

An evaluation of how Personal Independence Payment (PIP) is working for people living with cancer



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It is vital that the Department for Work and Pensions (DWP) work towards a PIP system that people have trust and faith in, a system that both works for them and is responsive to their needs.



Each year, more than 100,000 people of working age in the UK will be diagnosed with cancer. In addition to the physical and emotional impacts most commonly associated with diagnosis and treatment, cancer brings with it a real risk of financial hardship. Macmillan talks to people affected by cancer about their money worries every day. People often experience a drop in income as they are unable to work at the same time that their outgoings increase.

Personal Independence Payment (PIP), the successor benefit to Disability Living Allowance (DLA), was introduced across Great Britain in June 2013. It was designed to help cover the additional costs arising from long-term illness or disability for people of working age and target support at those most in need. In November 2013, following feedback from the cancer workforce, Macmillan publicly raised concerns about the processing of 'special rules' claims for the terminally ill. This research has been commissioned to understand the experience of all claimants.

A year on and this new research will give a valuable insight into the impact of disability benefit reform on people affected by cancer. We know that at least a quarter of those waiting for a decision as to whether they will qualify for the new benefit have been waiting for six months or more. This is unacceptable and the government must act quickly to fix the situation to fully support those most in need. The research further emphasises the impact these delays can have. While they wait many people are often unable to arrange support when they most need it, allow their carers to have a break or even heat their home. Consequently, people feel they have to fight to receive the support to which they are entitled, adding unnecessary stress at a time when they should be focusing on their health.

Where people have made their way through the system and been successfully awarded PIP despite the delays, most report benefits to their everyday lives. For many, receiving PIP reduces their financial worries and emotional strain and they can now, for instance, buy clothes that fit or pay for travel to hospital. A working system, therefore, has the potential to benefit a huge number of people.

The solutions proposed in this report are practical and mainly applicable to all claimants regardless of their condition. Proposals include pausing the ongoing 'migration' of DLA claims to make sure no one is placed in a system that isn't working effectively. It is vital that the Department for Work and Pensions (DWP) work towards a PIP system that people have trust and faith in, a system that both works for them and is responsive to their needs.

Ciarán Devane

Ciarán Devane Chief Executive, Macmillan Cancer Support

Executive summary

Macmillan wants to make sure no one faces cancer alone and this includes making sure people affected by cancer are able to access the financial support they need.

This report sets out Macmillan's new research looking at how PIP, in its early stages, is working for people affected by cancer. Pathfinder areas started rolling out the benefit in April 2013, before a Great Britain-wide launch in June 2013. Since then, our benefit advice services and people living with cancer have consistently fed back the problems they've encountered with PIP claims. This research captures those issues and more. The key findings include:

- → There are significant delays in processing PIP the majority (60%) of claimants had yet to be informed of an outcome, waiting on average just under four and a half months. We found that 25% of respondents had been waiting at least six months.
- → Where claims are delayed, communication is poor the majority of respondents (68%) felt that they were not kept informed about any delays, while over half (58%) felt the next steps in the process were unclear.
- → People are more likely to be dissatisfied with the process than satisfied almost half (47%) of respondents were dissatisfied with the overall experience of making a claim, compared to just 28% who felt they were satisfied.

Some of these problems will not be unique to people with cancer and people with a range of conditions are likely to be experiencing similar problems. To this end, Macmillan has worked to develop recommendations which we believe will benefit all claimants.

Macmillan wants to see a PIP system that works effectively for people living with cancer and is responsive to their needs, during and after the claims process. This will ensure that the government's ambition of a system that supports those most in need is realised. Cancer and its treatment can have immediate physical, emotional and financial support needs for people living with cancer. As a matter of urgency, the DWP must take immediate action to bring down delays.

Macmillan's recommendations

This report contains a number of recommendations for the DWP to put in place to improve the PIP system. These will make sure that PIP works for people living with cancer and is transparent, respectful and responsive to their needs, resulting in renewed trust in the government's ability to deliver it. These include pausing the reassessment of existing DLA claims until PIP is working effectively, and including data on processing times as part of the DWP's quarterly statistics. As more people pass through the PIP system. Macmillan will continue to monitor their experience. We will seek to work with other organisations and the government to improve this benefit.

1. Methodology

Due to our concerns around the delays in processing PIP, Macmillan commissioned IFF Research to conduct a quantitative and qualitative study in late 2013. This explored the impact of PIP on the financial status, standard of living and wellbeing of people living with cancer.

The research

The study consisted of two phases; firstly a qualitative phase, which comprised eight in-depth telephone interviews. These interviews informed the structure of a survey for the quantitative phase which consisted of 210 interviews. Of these, 75 were carried out by telephone and 135 online. These phases were conducted from December 2013 to February 2014.

As part of the research participants were asked questions surrounding:

- their support and care needs
- the financial impact of their cancer and its treatment
- their current status in the claims process
- length of time spent in the claims process so far
- satisfaction with the PIP process as a whole and at each stage
- communication and customer service from the DWP, Atos and Capita.

