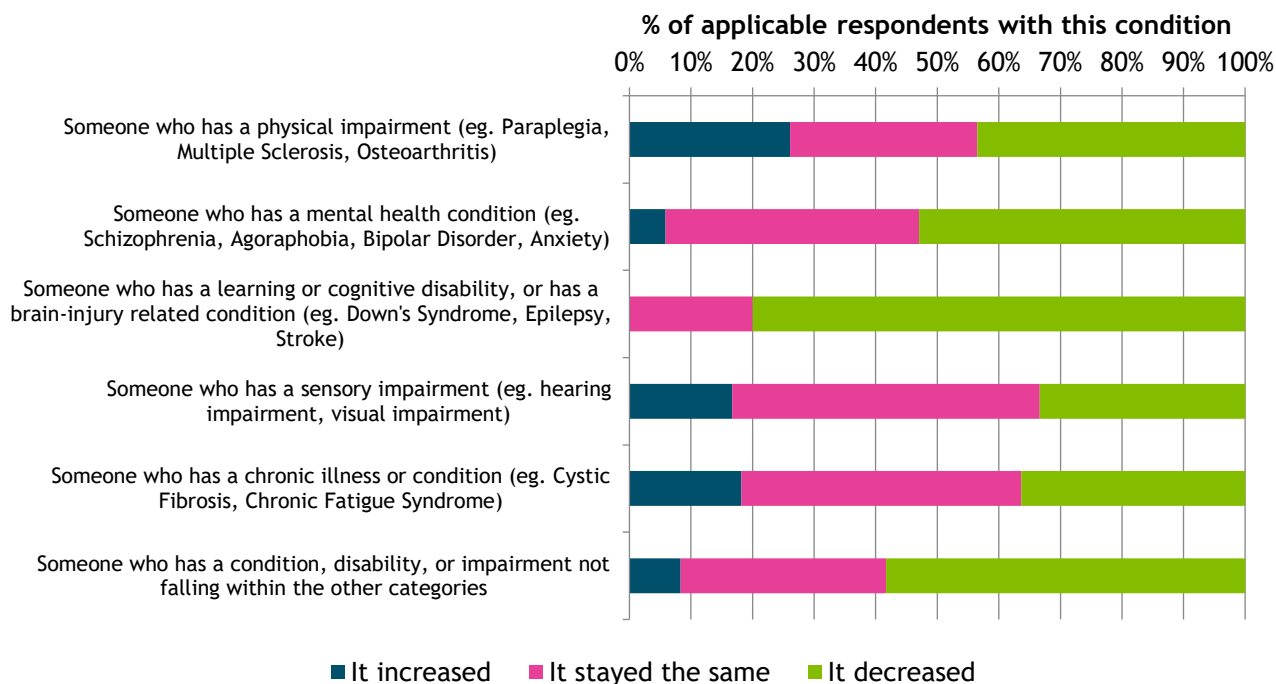
Those with learning or cognitive disabilities, or who had brain-injury related conditions were the only group to not report any increase in their living award. They also had the greatest proportion of people receiving a reduction, at 80.0% - far higher than the next most affected group reporting this change, those with mental health conditions, at 52.9%. The most 'successful' group were those with a physical impairment; more than a quarter (26.1%) received an increased level of living support.



## Q22. How did the care or living element of your award change in moving from DLA to PIP? - applicable respondents



## Q22. Condition breakdown - applicable respondents

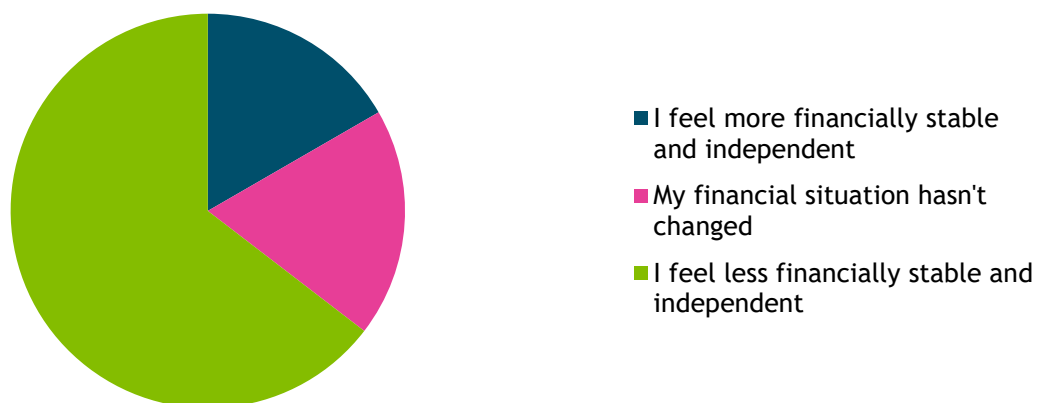




### Q23. - Looking at the financial impact of change in the living element of awards

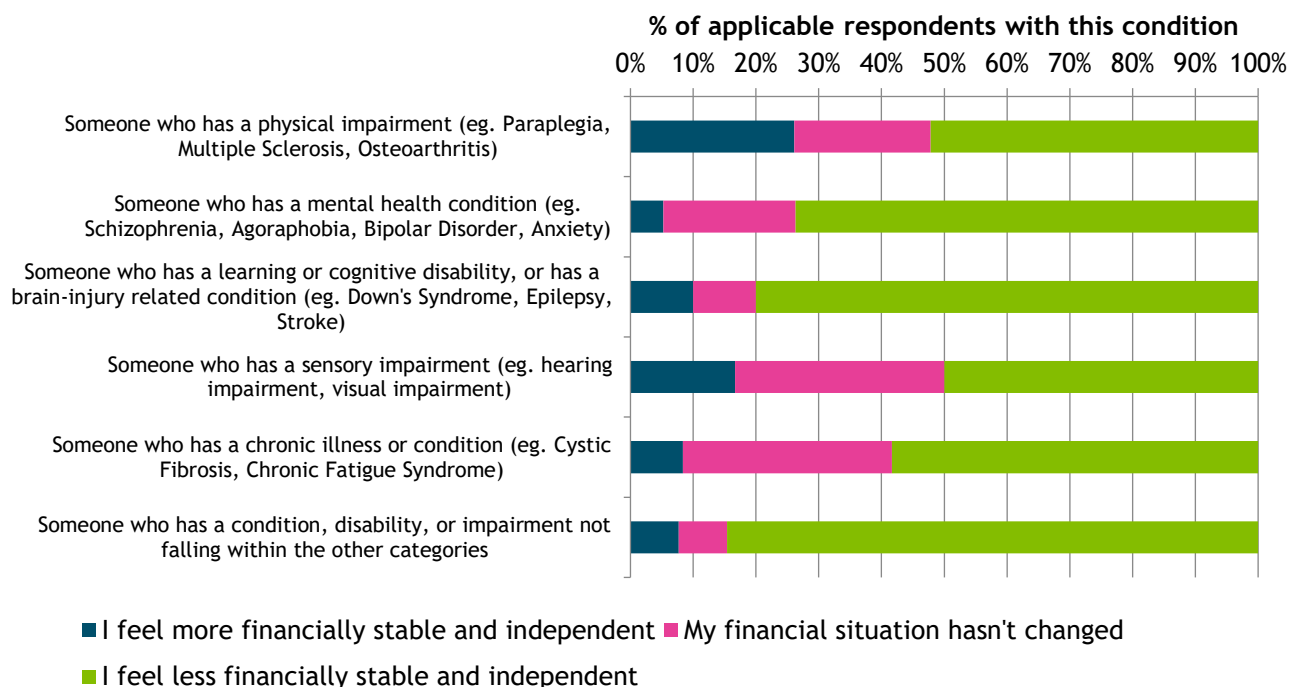
96.7% of surveyees responded to this question (58 respondents). The question was applicable to 82.8% of respondents (48), based on how far they had progressed through the PIP process according to their answer. Almost two thirds (64.5%) reported feeling less financially stable as a result of the change, and almost equal proportions felt more stable (16.7%) and reported no difference (18.8%). In line with the proportion receiving a greater amount of living support, those with physical impairments were most likely to say they felt more financially stable (26.1%, over a quarter, compared to the next highest proportion, 16.7% of those with sensory impairments). Those with mental health conditions were least likely to report feeling more financially stable, with only 5.3% of this group answering in this way. The category most negatively affected was those with a condition not falling in the other categories, with 84.6% feeling less financially stable. Four out of five (80.0%) with learning or cognitive disabilities or brain-injury related conditions also reported this reduced stability. At least half (50.0%-84.6%) of every group were left less financially stable as a result of the change in their living award.

### Q23. What financial impact has the change to your care or living award had? - applicable respondents





## Q23. Condition breakdown - applicable respondents

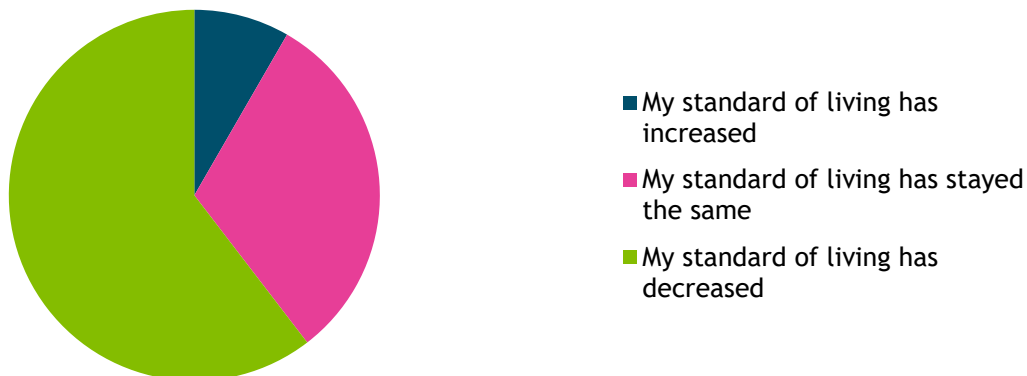


### Q24. - Looking at the impact on claimants' standard of living as a result of change in the living element of awards

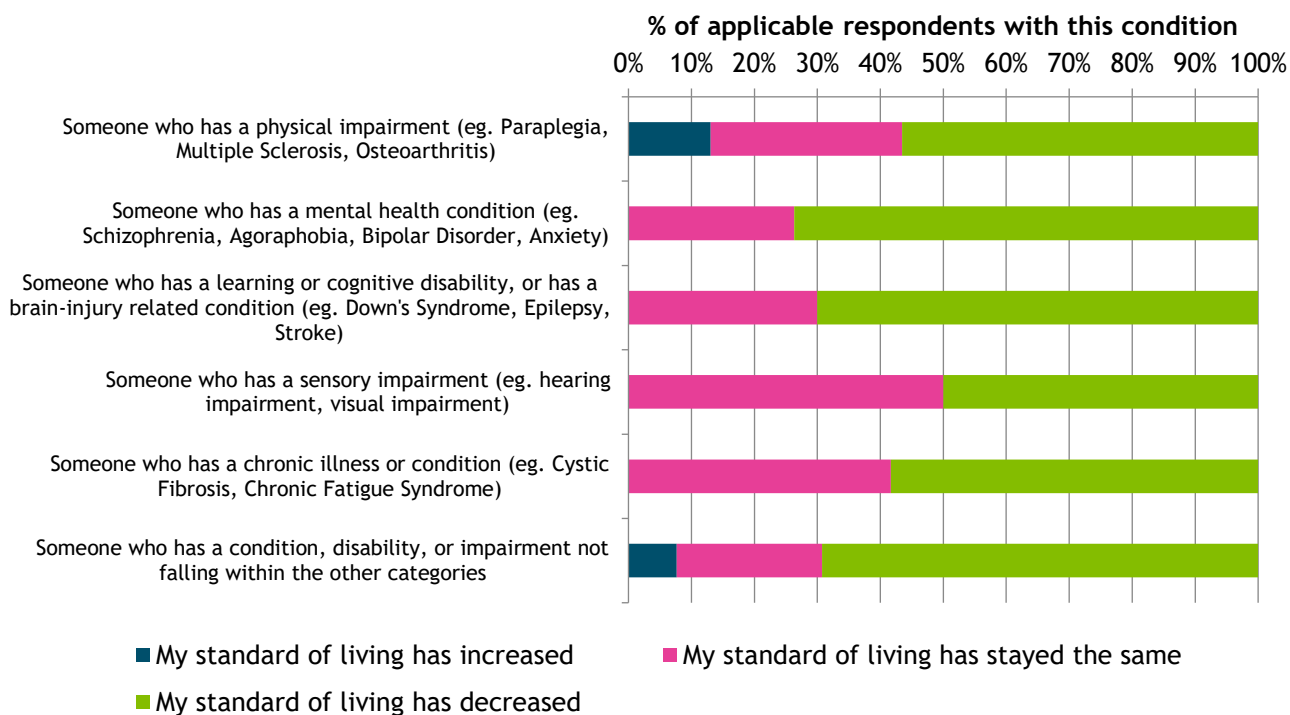
96.7% of surveyees responded to this question (58 respondents). The question was applicable to 82.8% of respondents (48), based on how far they had progressed through the PIP process according to their answer. A small proportion (8.3%) saw an increase in their standard of living as a result of the change in their living award. Almost a third (31.3%) saw no difference, and three in five saw a reduction in their standard of living (60.4%). Those reporting an improvement only had two types of condition: physical impairments and uncategorised conditions. People with a mental health condition were the worst affected, with almost three quarters (73.7%) saying their standard of living had decreased. Exactly half of those with a sensory impairment reported a drop, and this was the lowest proportion across the different condition categories.