The participants

Participants were recruited from across Great Britain¹ and included people affected by cancer who had called the Macmillan Support Line or who had been referred from Macmillan's face-to-face benefit advice services. These participants had a wide range of cancer types, were at different stages of their cancer journey, and had differing support needs.

The most common cancer among survey respondents was breast cancer (34%), followed by bowel cancer (16%) and Non-Hodgkin lymphoma (9%). Respondents most commonly had localised or stable cancers (24%), had advanced cancers (20%), or were at the point of diagnosis or unaware of their diagnosis (20%).

The majority of respondents (63%) had claimed benefits before. Almost half (44%) had an income of less than £15,000 a year. Delays in processing the benefit may have meant that a smaller number of people reached an outcome for their claim. This, in turn, means some sample sizes are lower and therefore should only be seen as indicative.

2. What is PIP and why do people with cancer need it?

What is PIP?

Aims of PIP

PIP is designed to help towards some of the extra costs arising from a long term ill-health condition or disability. It is not means tested and is payable to people who are both in and out of work. The DWP has said that reform of DLA will target its resources 'at those most in need'.²

The DWP originally expected PIP to reduce DLA caseloads and expenditure by 20%. Savings from the reform were expected to be equivalent to 20% of forecast working age DLA expenditure.³

New claims for PIP began in pilot areas in April 2013 before going live across Great Britain in June. Claimants who already receive DLA will be migrated across to PIP on a phased basis, at the point when their award ends or if they report a change in circumstance.

Who is eligible?

To be eligible for PIP under 'normal rules' you must have experienced the symptoms of your condition or disability for at least three months. Furthermore, it must be expected to last at least another nine months. Eligibility for PIP is determined by how a person's condition affects them, with supporting evidence and, in the majority of cases, a face-to-face assessment used. This then determines whether someone is eligible for PIP and, if they are, the level of award that is deemed appropriate. Independent assessments are carried out by assessment providers Atos and Capita, who work across different parts of Great Britain. The DWP subsequently makes a decision on eligibility on the basis of the evidence collected.

There is also a fast-tracked special rules process for those people considered terminally ill. To be eligible, a person must be reasonably expected to die within six months. They then access a faster and streamlined claims process, including not having to satisfy the three and nine-month qualifying period requirements.

Why do people with cancer need it?

Support needs

People with cancer often have support needs. Cancer and its treatment can result in a sudden onset of daily living and/or mobility needs and can have long-term physical impacts.

'It's 24 hours a day: I'm very unsteady on my feet. I have the shakes, my fingers and my feet are affected (I have to wear thermal gloves and socks) and I also have nausea day and night.'

Susan, 56, who has bowel cancer

Recent research shows that at least 200,000 cancer survivors are estimated to be left with pain, often with nerve changes after surgery, radiotherapy or chemotherapy.⁴ In addition, cancer-related fatigue is one of the most common side effects of cancer and its treatment.⁵ Fatigue is not merely passing tiredness but is experienced as a chronic and debilitating consequence of the treatment of cancer.

A cancer diagnosis can also place an emotional strain on people, with more than one in eight of those diagnosed up to five years previously saying they experience moderate to extreme anxiety or depression.⁶

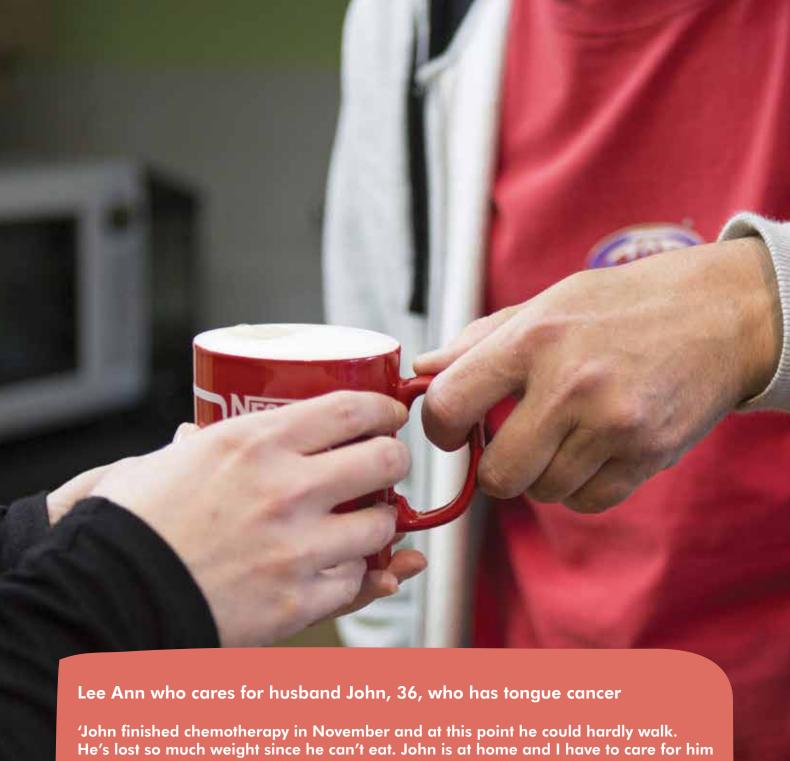
Almost half (47%) of this survey's respondents told us that they require support 24 hours a day, with a further 30% requiring support every day during the night or day. PIP can be key to getting a number of means of support in place. This means the delays explored later in this report can have wide-reaching effects on the ability to get vital support when it's most needed.