**Q24. What impact has the change to your care or living award had on your standard of living? (eg. taking into account your general health and wellbeing, social life, independence etc.) - applicable respondents**



**Q24. Condition breakdown - applicable respondents**



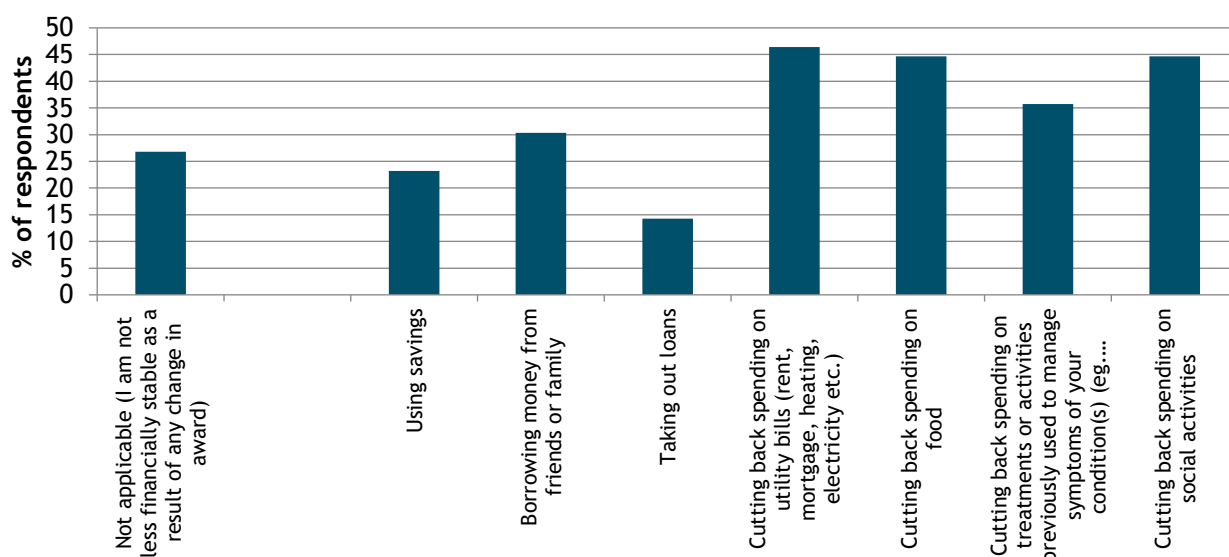




Q25. - Looking at ways in which claimants have coped with a change in financial stability as a result of a change in award

93.3% of surveyees responded to this question (56 respondents). 26.8% of respondents (15) answered 'Not applicable (I am not less financially stable as a result of any change in award)'. Of the 41 who had made changes to cope with a change in award, the most common way of handling financial change was spending less on bills, including rent, heating etc. This made up almost one fifth of all applicable responses (19.4%), and was reported by almost two thirds of these applicable respondents (63.4%). A similar proportion of responses concerned cutting back on food spending and social activities to save money (each activity making up 18.7% of applicable responses, and affecting 61.0% of applicable respondents). Fewer people said they had taken out loans (6.0% of all applicable responses, with 19.5% of applicable respondents giving this answer) than had used savings (9.7% of all applicable responses, 31.7% of applicable respondents said they has done this, potentially as they may not have savings to draw on).

Q25. If a change in your overall award has meant you are less financially stable, how have you handled this? Please select all options which apply



Q26. - Looking at the impact of a change in award on claimants' physical health

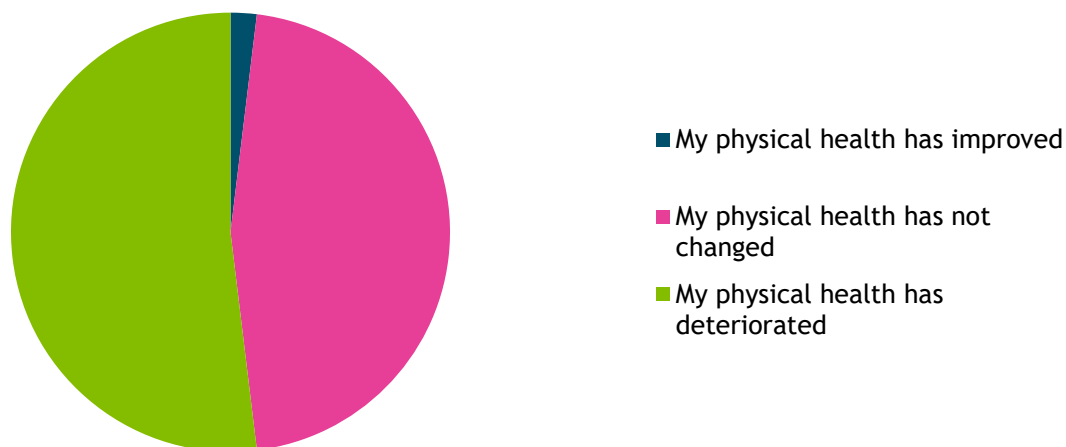
96.7% of surveyees responded to this question (58 respondents). The question was applicable to 89.7% of respondents (52), based on how far they had progressed through the PIP process according to their answer.

A very small proportion (3.3%) of applicable respondents said their physical health had improved as a result of a change in their overall award, and these only came from one group; those with uncategorisable conditions. Over three quarters (76.7%) reported no difference, and one in five (20.0%) said their physical health had deteriorated. No respondents with sensory impairments or learning or cognitive disabilities, or brain-injury related conditions felt their physical health had changed at all in response to a change in

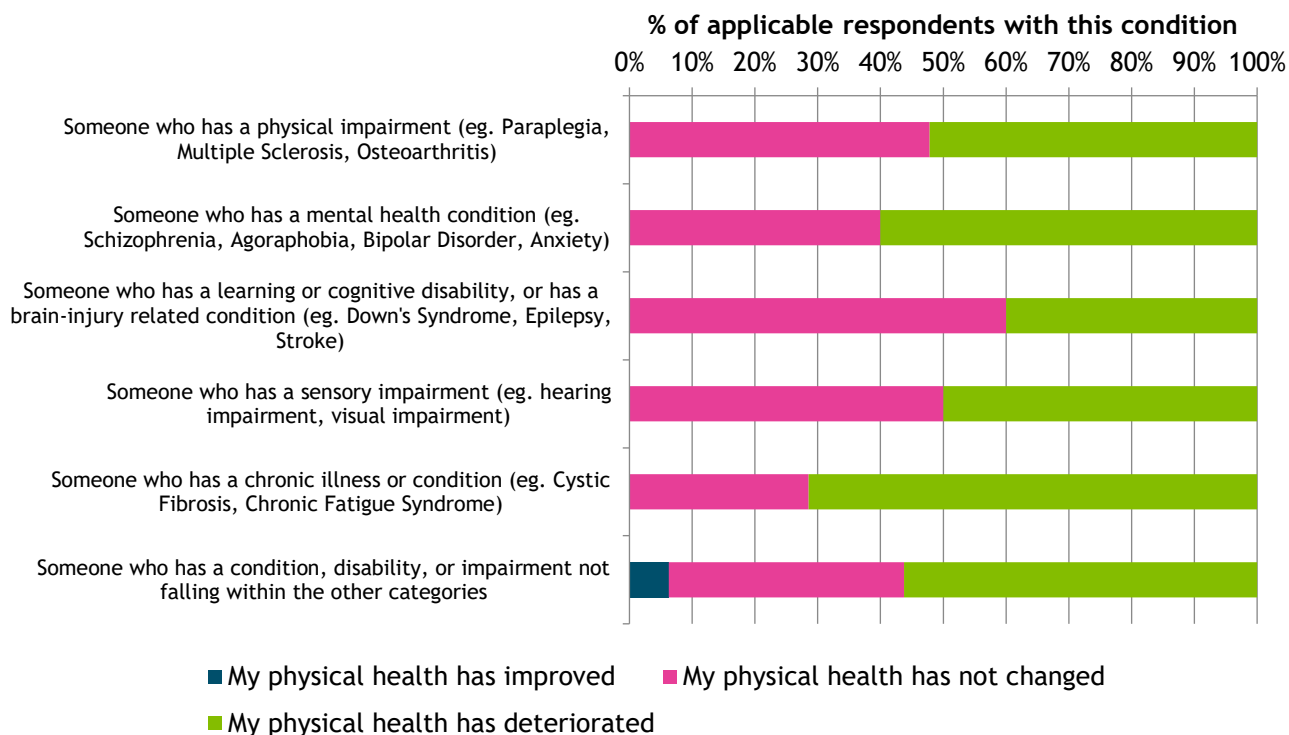


their award. A third of those with chronic illnesses or conditions (33.3%, the highest proportion by condition) experienced a decrease in the level of their physical health.

### Q26. How do you feel your physical health has changed, if at all, as a result of the change in your award? (Please try to answer just considering the change in award, not the assessment process) - applicable respondents



### Q26. Condition breakdown - applicable respondents





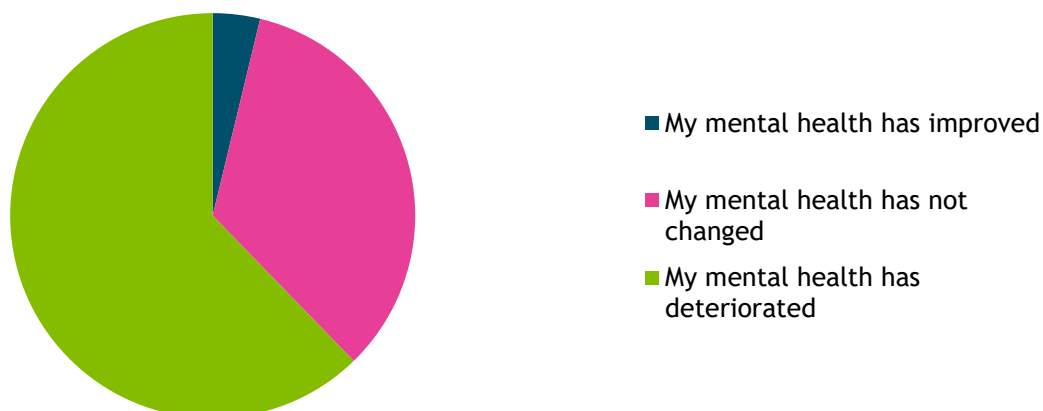
### Q27. - Looking at the impact of a change in award on claimants' mental health

96.7% of surveyees responded to this question (58 respondents). The question was applicable to 91.4% of respondents (53), based on how far they had progressed through the PIP process according to their answer.

Again, a very small proportion (3.8%) of respondents reported an improvement in their mental health as a result of the change in their reward. Mirroring the responses to question 26 regarding physical health, just over a third (34.6%) reported no change and 61.5% reported a deterioration of their mental health. Those reporting an improvement either had a physical impairment or an uncategorisable condition. No change was seen by around a third of most groups, with the notable exceptions of those with physical impairments, for whom it was a greater proportion of 43.5%, and those with mental health conditions for whom it was less than one in five (19.0%). At least half of applicable respondents, regardless of condition, said their mental health had deteriorated, with the lowest proportion being 52.2% (physical impairments, and the highest 81.0% (mental health conditions). The other three categories saw around two thirds reporting a decrease in the level of their mental health.