Almost half (47%) of this survey's respondents told us that they require support 24 hours a day, with a further 30% requiring support every day during the night or day.

Financial burden

Cancer is not only physically and mentally gruelling for many people but it's also expensive. Previous Macmillan research revealed the sheer scale of the financial burden faced by people living with cancer – four in five people (83%) are, on average, £570 a month worse off as a result of a cancer diagnosis. The financial impact of cancer can have serious knock-on effects on wellbeing. This can place a huge amount of additional pressure on people at a time when they should be focusing on their treatment and recovery.

Many people with cancer now receive their treatment as outpatients and need to make regular trips to hospital. As cancer treatment often puts people at greater risk of fatigue and infection, public and hospital transport is not always suitable for them. People are forced to rely on travelling by car or taxi, and often find themselves out of pocket for fares, petrol and car parking charges. In addition, cancer and its treatment can cause people to feel the cold more and they spend more time than usual at home, meaning the cost of heating the home increases.



but, with my two teenage boys, it's just too much.

With two young boys, it has been a nightmare and we haven't been given any extra money at all. John can't eat and he has to be fed by a tube – we do have a nurse who comes around but it's mainly me who cares for him on a day-to-day basis.

When John had to go to hospital, I couldn't even go to see him as I didn't have any money and the hospital is rather far from us. John has had to go to hospital twice: once for pneumonia and once for a low platelet count as a result of the chemotherapy. I was incapable of getting to the hospital with no extra money.

I've struggled with putting money on the gas. I'm so worried about the amount of money I'm able to put on the gas meter. I don't feel well myself and my boys are suffering – it has affected all of us."

3. Delays to claims

There is often an immediate onset of support and financial needs following diagnosis and treatment. Because of this Macmillan believes people living with and beyond cancer should receive PIP in a timely manner. Benefits are crucial for people living with cancer at a time when they risk real financial hardship.

One of the most striking aspects of this research is the length of time people living with cancer have to wait to receive benefit payments. This is clearly shown in Table 1. This delay in support is in addition to the person having experienced their symptoms for three months before they're eligible for PIP. This is known as a 'backwards' test.

The overall time taken to reach a decision varies considerably. Previously, DLA claims typically took 11 weeks to process and be paid. It is vital that the government's reform, designed to improve the system, should be at least as responsive to the needs of people living with cancer and other conditions. Moreover, to ensure there is transparency and to create greater trust in the system among claimants, it is important the DWP regularly reports on its performance in processing claims. This will allow progress on reducing delays to be measured.

Excluding fast-tracked special rules claims for the terminally ill, more than half of applicants (55%) said that it took three months or more for a decision on their claim to be reached. For the 6 in ten who had undergone a face to face assessment (58%), it had taken at least six months to reach this stage. Among those who have not yet received a decision under normal rules, on average the application process took almost four and a half months in total. For the 25% of those who have not yet received a decision under normal rules, the application process has taken at least six months so far.

The application process took longer than expected for just under six in 10 of those who had received a decision (58%). However, this rises to seven in 10 (70%) when looking at just normal rules claims. The DWP's expectation is that special rules claims are fast tracked and, typically, in our sample they are dealt with more quickly than normal rules claims. Issues around special rules claiming are explored in more depth later in this report.

'I thought it would have taken six weeks not six months.'

Julie Anne, aged 62, who has breast cancer

Table 1: Time spent in process among those surveyed at different stages of the PIP application process

Time taken	Stage of process					
	Submitted claim form ⁹	Invited to assessment	Had assessment	Received decision		
Base	74	7	24	40		
Less than one month	8%	_	_	13%		
At least one month but less than two months	20%	-	-	13%		
At least two months but less than three months	15%	-	-	18%		
At least three months but less than four months	12%	-	17%	13%		
At least four months but less than five months	9%	29%	8%	8%		
At least five months but less than six months	14%	14%	13%	18%		
At least six months but less than seven months	11%	14%	29%	8%		
At least seven months but less than eight months	5%	43%	17%	10%		
At least eight months	5%	_	13%	3%		

Impact of delays

The delays in processing claims meant that more than half of respondents (56%) had increased financial worries while 51% felt the process caused emotional strain. Worryingly, 40% of people were unable to heat their homes when they needed. This is something that could impact on recovery given that people living with cancer tend to feel the cold more as a result of treatment. When asked, 34% of respondents said the process had a negative impact on their mental health and a third (33%) were unable to pay for support when they felt they most needed it.

As well as contributing to the financial impact of a disability or long-term illness, PIP also acts as a 'passport' benefit. This means that a PIP award determines eligibility for other help and support provided by the DWP, other government departments, devolved administrations and local government.