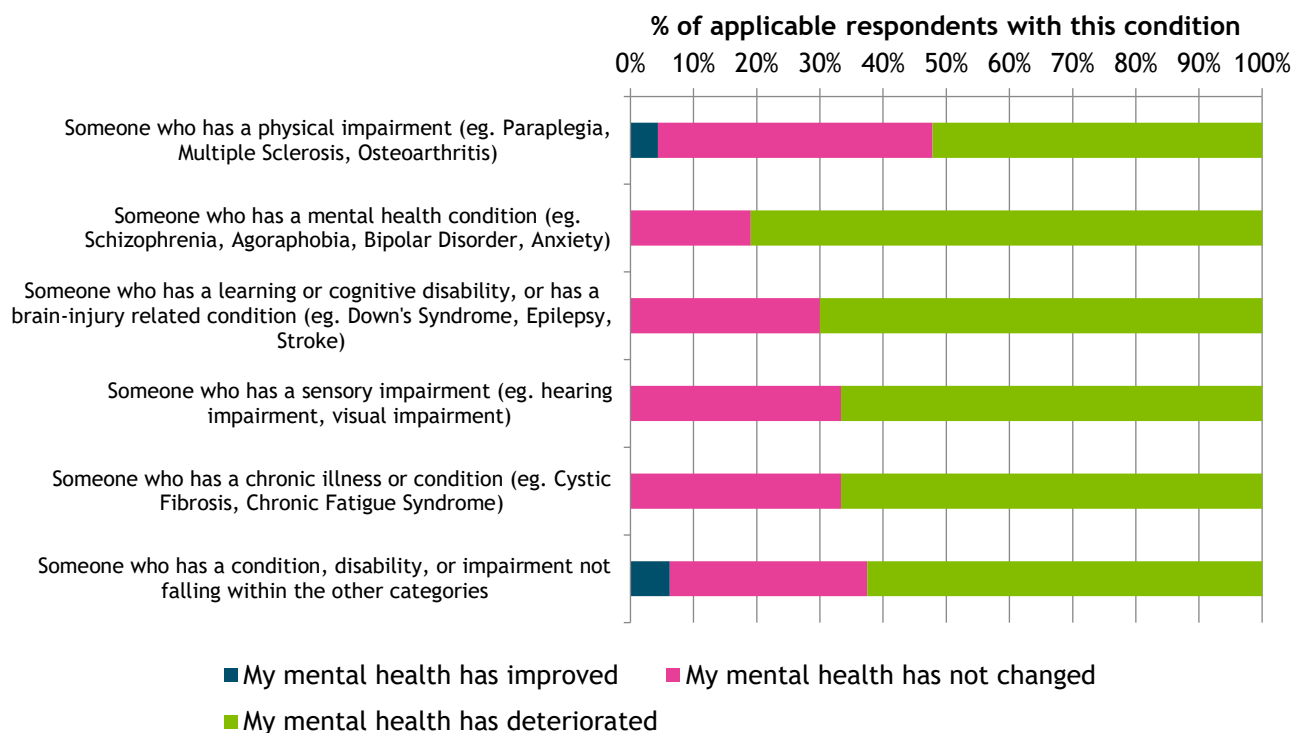
A greater proportion of respondents reported deterioration in their mental health than their physical health in regard to the change in their award.

### Q27. How do you feel your mental health has changed, if at all, as a result of the change in your award? (Please try to answer just considering the change in award, not the assessment process) - applicable respondents





## Q27. Condition breakdown - applicable respondents



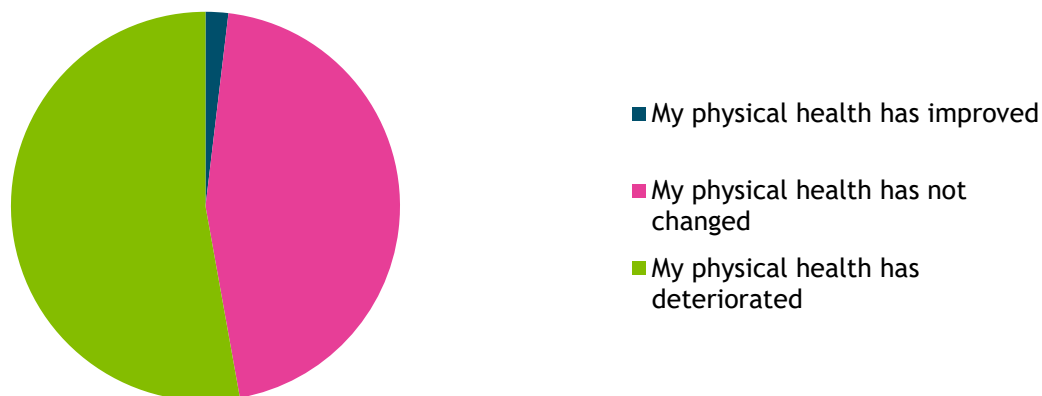
### Q28. - Looking at the impact of the application process on claimants' physical health

96.7% of surveyees responded to this question (58 respondents). The question was applicable to 91.4 % of respondents (53), based on how far they had progressed through the PIP process according to their answer.

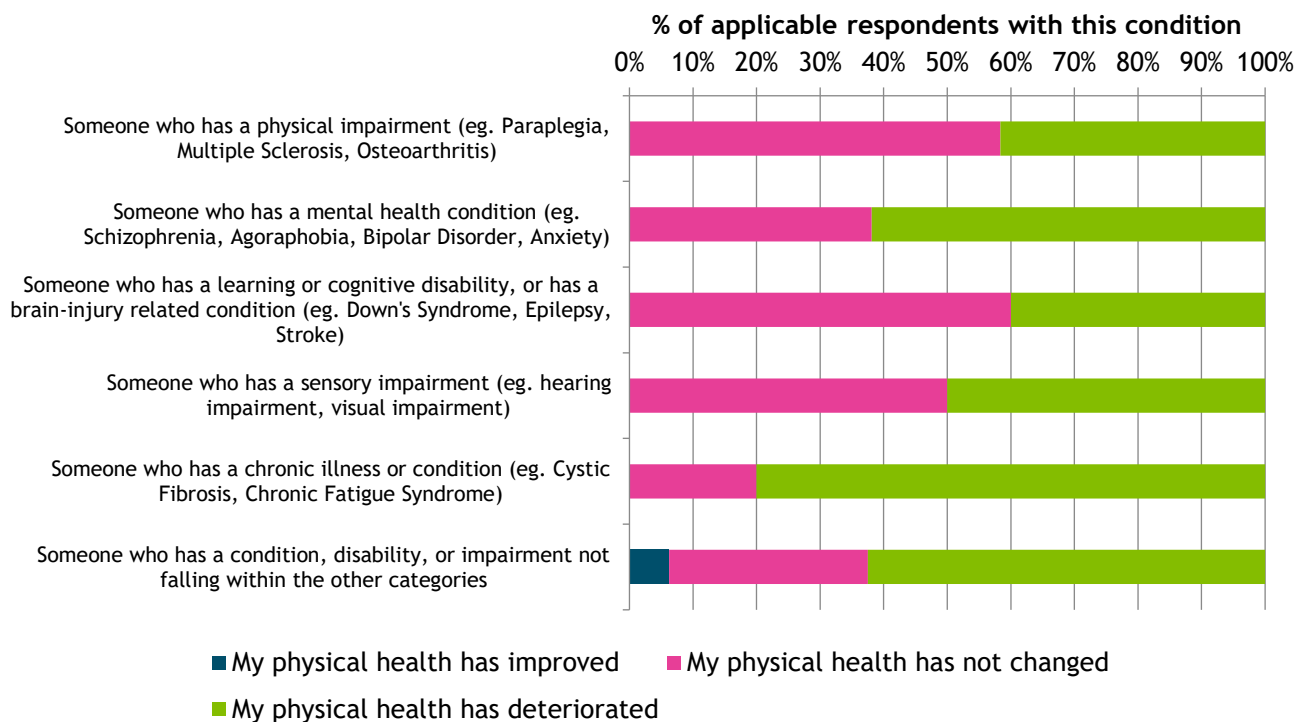
A very small proportion (1.9%) of applicable respondents felt their physical health had improved as a result of the PIP assessment process, but more than half (52.8%) said theirs had deteriorated. The only group reporting an improvement were those with an uncategorisable condition. Four out of five (80.0%) applicable respondents with a chronic illness or condition felt their physical health had worsened, and at least 40% of all condition category groups responded in this way.



Q28. How do you feel your physical health has changed, if at all, as a result of the PIP assessment process? (Please try to answer just considering the assessment process, not the change in award) - applicable respondents



### Q28. Condition breakdown - applicable respondents



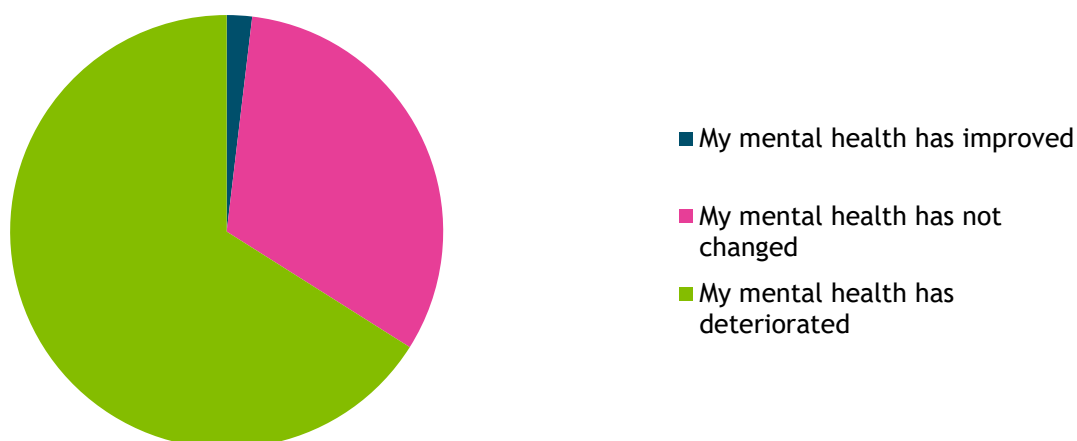


### Q29. - Looking at the impact of the application process on claimants' mental health

96.7% of surveyees responded to this question (58 respondents). The question was applicable to 91.4 % of respondents (53), based on how far they had progressed through the PIP process according to their answer. Only 1.9% of applicable respondents reported an improvement, while just under two thirds (66.0%) of applicable respondents reported that their physical health had deteriorated as a result of the process. This was overwhelmingly the most common answer from applicable respondents with a mental health condition - 90.5% of whom reported their mental health had deteriorated due to the PIP assessment process. At least half of respondents in each condition category group felt their mental health had been negatively affected.

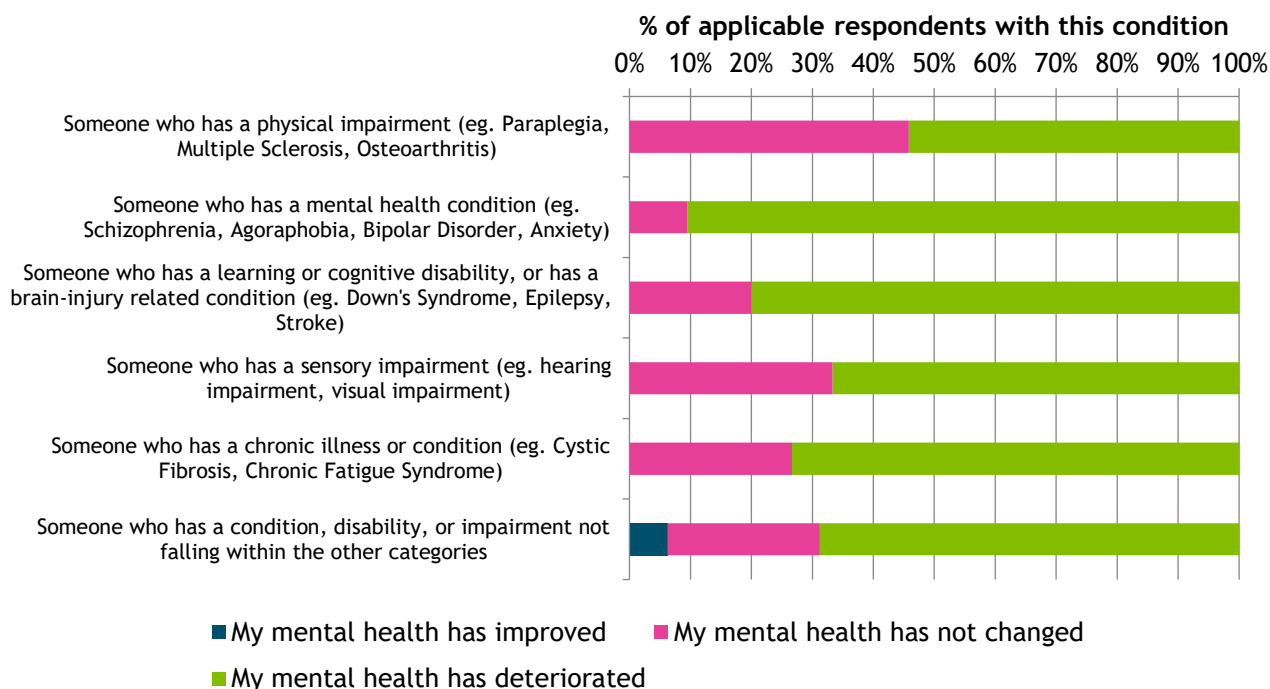
A greater proportion of respondents reported deterioration in their mental health than their physical health in regard to the PIP assessment process.

**Q29. How do you feel your mental health has changed, if at all, as a result of the PIP assessment process? (Please try to answer just considering the assessment process, not the change in award) - applicable respondents**





## Q29. Condition breakdown - applicable respondents



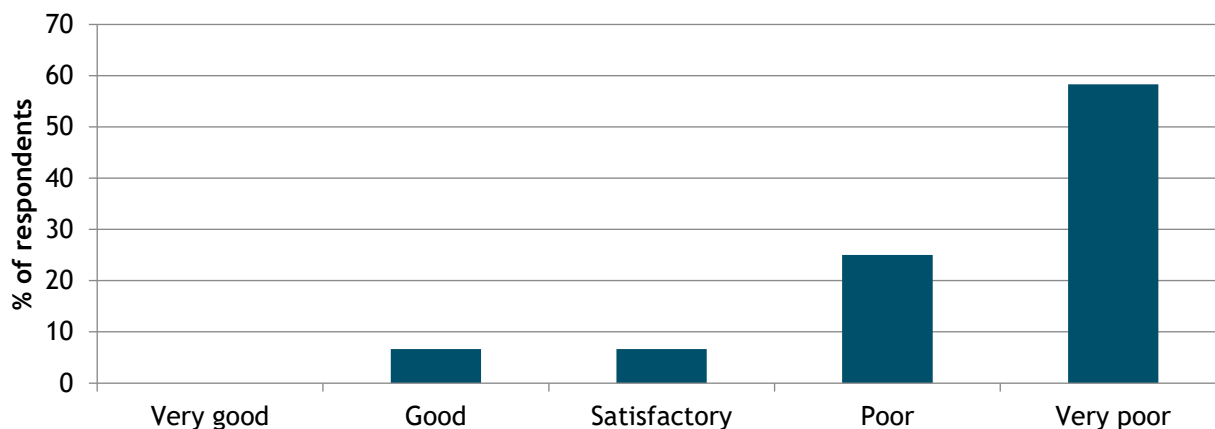
### Q30. - Looking at claimants' general experience of the assessment process as a whole

96.7% of surveyees responded to this question (58 respondents). The question did not specify a particular phrase of the process, and was generally applicable to all respondents. Overall an overwhelming majority (86.2%) said they found it 'poor' (25.0%) or 'very poor' (60.9%). No respondents, regardless of their type of condition, called the process 'very good'. 6.9% labelled it 'good', but these respondents only represented three categories of condition: physical impairments, mental health conditions, and chronic illnesses or conditions. Respondents with a learning or cognitive disability, or brain-injury related condition seem to have had the worst experience, with none of the group considering the process satisfactory or better. The category of condition with the greatest proportion of 'very poor' experiences was those with sensory impairments, which is likely related to the issues of accessibility and interpreters raised in conversations detailed in the section entitled 'Organisation and individuals' perspectives'. The lowest proportion of people reporting a 'very poor' experience were those with chronic illnesses or conditions, although it should be noted that the proportion was still nearing half of the group (43.8%).

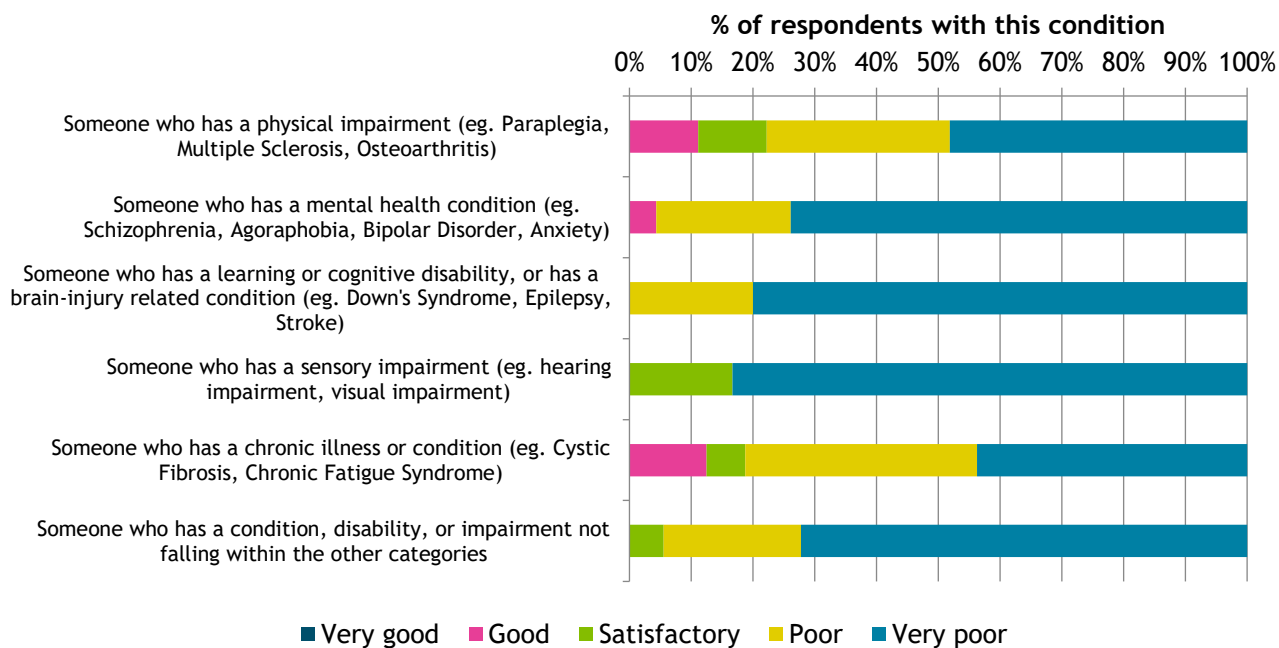




### Q30. How did you find the whole assessment process?



### Q30. Condition breakdown





Q31. - Opportunity for surveyees to share anything else about their experience of the PIP application and assessment process

81.7% of surveyees responded to this question (49 respondents). The question did not specify a particular phrase of the process, and was generally applicable to all respondents.

Responses have been loosely categorised to look for common themes and some quotations have been used as examples of what was said. Punctuation has been added without altering the meaning.

**Many respondents said explicitly or implied that they had a negative experience, and several spoke directly about their mental health as a result of this.**

“The whole thing is degrading and terrifying.”

“I was made to feel like I was a criminal, a beggar and a liar, then sent on my way. I struggle with mental health conditions, and the whole process of renewing my claim for PIP exacerbated the symptoms of my conditions and left me in a vulnerable state of mind. ”

“One of the worst experiences of my life”

“The PIP system definitely affected my mental health. I felt that I had to give my worst ever symptoms on the forms (my friend had to write it for me as I couldn’t bear the stress of having to describe my worst days), I had to share deeply personal and horrible information with a complete stranger at the interview who wasn’t properly qualified and doesn’t know me- only gets a glimpse of me in 1 hr to determine my life, despite other evidence from healthcare professionals. Surely testimonies from professionals that work with you should be enough rather than going through harrowing interviews. I felt dehumanised, degraded and disbelieved through the whole process, including on the phone. I have a postgraduate degree and yet they made me feel like an imbecile - I dread to think how people with learning disabilities and illiterate people are made to feel.”

“As a mother and carer of my son who has huge health and mental health problems it was a huge ordeal.”

“It is grotesque. Anyone employed in this should be ashamed.”

**10 out of 49 (20.4%) said they found the process intimidating or daunting in some way, and 9 out of 49 (18.4%) talked about how stressful it was.**

“The whole process was daunting and my son’s disability was questioned at every turn.”

“It’s like being interviewed by the police; very stressful and overwhelming.”

“The process of doing this was fraught with anxiety which had a detrimental effect on my mental health.”



**7 out of 49 respondents (14.3%) mentioned ulterior motives they felt were behind the PIP process.**

“I felt the assessor tried to lead me to answer in a more positive way than my condition dictates.”

“It is a blatant attempt to take money away from sick and disabled people.”

“I felt all they were trying to do was catch me out!”

“The whole system is corrupt and set up to make people on benefits feel like they are the criminals when it is the politicians who oversee these systems that are far more morally objectionable.”

“They rely heavily on people not wanting to fight them.”

“I couldn't face the appeals process which I guess is their aim.”

**8 out of 49 (16.3%) experienced difficulties explaining or communicating their condition(s) or its impact either on the forms or to the assessor because of the way the questions were asked.**

“I wasn't given much opportunity to explain, it was more yes or no answers.”

“It's extremely hard putting down on paper how you feel each and every day and night.”

“A 15-minute interview in a quiet and ordered space would not show enough of who I am to the assessor for them to be able to make a fair judgement.”

**11 out of 49 respondents (22.4%) felt their assessment gave a false account of their condition(s) or the way their condition affects their lives, or was not representative.**

“Assessor was nice during face to face meeting, but wrote the opposite of what was said for some things while making up other things that were not discussed. All evidence was refused including official diagnosis and additional evidence was also refused [when I asked] for a Mandatory Reconsideration.”

“The assessor took no notice of anything he was told and told lies.”

“I didn't believe the reports about assessors lying within reports and fabricating their 'evidence'. But then I experienced it too. And DWP did not want to know, let alone take any action.”

“Far too many assumptions were made.”



**11 out of 49 respondents (22.4%) talked about a lack of understanding of either the whole process or specifically the assessor, in respect to their condition(s) and/or its impact on their lives.**

“Being seen by a physiotherapist at the face to face assessment is not right when you have a neurological disability. The guy didn't have a clue about how my condition affects me.”

“PIP assessment forms do not take into account autism.”

“It's heavily biased towards physical disabilities.”

“The assessors fabricate the truth, they have no in-depth knowledge of many illnesses, and they assume and lie in reports and contradict previous assessments.”

“It was complicated for an adult with learning difficulties. I was fortunate - I could not have done it alone. Some words the assessor used had to be explained by my family who were present.”

“It's nigh on impossible to get an award now if you have Asperger's Syndrome.”

“They don't understand how a mental health condition can affect you.”

“The assessor was a physiotherapist. They asked intrusive questions about self-harm and suicidal symptoms which I suffer with I thought it was inappropriate to be asking me such questions without specific, professional training.”

**7 out of 49 (14.3%) of respondents mentioned the length of the process, or the waiting times involved, and 2 out of 49 (4.1%) referred to the length of award granted.**

“Misleading, it's very difficult to be honest at times re. your illness when you have to be positive to carry on! I found the interviewer a bit two faced, the whole experience has taken nearly a year which is a long time when you get older!”

“My son has a lifelong condition and he previously had an indefinite award. He now has been awarded a limited award and we have to go through the whole process again which is farcical.”

“I was awarded disability for life and now they're stopping my money.”

**5 out of 49 respondents (10.2%) expressed concern over the financial impact of the PIP process and potential change in award.**

“The bills and the mortgage do not stop because you are ill.”

“I am constantly in debt awaiting the decision.”

“It's left me having to sell possessions and beg and borrow to be able to keep the help I need. It's taken a whole year so far.”

“It wasn't taken into account how you would cope financially and physically after your drop of mobility care.”



“I think if PIP has evidence from your doctor that should be it, not putting us though more stress.”

**Other comments made include the following:**

“I have letters from a cancer specialist confirming my diagnosis but still I was questioned on my illness.”

“I only succeeded as a result of persistent applications and appeals.”

“The assessor was in a rush.”

“Disabled Parking at Salford Assessment Centre was dreadful. Parking ticket machine was blocked by parked cars. I parked 20 minutes too long and was sent a parking ticket as my assessment was late and took 90 minutes”

“My son was born with a disability. This has not changed but the goal posts have.”

“On the morning of the assessment the DWP cancelled with one hour’s notice. I had to reorganise childcare, which meant grandparents had to both take two days off work.”

“It’s disgusting the way they are treating people.”

**Other things mentioned included accessibility (both of reaching assessment centres and the formats in which the initial forms are available), cancellations on the part of the assessors, and general feelings that the process is unfair.**

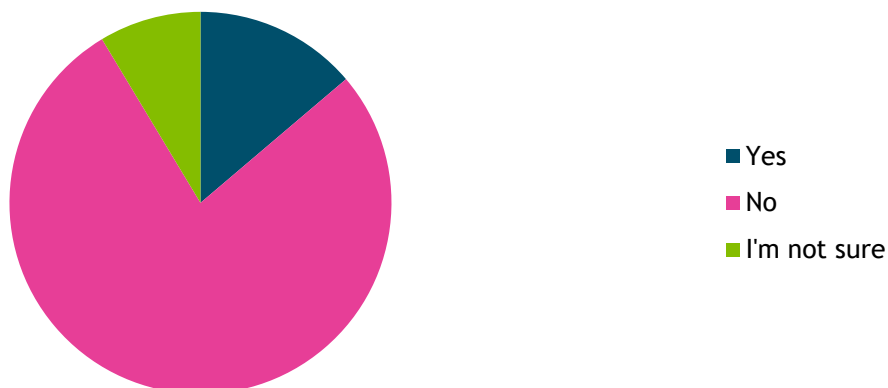
**None of the 49 respondents to this question indicated that they had a positive experience.**

**Q32. - Looking at awareness of NHS Continuing Healthcare**

96.7% of surveyees responded to this question (58 respondents). The question was generally applicable to all respondents. 13.8% of respondents had heard of NHS Continuing Healthcare, three quarters (75.0%) had not, and 8.6% weren’t sure.