Such 'passported' benefits include disability premiums in Housing Benefit and Employment and Support Allowance, access to motability schemes and blue badges for parking, exemption from the benefit cap and possible local council tax reductions.¹⁰

On top of this, delays in paying PIP mean carers are unable to receive Carer's Allowance for the person they support. Delays in payment can therefore adversely impact on the ability of people affected by cancer to access the support available. Promptly administering PIP claims is vital, and not just for the immediate financial benefits of helping with extra costs. It also ensures people can access the full suite of support when they need it.

Reassessing existing DLA claims

The 'natural reassessment' of PIP claims – that is reassessing people once their DLA claim has ended – is ongoing in certain postcodes and will continue to roll-out across Great Britain. Where people report a change of circumstances, for instance a change in prognosis, their claim is also reassessed.

Given the severe delays already facing PIP claimants, there is a significant risk in continuing to place more claims in the system. While PIP has struggled, DLA for children and Attendance Allowance have continued to be processed at acceptable speeds, resulting in an inequity of service depending on a claimant's age. No person living with cancer should be placed into a system that isn't working.

Susan, 56, who has bowel cancer

'My husband is my full-time carer; however, he's not allowed to receive Carer's Allowance until my claim has been approved. I'd say this is a full-time job for him. My husband not being able to work means he is losing £1,500 a month of income every month. Our heating is on 24/7 at the moment so our bill will be high.

Because I didn't know my cancer had spread after my surgery, I intended to go back to work six weeks down the line. Although during my period of convalescence, I was told the cancer had spread and come through my bowel, meaning I will need chemotherapy. The mortgage company gave us a three-month break for August, September and October. But now we have to pay it so my husband's redundancy money is almost gone.

I have worked all my life and so had my husband, so claiming benefits was not an easy thing to do. But the fact that we had no money coming in meant we didn't have a choice. I thought my claim would go through with no problem.

When I posted [the application form], I assumed that within a month to six weeks someone would get back to me to do an assessment. When I didn't hear anything I rang them, only to be told they couldn't find anything on the screen with my name which was very frustrating. We sent the form back and still haven't heard anything four months later.'



Using supporting evidence

Problems in arranging assessments, a significant factor in delays, are further compounded by the system not working as modelled. As shown by a recent National Audit Office report on PIP, the DWP had expected more claims would be progressed on the basis of supporting evidence alone. The expectation was that 75% of claims would require a face-to-face assessment, with the actual percentage 97% for Atos and 98% for Capita.

Arranging a face-to-face assessment appears to be a significant bottleneck in the claims process. Being able to better identify the claims that can progress on the basis of supporting evidence alone would be less resource intensive. This would work to reduce the existing backlog in arranging assessments.

Recommendations

- The DWP should make sure that the PIP assessment process takes no longer than 11 weeks.
- To allow this to be monitored the DWP should include data on claim processing times in its quarterly statistics.
- The DWP should not continue with natural reassessment of DLA claims until the PIP backlog is down.
- The DWP should work with providers to better identify claimants who can be assessed on the basis of evidence alone, without the need for face-toface assessments.

4. Claim outcomes

Of our 210 survey respondents the majority (60%) had not seen their claim reach an outcome. While some are in the early stages of their claim, a significant number have been waiting considerable lengths of time for their claim to progress.

'I was told that it shouldn't take that long initially. It's been four months. The process really shouldn't take that long. They need to change everything. They should give a clear idea on timescale and how long it is going to take exactly.'

Lee Ann who cares for husband John, 36, who has tongue cancer

Of our 210 survey respondents the majority (60%) had not seen their claim reach an outcome.

Over a guarter had reached a decision (28%), with twice as many receiving a decision via normal rules claiming (19%) than via special rules claiming (9%). PIP has two components - a Mobility component, which is based on planning journeys and moving around, and a Daily Living component, which is focused on the ability to undertake practical daily tasks and subsequent care needs. They are paid at an Enhanced or Standard rate, depending on need as determined by the application process. Where respondents reached a decision, the vast majority (86%) were awarded PIP and 65% were awarded the Enhanced Rate Mobility component. 10% were awarded the Standard Rate Mobility component, 41% the Enhanced Rate Daily Living component and 10% the Standard Rate Daily Living component.

It is worth recognising that these figures compare favourably with national statistics of PIP claims made and the proportions of those awarded.¹² There may, however, be mitigating factors for this, particularly given that our sample was recruited from Macmillan's benefit advice services. The support and advocacy respondents received from these services may have been helpful in progressing their claims. When chasing delayed claims respondents to the qualitative interviews reflected that getting their local MP, Macmillan or other advice agencies involved was of benefit. The DWP's quarterly statistics, which are broken down by condition-type, will give a fuller picture of the awards people living with cancer are receiving. Where claimants disagree with their decision or award they can challenge the outcome. For the 14% of respondents who had reached a decision but not been awarded PIP, 4% of the total sample, the majority did not intend to challenge the decision. Various reasons were given, including that they felt the DWP would not change their mind or that they hadn't listened before so were unlikely to again. Other reasons were that the respondent had given all the evidence they could, it would be too time consuming and/or they didn't feel well enough to challenge the decision.