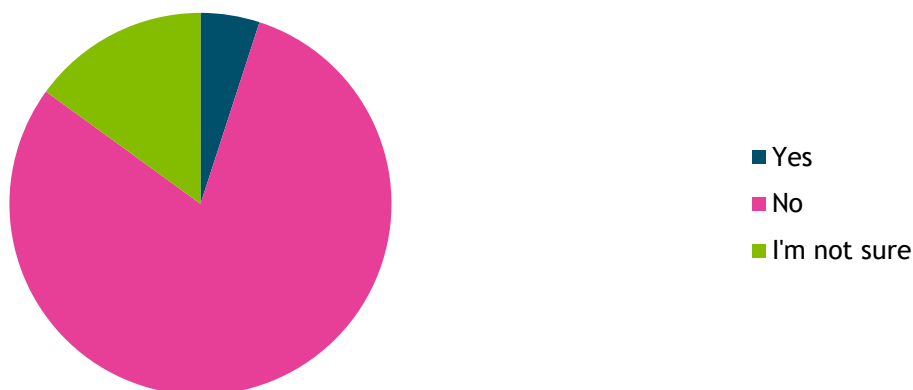
## Q32. Have you heard of NHS Continuing Healthcare?



### Q33. - Ascertaining prevalence of NHS Continuing Healthcare recipients

All surveyees responded to this question. The question was generally applicable to all respondents. One in twenty respondents (5.0%) said they receive NHS Continuing Healthcare. The vast majority (80.0%) did not, and again a number (15.0%) didn't know.

## Q33. Are you a recipient of NHS Continuing Healthcare?

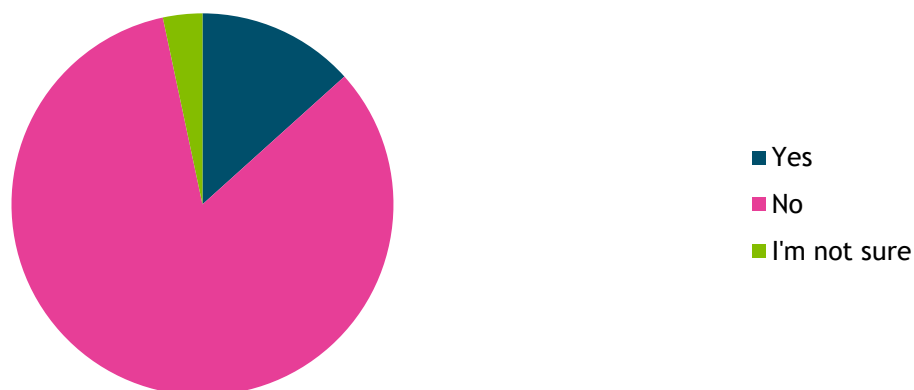




### Q34. - Looking at awareness of Personal Health Budgets

All surveyees responded to this question. The question was generally applicable to all respondents. A similar proportion of respondents had heard of Personal Health Budgets (13.3%) as had NHS Continuing Healthcare (13.8%). A greater proportion, and more than four in five (83.3%) hadn't heard of them. A small proportion (3.3%) weren't sure.

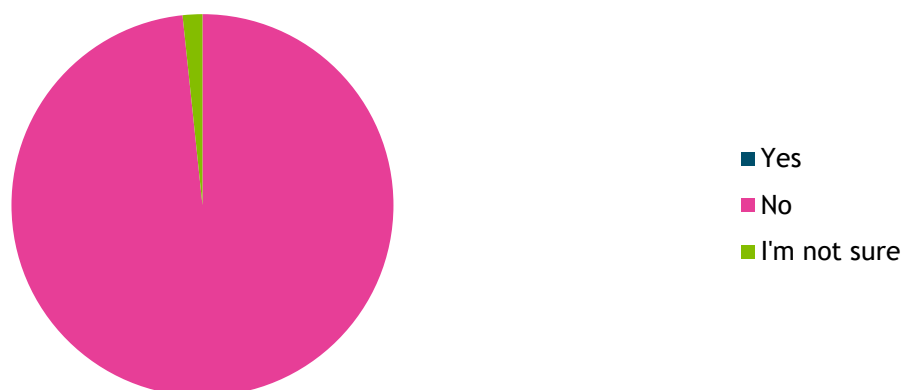
## Q34. Have you heard of Personal Health Budgets?



### Q35. - Ascertaining the prevalence of Personal Health Budget recipients

All surveyees responded to this question. The question was generally applicable to all respondents. No respondents said they were recipients of Personal Health Budgets, while a vast majority said that they weren't (93.3%). 1.7% of respondents didn't know if they were recipients or not.

## Q35. Are you a recipient of a Personal Health Budget?



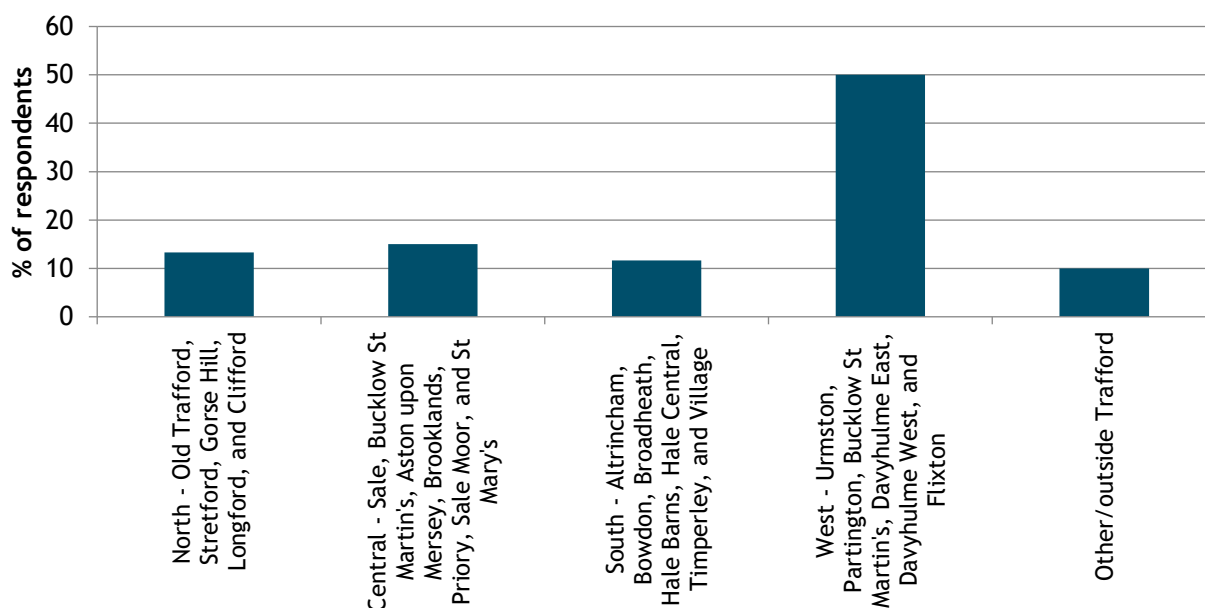




### Q36. - Demographic information - determining the locality of surveyees

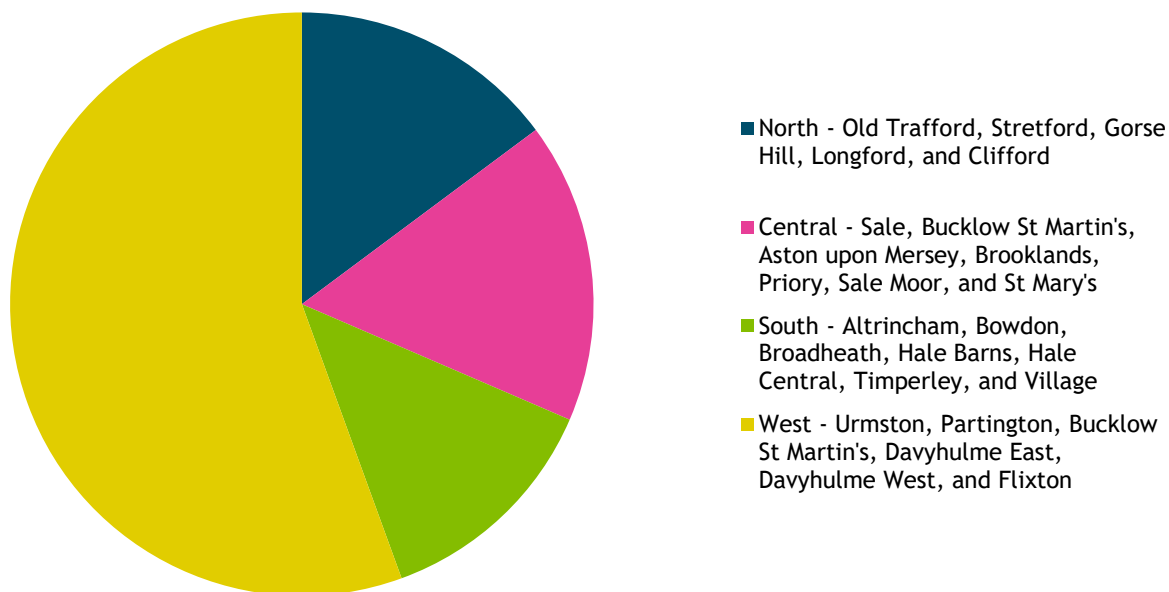
All surveyees responded to this question. The question was generally applicable to all respondents, although it was phrased specifically to determine the locality of Trafford residents, who made up 90.0% (54) of respondents. 10% of respondents were from outside Trafford. The most represented Trafford locality was West Trafford, which accounted for more than half (55.6%) of all Trafford respondents. The next most common locality was Central Trafford, with 16.7% of Trafford respondents living there. A slightly smaller proportion (14.8%) came from North Trafford. The locality with the lowest representation was South Trafford, which made up just 13.0% of Trafford residents.

### Q36. In which area/locality in Trafford do you live?





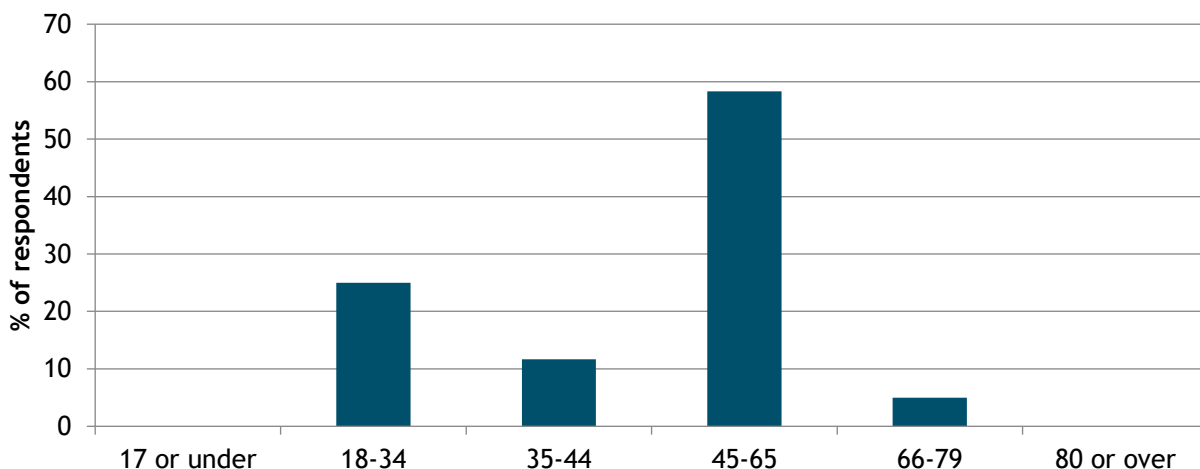
### Q36. In which area/locality in Trafford do you live? - Trafford respondents



### Q37. - Demographic information - looking at the age of surveyees

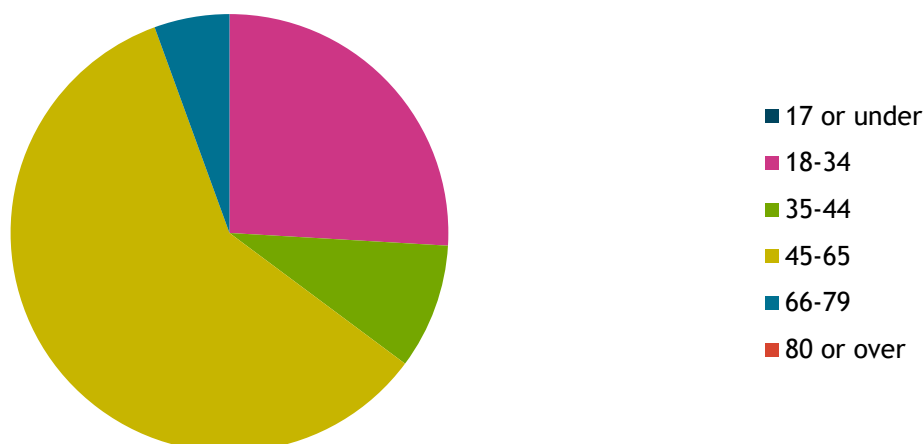
All surveyees responded to this question. The question was generally applicable to all respondents. The most represented age group was those between 45 and 65 (58.3%), although it should be noted that this age band is the broadest. The least represented group, besides those under 17 (0.0%), is those between 66 and 79 years. This is unsurprising as to be eligible for PIP you must be below 65, and as the transfer from DLA only started in 2013 and has made slow progress it is unlikely that a high proportion of 66-79 year olds will be PIP claimants.

### Q37. How old are you?





## Q37. How old are you? - Trafford respondents



Further consideration of respondents' age can be found in 'Findings' discussion of question 2. It would not necessarily be expected that surveyees' ages reflected the general population of Trafford.

### Q38. - Demographic information - looking at the gender identity of surveyees

All surveyees responded to this question. The question was generally applicable to all respondents.

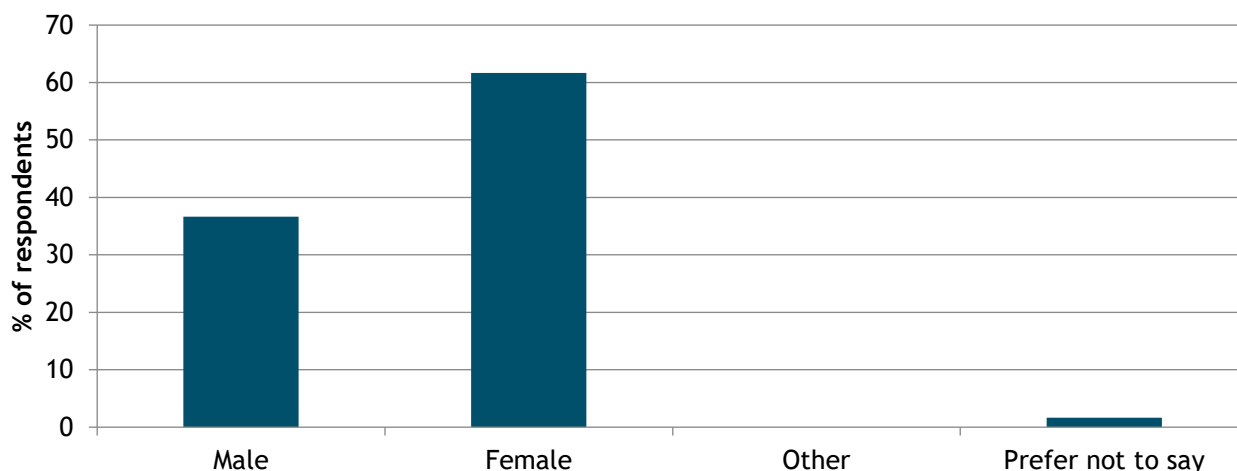
More than half of respondents (61.7%) identify as female, while over a third identify as male (36.7%). It might be expected that this would be the case in a sample of people where physical impairments are the most common type of condition, due to their higher prevalence in women, as discussed in the dissection of the results of question 2.

Trafford Joint Strategic Needs Assessments' demographic statistics<sup>40</sup> uses census data to estimate the Trafford gender split to be 48.9% male and 51.1% female. The surveyees are therefore not closely reflective of the wider Trafford population, with females overrepresented by over 10%. As the survey was not aimed at the general population, but at people who a potentially eligible or PIP support due to a disability, impairment or condition it is possible that the potential sample group also does not have the same proportions. Further consideration of respondents' gender can be found in 'Findings' discussion of question 2.

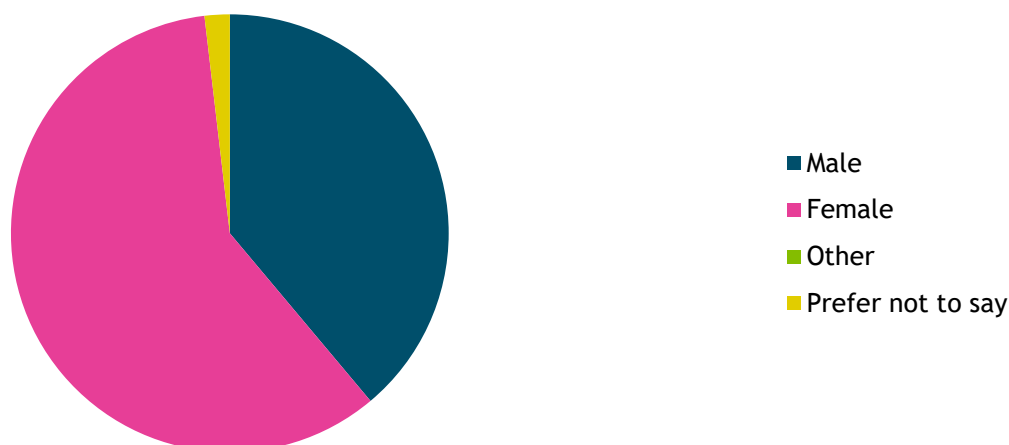
<sup>40</sup> Trafford Joint Strategic Needs Assessments, Population estimates, Table 2 <<  
<http://www.traffordjsna.org.uk/About-Trafford/Key-demographics/Population-estimates.aspx> >>



## Q38. How do you identify?



## Q38. How do you identify? - Trafford respondents



### Q39. - Demographic information - looking at the ethnicity of surveyees

All surveyees responded to this question. The question was generally applicable to all respondents. Survey respondents were overwhelming White British (95.0%), with just three people reporting a different ethnicity - White Irish (1.7%), Multiple Heritage - mixed race (1.7%), and 'Other' (1.7%), to which the response was 'Human'.

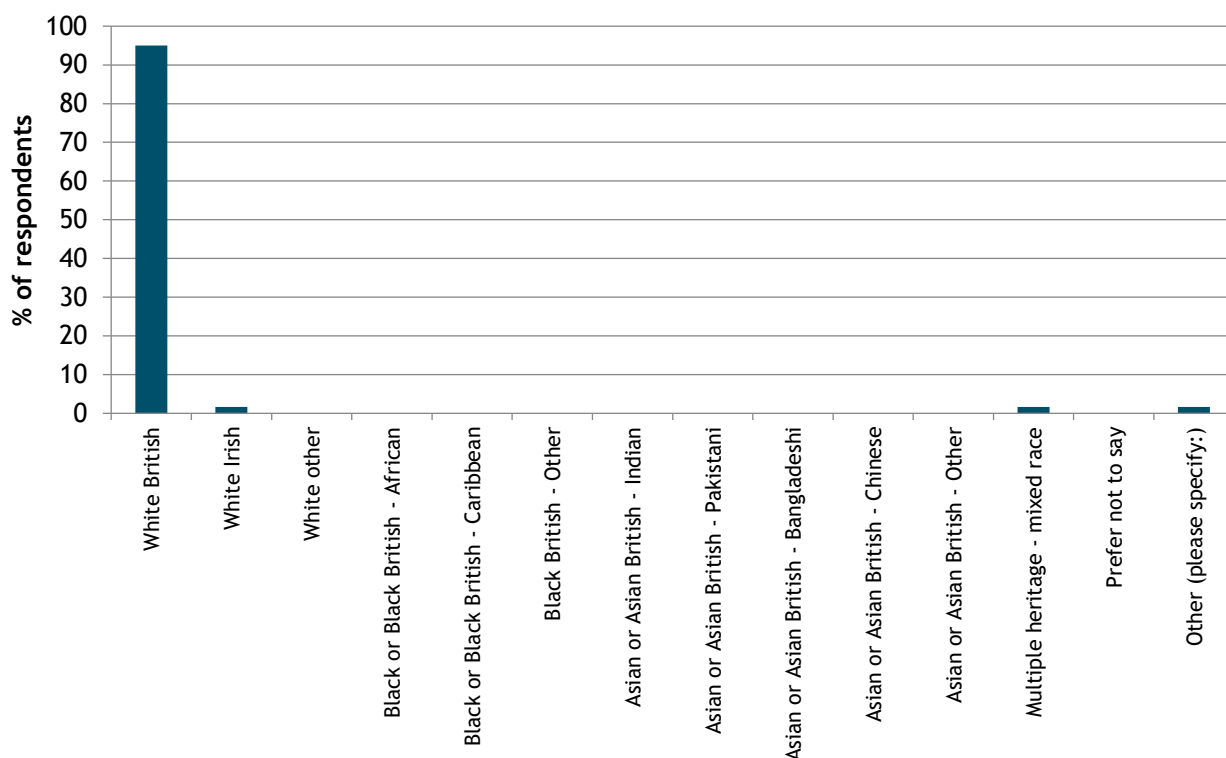
Trafford Joint Strategic Needs Assessments' (Trafford JSNA) demographic statistics<sup>41</sup> uses census data to estimate ethnic demographic statistics for Trafford. These estimate the borough to be 85.5% White, and 2.7% Mixed race. The surveyees are therefore fairly reflective of the wider Trafford population, with White ethnic groups overrepresented by about 12%. There were no respondents with Black or Asian heritage, and generally the representation of Black and minority ethnic groups (BAME) was well below the Trafford

<sup>41</sup> Trafford Joint Strategic Needs Assessments, 'Ethnic groups' << <http://www.traffordjsna.org.uk/About-Trafford/Key-demographics/Ethnic-groups.aspx> >>



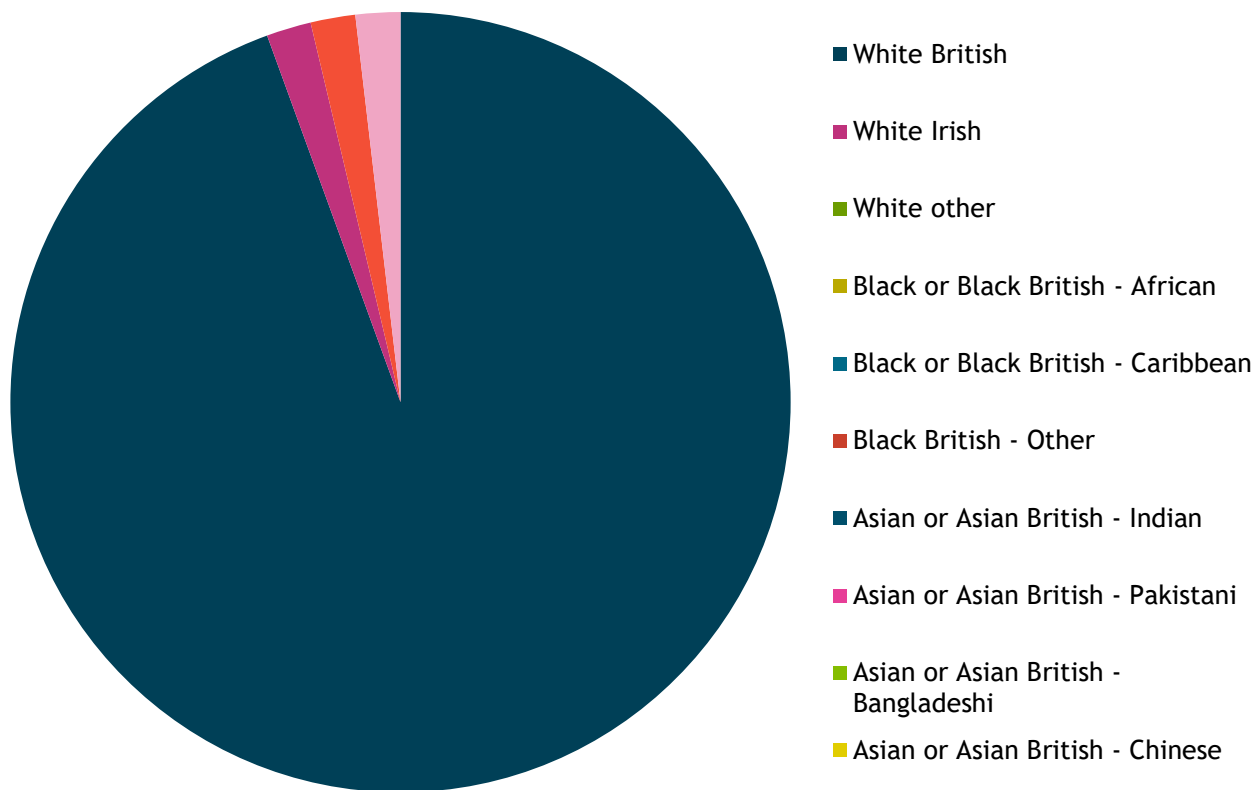
reported 2011 census level of 14.5%. It is possible that some ethnic groups are less likely to take up health and social care, including things like disability benefits, and so may be underrepresented in the pool of Trafford PIP claimants and potential surveyees. There are also other factors which could be the reason for this, as considered by Trafford JSNA in their section on ethnicity.