The DWP recently introduced a process called mandatory reconsideration to resolve disputes before an appeals process. This involves a phone call from the DWP to the claimant to explain the decision and offer an opportunity to provide further evidence. Of those whose claim was disallowed, none of the respondents could recall receiving this call from the DWP. This is unacceptable.

'We didn't hear anything until we got our local MP involved. Things then sped up very quickly – within a couple of weeks he heard something back. If our MP hadn't got involved God knows how much longer it would have taken. I don't think we would have ever heard anything back – they just would have left us.'

Lee who cares for Laura, 27, who has anaplastic astrocytoma grade 3

'Receiving the money from PIP, and the grant from Macmillan, has made a big difference. I'm starting to get more clothes for myself as they don't fit any more. I am feeling more motivated than I did before. I was feeling a bit depressed. It's really benefitted my life. I feel much happier – it's made my life better and easier."

John, 50, who has bowel cancer

One in 12 (8%) stopped their claim, with more than half of those (5%) deciding to give up their claim themselves. Reasons given included a feeling that they wouldn't be awarded PIP, didn't have enough support from the DWP or the process was too time consuming, upsetting and/or too difficult. A smaller group of individuals (3%) said they were advised by the DWP or someone else to discontinue their claim. The typical reason given was that their symptoms or support needs were not great enough, while one respondent was told the process would take too long. As the number of people moving through the claims process increases we will monitor whether this becomes a more significant problem.

Impact of awards

Due to the significant delays in the claiming process, fewer people had reached an outcome and were able to answer questions on the impact of awards. Nearly three fifths of those who reached an outcome (57%) were satisfied with it, although just under a quarter (24%) were dissatisfied with the decision. Those who had been awarded PIP (88%) were satisfied with the outcome of their claim and were more likely to be so than those who weren't awarded. Being awarded PIP was more likely to have had a positive impact than a negative one on financial worries and emotional strain (net positive impacts of +67% and +51% respectively).13 From this, we can see the positive impact that receiving this extra financial support can have, further emphasising the need to receive it in a timely manner.

Almost half (47%) thought that their award was about the right amount to cover their support needs, while a third (33%) thought that the amount of money they were awarded did not cover their support needs. Where people felt their award fell short, a number of impacts were felt. These included family members being unable to take a break from caring, increasing emotional strain and/or having a negative impact on mental health, and more difficulty in paying for heating.

It is vital that PIP keeps pace with the cost of living, given there are some people who already feel that the payment is not meeting their needs. Almost half of our respondents (44%) have an income of less than £15,000 a year while facing increased costs as a result of cancer and its treatment. While DLA and PIP were protected from 2013's three-year freeze in benefits uprating, the amount by which benefit payments are increased annually, they must continue to rise in line with inflation. Failure to do so will mean PIP falls further behind the cost of household energy or other essentials. Support must be provided on the basis of need and freezing the up-rating of PIP must not be seen as an easy way to make savings in the future.

Almost half (47%) thought that their award was about the right amount to cover their support needs, while a third (33%) thought that the amount of money they were awarded did not cover their support needs.

Recommendation

• The DWP should also continue to up-rate PIP in line with inflation.

5. Satisfaction with the process

Respondents were asked whether they were satisfied with the process of applying for PIP overall and about their satisfaction with each stage of the process. The satisfaction levels recorded are shown in Table 2 below. Almost half (47%) were dissatisfied with the overall experience of making a claim, compared to just 28% who felt they were satisfied.

Those who were yet to reach an outcome (58%) were more likely to be dissatisfied with the process, reflecting the impact systemic delays can have on overall experience. The most common reasons for dissatisfaction were that the process was taking too long (33%), poor communication from the DWP (23%), the process was too stressful (10%) and the poor attitude of the staff dealing with claims (9%).

Table 2: Satisfaction level across different stages of the PIP claims process

Stage of claim	Very dissatisfied	Fairly dissatisfied	Fairly satisfied	Very satisfied	Base
Initial phone call	8%	10%	31%	30%	207
Filling in the form	18%	15%	29%	12%	185
Submitting evidence	15%	13%	31%	23%	144
Arranging the face-to-face assessment	48%	8%	18%	18%	50
Undergoing the face-to-face assessment	11%	5%	35%	41%	37
The decision letter's communication	9%	3%	26%	41%	59
Special rules claiming process ¹⁴	15%	0%	26%	41%	27

Almost half (47%) were dissatisfied with the overall experience of making a claim, compared to just 28% who felt they were satisfied.

Form completion

Prior to the research reporting we received anecdotal feedback from Macmillan benefit advisers. They felt that the questions on the application form were inadequate. They were poorly laid out and missed key information to support faster evidence gathering, such as hospital-reference numbers.