### Q39. How would you describe your ethnicity?





### Q39. How would you describe your ethnicity? - Trafford respondents



Q40. - Opportunity for surveyees to give their contact information in order to receive updates on the progress of the project

50.0% of surveyees responded to this question (30 respondents).



## Sources

<< <https://recoveryinthebin.org/> >>

Department for Work and Pensions, 'Personal Independence Payment: Official Statistics to July 2018' <<

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/739224/pip-statistics-to-july-2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/739224/pip-statistics-to-july-2018.pdf) >> (11 September 2018).

Department for Work and Pensions, 'PIP Assessment Guide Part Two - The Assessment Criteria' (16 July 2018) <<

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/725533/pip-assessment-guide-part-2-assessment-criteria.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/725533/pip-assessment-guide-part-2-assessment-criteria.pdf) >>

Department for Work and Pensions, 'The Government's response to the consultation on the PIP assessment Moving around activity' (October 2013) <<

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/251631/pip-mobility-consultation-government-response.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/251631/pip-mobility-consultation-government-response.pdf) >>

Department for Work and Pensions, Stat-Xplore 'Field: Disability Category / Disability Sub Group' << [https://stat-xplore.dwp.gov.uk/webapi/metadata/PIP\\_Monthly/Disability.html](https://stat-xplore.dwp.gov.uk/webapi/metadata/PIP_Monthly/Disability.html) >>

Department for Work and Pensions, Stat-Xplore statistics << <https://stat-xplore.dwp.gov.uk/webapi/jsf/dataCatalogueExplorer.xhtml> >> (11 September 2018).

Disability Rights UK, 'Senior Judge says DWP evidence to tribunals so poor it would be wholly inadmissible in any other court' (November 2017) <<

<https://www.disabilityrightsuk.org/news/2017/november/senior-judge-says-dwp-evidence-tribunals-so-poor-it-would-be-wholly-inadmissible> >>

Epilepsy Action, 'PIP Pledge' << <https://www.epilepsy.org.uk/involved/campaigns/pip-pledge> >>

Equality Act 2010.

Greater Manchester Law Centre, 'Blatantly discriminatory' PIP criteria cost £3.6bn and 2.5 years of unnecessary suffering for claimants' <<

<https://www.gmlaw.org.uk/2018/07/16/blatantly-discriminatory/> >>

Healthwatch Brighton and Hove, 'Personal Independence Payments and Employment Support Allowance - Examining the impact of PIP and ESA assessments on vulnerable people in Brighton and Hove' (February 2018).

Healthwatch Kirklees, 'Personal Independence Payment (PIP) claimants accessing Atos assessment centre' << <https://healthwatchkirklees.co.uk/personal-independence-payment-pip-claimants-accessing-atos-assessment-centre/> >>

Human Rights Act 1998.



Independent Assessment Services, 'What are the 'reliability' criteria that are used during the PIP Assessment?' << <https://www.mypipassessment.co.uk/news/what-are-the-reliability-criteria-that-are-used-during-the-pip-assessment/> >>

MS Society , 'PIP: A step too far'(2018).

National Autistic Society, 'Gender and Autism' << <https://www.autism.org.uk/about/what-is/gender.aspx> >>

NHS, 'Arthritis' << <https://www.nhs.uk/conditions/arthritis/> >>

Parliamentary business, Publications & records, 'Personal Independence Payment: Epilepsy: Written question - 162167' (9 July 2018) << <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2018-07-09/162167/> >>

Paul Gray, 'Personal Independence Payment (PIP) assessment: second independent review' (March 2017).

Rethink Mental Illness, 'It's broken her' (2017).

Scope, 'Is it possible to record my assessment?' << <https://www.scope.org.uk/support/disabled-people/money/pip/faqs> >>

SignHealth, 'Mental Health' << <https://www.signhealth.org.uk/about-deafness/mental-health/> >>

They Work For You, Advanced search in debates, speaker "Kate Green" includes "PIP" << <https://www.theyworkforyou.com/search/?q=section%3Adebates+section%3Awhall+section%3Alords+section%3Ani&pid=24896&phrase=PIP&exclude=&from=&to=&person=&section=&column=> >> and in speeches , speaker "Kate Green", includes "PIP" << <https://www.theyworkforyou.com/search/?q=PIP&pid=24896> >><sup>1</sup>

Trafford Council, 'Council Tax Support - Protection' << <http://www.trafford.gov.uk/residents/benefits-and-council-tax/benefits/welfare-reform-changes/council-tax-support.aspx> >>

Trafford Council, 'Council Tax Support - Universal Credit (UC)' << <http://www.trafford.gov.uk/residents/benefits-and-council-tax/benefits/welfare-reform-changes/council-tax-support.aspx> >>

Trafford Council, 'Disabled Relief' << <http://www.trafford.gov.uk/residents/benefits-and-council-tax/council-tax/reducing-your-bill.aspx> >>

Trafford Council, 'Reducing your bill' << <http://www.trafford.gov.uk/residents/benefits-and-council-tax/council-tax/reducing-your-bill.aspx> >>

Trafford Joint Strategic Needs Assessments, 'Ethnic groups' << <http://www.traffordjsna.org.uk/About-Trafford/Key-demographics/Ethnic-groups.aspx> >>





Trafford Joint Strategic Needs Assessments, Population estimates, Table 2 <<  
<http://www.traffordjsna.org.uk/About-Trafford/Key-demographics/Population-estimates.aspx> >>

UN Convention on the Rights of Persons with Disabilities

What DO They Know, Department for Work and Pensions Freedom of Information request (May 2017) <<  
<https://www.whatdotheyknow.com/request/402400/response/978248/attach/2/FOI%2017%20response.pdf> >>

Work and Pensions Committee, 'Victory for claimants as Government agrees to drop MR measure' (December 2017) <<  
<https://www.parliament.uk/business/committees/committees-a-z/commons-select/work-and-pensions-committee/news-parliament-2017/reform-pip--esa-process-statement/> >>



## **Appendix 1 - The survey**

# **Personal Independence Payment (PIP) Trafford claimant experience survey**

**We're working on a project looking at the impact of the change from Disability Living Allowance (DLA) to Personal Independence Payment (PIP) on the health and wellbeing of Trafford residents, both in terms of the change in award and the effect of the application and assessment process. We have had concerns raised to us about how local people have been affected and so decided to look into this further. As part of our research we want to collect the experiences of as many Trafford PIP claimants as possible.**

**The information collected will always be anonymised so you won't be identifiable by your answers, meaning you can be completely open and honest. Your contact information, should you choose to give it, is used only by Healthwatch Trafford to let you know the findings of the report. We also ask some questions about your background to make sure that our information is as representative of the people in the borough as possible. Your details will never be passed on or supplied to any other organisation.**

**Thank you for participating in our survey. Your feedback really is important and will help us make health and social care in Trafford better.**

**Deadline for submitted responses: 10pm Sunday 19th August**

**This survey assumes you, or the person you care for, have at least received the application forms for Personal Independence Payment, regardless of whether you have progressed any further with the assessment process. Please answer all questions honestly, selecting the most appropriate answer.**



**1. Are you:**

- Someone who is a PIP claimant
- Someone who is a friend, relative, or carer helping a PIP claimant to answer
- Someone who is a friend, relative, or carer answering on behalf of a PIP claimant
- Someone who is a friend, relative, or carer who has gone through the application process for a PIP claimant, answering about your own experience of it

**2. Please select all which apply to the person the claim concerns:**

- I have a physical impairment (eg. Paraplegia, Multiple Sclerosis, Osteoarthritis)
- I have a mental health condition (eg. Schizophrenia, Agoraphobia, Bipolar Disorder, Anxiety)
- I have a learning or cognitive disability, or have experienced brain injury (eg. Down's Syndrome, Epilepsy, Stroke)
- I have a sensory impairment (eg. hearing impairment, visual impairment)
- I have a chronic illness or condition (eg. Cystic Fibrosis, Chronic Fatigue Syndrome)
- I have a condition, disability, or impairment not falling within the above categories.

**3. Please select all which apply to the person the claim concerns:**

- My condition(s) is/are fluctuating
- My condition(s) is/are progressive
- My condition(s) is/are neither fluctuating, nor progressive



**4. At what stage of the PIP assessment process are you?**

- I've received the forms but have not been able to complete them
- I've filled in the application forms but got no further
- I've arranged the face-to-face assessment (if needed) but got no further
- I'm waiting to hear the result
- I've received the result and am not pursuing the claim any further
- I've received my result and am asking for Mandatory Reconsideration
- I've received the result of the Mandatory Reconsideration and am not pursuing the claim any further
- I've received the result of the Mandatory Reconsideration and am taking it to appeal
- I've appealed the claim following Mandatory Reconsideration and am pursuing the claim no further
- I've appealed the claim following Mandatory Reconsideration and am going to re-appeal
- I've re-appealed the claim following Mandatory Reconsideration and an appeal

**5. Please choose the most appropriate descriptor for how you found filling out the PIP application forms**

- I had no problems at all
- I had a few problems
- I had several problems
- I had lots of problems
- I couldn't answer the questions by myself

**6. Did you have any help and support to fill out the forms?**

- No - I completed it alone
- Yes - a friend or relative who isn't a carer
- Yes - a carer
- Yes - a health professional
- Yes - the Citizens Advice Bureau (CAB)
- Yes - a Welfare Officer or similar
- Yes - another organisation, support group, or charity (please specify):



**7. Where did you have the PIP face-to-face assessment?**

- I haven't yet reached this stage of the process
- I attended an assessment centre
- I wasn't asked to attend a face-to-face assessment, I was assessed without one
- I had a home visit assessment

**8. Which assessment centre did you attend?**

- The Lilac Centre, North Manchester General Hospital
- St Petersgate, Stockport
- Trinity Way, Salford
- David Roberts Physiotherapy, Stockport
- Other (please specify:)
- I had a home visit
- I haven't yet reached this stage of the process

**9. Did you feel that the assessor understood your condition(s) and appreciated its impact on your daily life?**

- They were knowledgeable and supportive
- They were neither knowledgeable nor supportive
- They were not knowledgeable but were supportive
- I didn't have a face-to-face, I was assessed without one
- They were knowledgeable but not supportive
- I haven't yet reached this stage of the process

**10. Were you aware you could request a home visit if you would have difficulties attending an assessment centre?**

- Yes - and I had a home visit
- No - but I wouldn't have requested one anyway
- Yes - I requested one but was not granted one
- I wasn't asked to attend a face-to-face, I was assessed without one
- Yes - but I didn't request one
- I haven't yet reached this stage of the process
- No - but I would have requested one had I known



**11. Were you aware you could request a copy of the report made by the assessor after the assessment?  
Or, if you didn't need a face-to-face assessment, the report made following submission of your application forms?**

- |  |   |
|--|---|
| <input type="checkbox"/> Yes - I requested one                       | <input type="checkbox"/> No - but I wouldn't have wanted to see it anyway |
| <input type="checkbox"/> Yes - but I didn't want to see it           | <input type="checkbox"/> I haven't yet reached this stage of the process  |
| <input type="checkbox"/> No - I would have requested one had I known |   |

**12. Describe your experience of the PIP application and assessment process in 3 words** (eg. positive, scary, easy, long, straightforward, negative, fast, intimidating, fantastic, painful, understanding, complicated)

**13. From what you already knew about PIP, choose the best description of how you were feeling about the application process: before you applied for PIP**

- |                                    |                                       |
|------------------------------------|---------------------------------------|
| <input type="checkbox"/> Confident | <input type="checkbox"/> Worried      |
| <input type="checkbox"/> Neutral   | <input type="checkbox"/> Very worried |
| <input type="checkbox"/> Uncertain |                                       |

**14. Choose the best description of how you were feeling about answering the questions and providing evidence: when you were filling out the forms**

- |                                    |  |
|------------------------------------|--|
| <input type="checkbox"/> Confident | <input type="checkbox"/> Worried   |
| <input type="checkbox"/> Neutral   | <input type="checkbox"/> Very worried  |
| <input type="checkbox"/> Uncertain | <input type="checkbox"/> I've received the forms but have not been able to complete them |



**15. Choose the best description of how you were feeling about being assessed: leading up to your face-to-face assessment**