A significant minority of respondents were dissatisfied with filling in the form (32%), with 50% disagreeing that questions were suitable for applicants' conditions compared to 31% who agreed. More respondents felt the application form was not of a manageable length than did (43% compared to 37%), while a significant minority felt the form did not give sufficient opportunities to communicate support needs (27% compared to 44% who felt it did).

Those with five to nine or 10 to 14 support needs to communicate were more likely to feel this way than those with four or fewer support needs (35% and 32% respectively compared to 9%). This suggests that the application form may work better for those with fewer support needs to convey.

In some cases, individuals reported waiting for up to four months for their appointment.

Arranging a face-to-face assessment

When exploring experience at each stage of the PIP claim, the stage that respondents were most dissatisfied with was arranging the face-to-face assessment (56%). These applicants tended to cite the length of time that it took to arrange an appointment and the lack of communication they had from the assessment provider in that time period as the key reasons for dissatisfaction. In some cases, individuals reported waiting for up to four months for their appointment.

This reflects the findings outlined earlier that there appears to be a significant delay in arranging face-to-face assessments, creating a bottleneck in the system. Only 24% of respondents had been invited to an assessment. There is a risk that once this is cleared, the DWP may not be adequately prepared to deal with the surge in decisions it must make. It is vital that this is properly resourced.

Where face-to-face assessments are arranged, they can take place at either the applicant's home or in an assessment centre. More than half (56%) disagreed that it was easy to arrange an assessment, emphasising the problems applicants have in progressing their claims. Just under a quarter (24%) felt it was unclear when and where the assessment was and 20% felt that the location of the assessment was not easy to access. This reflects findings in the qualitative interviews and anecdotal feedback from Macmillan's benefits advisers that people are often forced to travel long distances to attend assessments.

Moreover, the qualitative interviews conducted as part of this study revealed worrying instances of home assessments being arranged and providers failing to turn up. This reflects anecdotal feedback from benefits advisers and people living with cancer across Great Britain since PIP went live.

Undergoing a face-to-face-assessment

Given delays in processing the benefit, a very small minority (18%) had actually undergone an assessment. Overall experiences appear largely positive at this stage, with 92% feeling the assessment staff were polite. More than three quarters (76%) felt that the assessment gave sufficient opportunities to communicate the condition and its impacts. This is something Macmillan will continue to monitor as more people begin to progress to assessments.

Despite these early encouraging signs there are indications that there is still room for improvement. Almost a quarter (24%) felt the questions asked were unsuitable and 22% that the questions were not encouraging in helping to explain their condition and its impacts. While 14% felt the assessment did not give them sufficient opportunities to communicate their support needs.

Anecdotal feedback from benefits advisers and claimants indicates that there is often a significant delay between an assessment and a decision. This further emphasises the need to report on processing times at each stage of the claiming process.

Recommendations

- The DWP ensures the application process allows claimants to accurately describe their support needs and captures key supporting information.
- The DWP enforces contract standards, including penalties, if providers do not meet their obligations to offer prompt face-to-face assessments (including home assessments).



6. Communication and customer service

With 63% of respondents having claimed benefits before, experiences of PIP in comparison are particularly poor. Of those who had applied for DLA previously, 45% felt claiming PIP was a worse experience, with 15% saying it was better. The picture was similar for those who had claimed Employment and Support Allowance (ESA), with 46% telling us that claiming PIP was worse and 17% saying it was better.

While it is possible to suggest that the delay in processing PIP is a significant factor in people's poor experiences, this research also suggests there are a number of areas where communication and basic customer service can be improved. Almost half of those who had previously applied for any benefit (48%) said the process was slower. Over a third (35%) thought that PIP was more complicated and three in ten (31%) thought that they had been updated less often about the status of their PIP claim in comparison to other claims.

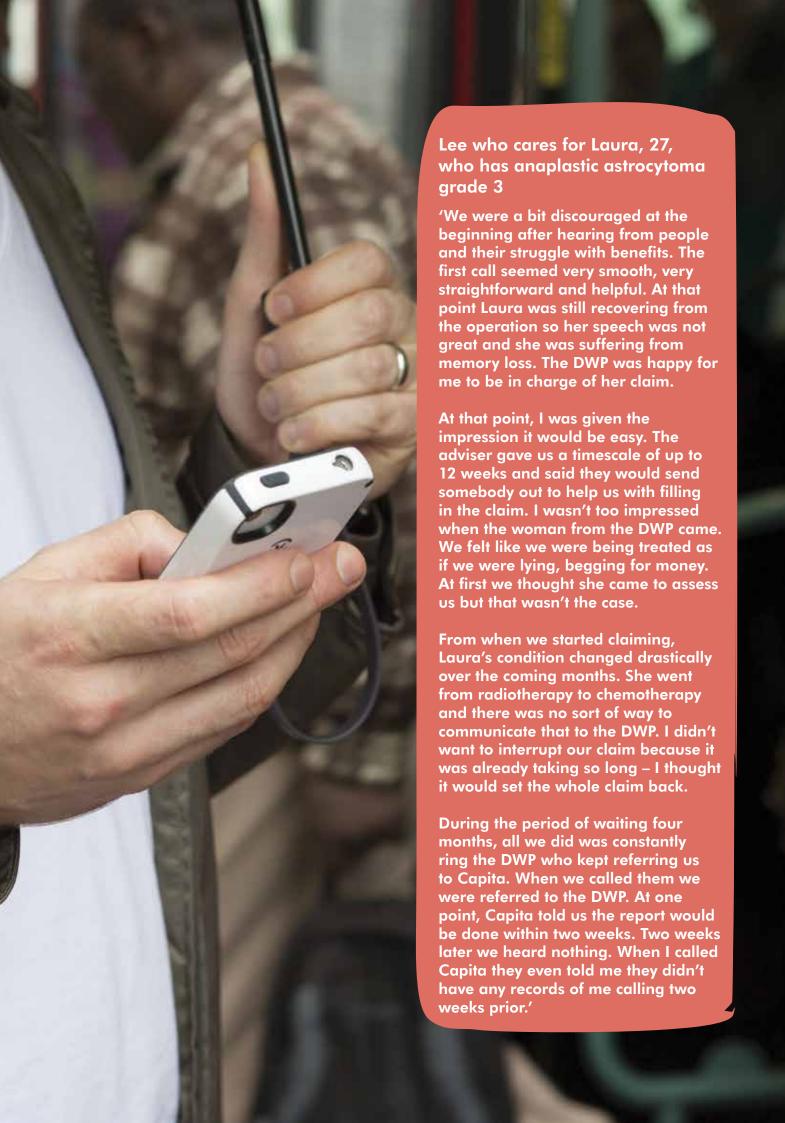
Almost half of those who had previously applied for any benefit (48%) said the process was slower.

Chasing a claim

Delays in advancing a claim, added to a lack of communication, left respondents unsure as to its status. This forced them to contact the DWP for an update. This was often distressing as they could be passed back and forth between the DWP and Atos or Capita, and for enquiries to be unresolved. The majority of respondents (68%) felt they were not kept informed about any delays, while over half (58%) felt the next steps in the process were unclear.

Almost two thirds of all respondents (65%) said they weren't told how long the application process would take by the DWP. This includes 20% who asked the DWP how long it would take but were not told. Out of the 50 individuals that were told, 42 were informed that the process would take less than three months.

There are parts of the application process that assessment providers Atos or Capita undertake on DWP's behalf. However, the DWP is ultimately responsible for administering PIP and should therefore lead on keeping claimants up to date as to the progress of their claims. Claimants should not be in a situation where they are passed back and forth between the DWP and the assessment provider. Claimants should not be penalised as a result of PIP's administration arrangements.



Submitting evidence

To support their claim people are encouraged to send further evidence. Examples of additional evidence include: prescription lists; care plans; and reports or information from professionals such as GPs, consultants, specialist nurses, physiotherapists or social workers.

More than half (54%) of those who submitted additional evidence felt it was unclear whether the DWP had received it. This may be because people's claims are taking so long that it's likely they send additional evidence as their condition changes. Although the DWP are not mandated to automatically acknowledge receipt, Macmillan believes it is important to acknowledge when someone has taken the time to provide personal information and remove this uncertainty. More than a quarter of people were unclear as to how the DWP used their evidence (28%) and/or were unsure whether it was their responsibility or not to obtain new evidence (26%).

Recommendations

- The DWP should ensure people are given an expectation of how long their claim will take to progress and are kept updated about any delays.
- The DWP should automatically acknowledge the receipt of evidence submitted by claimants.

7. Special rules claiming

PIP was rolled out across Great Britain for new claimants in June 2013. Since then, our benefit advice services began to report serious concerns about the processing of terminally ill claimants via special rules. Special rules claimants could be reasonably expected to die within six months and therefore undergo a more streamlined application. Their claim is progressed on the basis of evidence from medical professionals, they should not be subject to a face-to-face assessment and their claims are processed more quickly.

Under DLA, the DWP worked to a target of eight to 10 working days of processing special rules claims. While feedback from our benefits advisers said that under PIP it was taking about eight to 10 weeks. This was reflected by an informal survey of their experiences which we shared with the DWP. This situation was unacceptable and we raised these concerns immediately with the DWP.

We note that progress has been made on reducing delays since our research was conducted. However, there is more the DWP can do to ensure that people claiming under special rules receive the support they need. Subsequently, the DWP have announced that special rules claims are now down to 10 days and they are seeking to further lower them to seven. ¹⁵ Macmillan welcomes the progress made by the Department in ensuring that people with a terminal diagnosis receive support quickly. However, it is vital that the DWP publicly report on processing times for all claims. This will allow progress on reducing delays to be measured.

Of our sample just over one in 10 (13%) identified as claiming via special rules. Some had reported that they had submitted a claim form, been invited to an assessment and/ or been to a face-to-face assessment. This may be down to respondent confusion about 'special rules' or confusing the initial phone call as an application form. However, due to the sensitivities involved, these respondents were not re-contacted.