- |                                    |  |
|------------------------------------|--|
| <input type="checkbox"/> Confident | <input type="checkbox"/> Very worried  |
| <input type="checkbox"/> Neutral   | <input type="checkbox"/> I didn't have a face-to-face assessment, I was assessed without one |
| <input type="checkbox"/> Uncertain | <input type="checkbox"/> I haven't yet reached this stage of the process                     |
| <input type="checkbox"/> Worried   |  |

**16. Choose the best description of how you were feeling: during your face-to-face assessment**

- |                                    |  |
|------------------------------------|--|
| <input type="checkbox"/> Confident | <input type="checkbox"/> Very worried  |
| <input type="checkbox"/> Neutral   | <input type="checkbox"/> I didn't have a face-to-face assessment, I was assessed without one |
| <input type="checkbox"/> Uncertain | <input type="checkbox"/> I haven't yet reached this stage of the process                     |
| <input type="checkbox"/> Worried   |  |

**17. Choose the best description of how you were feeling: while waiting to hear the result**

- |                                    |  |
|------------------------------------|--|
| <input type="checkbox"/> Confident | <input type="checkbox"/> Worried   |
| <input type="checkbox"/> Neutral   | <input type="checkbox"/> Very worried                                    |
| <input type="checkbox"/> Uncertain | <input type="checkbox"/> I haven't yet reached this stage of the process |

**18. Choose the best description of how you were feeling: when you received the result**

- |                                    |  |
|------------------------------------|--|
| <input type="checkbox"/> Confident | <input type="checkbox"/> Worried   |
| <input type="checkbox"/> Neutral   | <input type="checkbox"/> Very worried                                    |
| <input type="checkbox"/> Uncertain | <input type="checkbox"/> I haven't yet reached this stage of the process |



**19. How did the *mobility element* of your award change in moving from DLA to PIP?**

- |   |  |
|---|--|
| <input type="checkbox"/> It increased       | <input type="checkbox"/> It decreased                      |
| <input type="checkbox"/> It stayed the same | <input type="checkbox"/> I haven't yet received my results |

**20. What financial impact has the *change to your mobility award* had?**

- |   |   |
|---|---|
| <input type="checkbox"/> I feel more financially stable and independent | <input type="checkbox"/> I feel less financially stable and independent |
| <input type="checkbox"/> My financial situation hasn't changed          | <input type="checkbox"/> I haven't yet received my results              |

**21. What impact has the *change to your mobility award* had on your standard of living? (eg. taking into account your general health and wellbeing, social life, independence etc.)**

- |  |  |
|--|--|
| <input type="checkbox"/> My standard of living has increased       | <input type="checkbox"/> My standard of living has decreased |
| <input type="checkbox"/> My standard of living has stayed the same | <input type="checkbox"/> I haven't yet received my results   |

**22. How did the *care or living element* of your award change in moving from DLA to PIP?**

- |   |  |
|---|--|
| <input type="checkbox"/> It increased       | <input type="checkbox"/> It decreased                      |
| <input type="checkbox"/> It stayed the same | <input type="checkbox"/> I haven't yet received my results |

**23. What financial impact has the *change to your care or living award* had?**

- |   |   |
|---|---|
| <input type="checkbox"/> I feel more financially stable and independent | <input type="checkbox"/> I feel less financially stable and independent |
| <input type="checkbox"/> My financial situation hasn't changed          | <input type="checkbox"/> I haven't yet received my results              |





**24. What impact has the *change to your care or living award* had on your standard of living?**

(eg. taking into account your general health and wellbeing, social life, independence etc.)

- |  |  |
|--|--|
| <input type="checkbox"/> My standard of living has increased       | <input type="checkbox"/> My standard of living has decreased |
| <input type="checkbox"/> My standard of living has stayed the same | <input type="checkbox"/> I haven't yet received my results   |

**25. If a *change in your overall award* has meant you are less financially stable, how have you handled this?**

Please select all options which apply

- Not applicable (I am not less financially stable as a result of any change in award)
- Using savings
- Borrowing money from friends or family
- Taking out loans
- Cutting back spending on utility bills (rent, mortgage, heating, electricity etc.)
- Cutting back spending on food
- Cutting back spending on treatments or activities previously used to manage symptoms of your condition(s) (eg. counselling, physiotherapy, etc.)
- Cutting back spending on social activities

**26. How do you feel your physical health has changed, if at all, as a result of the *change in your overall award*?**

(Please try to answer just considering the change in award, **not** the assessment process)

- |   |  |
|---|--|
| <input type="checkbox"/> My physical health has improved    | <input type="checkbox"/> My physical health has deteriorated             |
| <input type="checkbox"/> My physical health has not changed | <input type="checkbox"/> I haven't yet reached this stage of the process |



**27. How do you feel your mental health has changed, if at all, as a result of the *change in your overall award*?**

(Please try to answer just considering the change in award, **not** the assessment process)

- |   |  |
|---|--|
| <input type="checkbox"/> My mental health has improved    | <input type="checkbox"/> My mental health has deteriorated               |
| <input type="checkbox"/> My mental health has not changed | <input type="checkbox"/> I haven't yet reached this stage of the process |

**28. How do you feel your *physical* health has changed, if at all, as a result of going through the assessment process?**

(Please try to answer just considering going through the assessment process, *not* the change in award)

- |   |  |
|---|--|
| <input type="checkbox"/> My physical health has improved    | <input type="checkbox"/> My physical health has deteriorated             |
| <input type="checkbox"/> My physical health has not changed | <input type="checkbox"/> I haven't yet reached this stage of the process |

**29. How do you feel your *mental* health has changed, if at all, as a result of going through the assessment process?**

(Please try to answer just considering going through the assessment process, *not* the change in award)

- |   |  |
|---|--|
| <input type="checkbox"/> My mental health has improved    | <input type="checkbox"/> My mental health has deteriorated               |
| <input type="checkbox"/> My mental health has not changed | <input type="checkbox"/> I haven't yet reached this stage of the process |

**30. How did you find the whole assessment process?**

- |                                       |                                    |
|---------------------------------------|------------------------------------|
| <input type="checkbox"/> Very good    | <input type="checkbox"/> Poor      |
| <input type="checkbox"/> Good         | <input type="checkbox"/> Very poor |
| <input type="checkbox"/> Satisfactory |                                    |



**31. Is there anything else you would like to tell us about your experience of the PIP application and assessment process?**

**32. Have you heard of NHS Continuing Healthcare?**

- Yes  I'm not sure  
 No

**33. Are you a recipient of NHS Continuing Healthcare?**

- Yes  I'm not sure  
 No

**34. Have you heard of Personal Health Budgets?**

- Yes  I'm not sure  
 No

**35. Are you a recipient of a Personal Health Budget?**

- Yes  I'm not sure  
 No



**36. In which area/locality in Trafford do you live?**

- North - Old Trafford, Stretford, Gorse Hill, Longford, and Clifford
- Central - Sale, Bucklow St Martin's, Aston upon Mersey, Brooklands, Priory, Sale Moor, and St Mary's
- South - Altrincham, Bowden, Broadheath, Hale Barns, Hale Central, Timperley, and Village
- West - Urmston, Partington, Bucklow St Martin's, Davyhulme East, Davyhulme West, and Flixton
- Other/outside Trafford

**37. How old are you?**

- |                                      |                                     |
|--------------------------------------|-------------------------------------|
| <input type="checkbox"/> 17 or under | <input type="checkbox"/> 45-65      |
| <input type="checkbox"/> 18-34       | <input type="checkbox"/> 66-79      |
| <input type="checkbox"/> 35-44       | <input type="checkbox"/> 80 or over |

**38. How do you identify?**

- |                                 |  |
|---------------------------------|--|
| <input type="checkbox"/> Male   | <input type="checkbox"/> Other             |
| <input type="checkbox"/> Female | <input type="checkbox"/> Prefer not to say |

**39. Which ethnicity do you feel most closely describes you?**

- |   |   |
|---|---|
| <input type="checkbox"/> White British                      | <input type="checkbox"/> Asian or Asian British - Pakistani   |
| <input type="checkbox"/> White Irish                        | <input type="checkbox"/> Asian or Asian British - Bangladeshi |
| <input type="checkbox"/> White other                        | <input type="checkbox"/> Asian or Asian British - Chinese     |
| <input type="checkbox"/> Black or Black British - African   | <input type="checkbox"/> Asian or Asian British - Other       |
| <input type="checkbox"/> Black or Black British - Caribbean | <input type="checkbox"/> Multiple heritage - mixed race       |
| <input type="checkbox"/> Black British - Other              | <input type="checkbox"/> Prefer not to say                    |
| <input type="checkbox"/> Asian or Asian British - Indian    | <input type="checkbox"/> Other (please specify:)              |

If you would like to be emailed regarding the findings of the report please fill in your email address and a name you would like us to know you by.

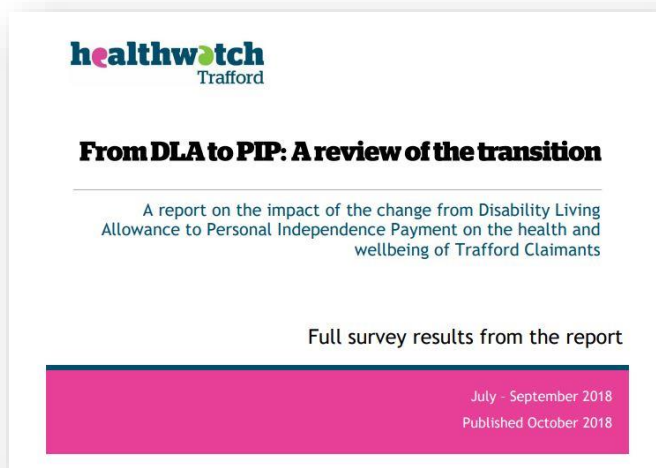
Email address:

Name:



## Appendix 2 - Full statistical breakdown

The full statistical breakdown of the information used to create this report can be found in a separate document which can be found on the Healthwatch Trafford website at <https://healthwatchtrafford.co.uk/wp-content/uploads/2018/10/HW-PIP-project-report-Appendix-2-Survey-Results.pdf>





## Appendix 3- DLA and PIP rates

Rates correct as of October 2018

All information taken verbatim from the Gov.uk website in October 2018.

DLA section : <https://www.gov.uk/dla-disability-living-allowance-benefit/DLA-rates>

PIP section : <https://www.gov.uk/pip/what-youll-get>

### DLA rates

You can no longer apply for Disability Living Allowance (DLA) if you're 16 or over. You might be able to [apply for Personal Independence Payment \(PIP\)](#) instead.

DLA is made up of 2 components (parts), the 'care component' and the 'mobility component'. To get DLA you must be eligible for at least one of the components.

How much DLA you get depends on how your disability or health condition affects you.

#### If you need help looking after yourself

You might get the care component of DLA if you:

- need help with things like washing, dressing, eating, using the toilet or communicating your needs
- need supervision to avoid putting yourself or others in danger
- need someone with you when you're on dialysis
- cannot prepare a cooked main meal

You can get this part if no one is actually giving you the care you need, or you live alone.

Care component	Weekly rate	Level of help you need
Lowest	£22.65	Help for some of the day or with preparing cooked meals
Middle	£57.30	Frequent help or constant supervision during the day, supervision at night or someone to help you while on dialysis
Highest	£85.60	Help or supervision throughout both day and night, or you're terminally ill



### If you have walking difficulties

You might get the mobility component of DLA if, when using your normal aid, you:

- cannot walk
- can only walk a short distance without severe discomfort
- could become very ill if you try to walk

You might also get it if you:

- have no feet or legs
- are assessed as 100% blind and at least 80% deaf and you need someone with you when outdoors
- are severely mentally impaired with severe behavioural problems and get the highest rate of care for DLA
- need supervision most of the time when walking outdoors
- are certified as severely sight impaired and you were aged between 3 and 64 on 11 April 2011

Mobility component	Weekly rate	Level of help you need
--------------------	-------------	------------------------

Lower	£22.65	Guidance or supervision outdoors
-------	--------	----------------------------------

Higher	£59.75	You have any other, more severe, walking difficulty
--------	--------	---



## **PIP rates**

### **What you'll get**

Personal Independence Payment (PIP) is usually paid every 4 weeks. It's tax free and you can get it whether you're in or out of work.

You'll need an [assessment](#) to work out the level of help you'll get. [Your rate will be regularly reviewed](#) to make sure you're getting the right support.

You need to tell DWP straight away if there's a [change in your personal circumstances](#) or how your condition affects you.

PIP is made up of 2 parts. Whether you get one or both of these and how much you'll get depends on how severely your condition affects you.

### **Daily living part**

The weekly rate for the daily living part of PIP is either £57.30 or £85.60.

### **Mobility part**

The weekly rate for the mobility part of PIP is either £22.65 or £59.75.

### **Terminal illness**

You'll get the higher daily living part if you're not expected to live more than 6 months. The rate of the mobility part depends on your needs.