However, of all those who had received a decision via special rules (9% of total sample) none had undergone a face-to-face assessment. Perhaps predictably given their fast track nature, the overwhelming majority of those claiming under special rules had reached an outcome at the time of survey. Special rules decisions represent just under half of all decisions made and were more likely to be dealt with quickly. Compared to those who claimed under normal rules, they were less likely to feel that the claims process was much longer than expected. They were also less likely to report dissatisfaction with the experience of making a claim.¹⁶

This may be in part attributable to a lack of understanding as to how long the process should take or lowered expectations. Only a small proportion of those who received decisions (13%) had their claims dealt with in one month or less. This does not encompass all special rules claims, which account for 48.5% of all decisions made.

We note that progress has been made on reducing delays since our research was conducted. However, there is more the DWP can do to ensure that people claiming under special rules receive the support they need. When DLA claimants, whose circumstances change, claim PIP they are protected for 28 days. This means that if their PIP award is lower than their DLA award they will receive the same payment for 28 days. This protection is welcome.

Where a person who is claiming DLA's condition deteriorates there is a delay in receiving an increase. This is particularly problematic for those claiming under special rules. The delay is 28 days from the date of decision, not the date of informing the DWP of a change in circumstances. This can take approximately 35 days, which is a significant amount of time for this claimant group. A well-meaning protection therefore negatively impacts on those most in need of support.

Recommendation

 The DWP should amend regulations for people claiming DLA whose circumstances change, eg those who receive a terminal diagnosis and are now eligible for a special rules claim. Regulations should be amended so that these people claiming PIP are not disadvantaged by the 28 day protection rule and receive increased support immediately.



following the date of the decision. This was almost two months after the DS1500 had been sent.

Entitlement should have begun from when the DS1500 was dated and immediately paid in my opinion, as it would have been under DLA. My client missed out on roughly seven weeks of the higher rates when they needed it most. They also died shortly after the award was made.

The financial loss to this person over someone who isn't in a PIP reassessment area is potentially almost as much as £700, not including the potential for lost free car tax, lost premiums in means tested benefits and other passported benefits.'

Conclusions

This report demonstrates the problems facing people living with cancer who are applying for PIP. Cancer can have an immediate physical, emotional and financial impact. Significant delays in processing mean that PIP is not responsive to the needs of people affected by cancer.

When added to the three-month 'backwards test', people living with cancer are waiting significantly more than six months before they can receive the support they are entitled to. Not only do they not receive PIP when they may be entitled to it, but there are further knock-on effects around entitlement to passported benefits and getting caring arrangements in place.

As soon as Macmillan became aware of special rules delays, we sought to work with the DWP to resolve the issues. We welcome the progress made to date. However, our new research demonstrates that there are significant problems with PIP claims under normal rules.

PIP is designed to support people who are the most in need and, to realise this policy intention, the DWP must act to resolve these issues as a matter of urgency. Even the DWP's PIP helpline now has an automated message which informs clients claims are taking longer than expected and could take up to 26 weeks. While it is welcome that the DWP are being realistic about the length of time claims are taking immediate action must be taken to tackle the delays.

Macmillan will continue to monitor the impact of PIP and raise the concerns of people affected by cancer. We want to see a PIP system that works effectively for people living with cancer and is responsive to their needs. We look forward to discussing our recommendations with the DWP and strongly believe they should be implemented as quickly as possible.

Recommendations

To ensure the PIP claiming process is transparent and responsive to the needs of people living with cancer, Macmillan recommends the DWP:

- makes sure that the PIP assessment process takes no more than 11 weeks
- includes data on claim-processing times in its quarterly statistics
- ensures people are given an expectation of how long their claim will take to progress and are kept updated about any delays
- automatically acknowledges receipt of evidence submitted by claimants.

To ensure the PIP claiming process works for people living with cancer, Macmillan recommends the DWP:

- should not continue with natural reassessment of DLA claims until the PIP backlog is down
- enforces contract standards, including penalties, if providers do not meet their obligations to offer prompt face-to-face assessments (including home assessments)
- continues to up-rate PIP in line with inflation
- ensures the application process allows claimants to accurately describe their support needs and captures key supporting information
- works with providers to better identify claimants who can be assessed on the basis of evidence alone, without the need for face to face assessments
- changes regulations for people claiming DLA whose circumstances change,
 eg those who receive a terminal diagnosis and are now eligible for a special rules
 claim. Regulations should be amended so that these people claiming PIP are
 not disadvantaged by the 28-day protection rule and receive increased support
 immediately.

References

- 1. PIP has yet to start in Northern Ireland.
- 2. Minister for Disabled People. Oral statement on Personal Independence Payment. December 2012.
- 3. Department for Work and Pensions. DLA reform Impact Assessment. 2012.
- 4. Macmillan, Cured but at what cost? 2013.
- 5. Medicinenet. Coping with fatigue. medicinenet.com/cancer_fatigue/article.htm (date accessed 13 May 2014)
- Macmillan. Cured but at what cost? 2013.
- 7. Macmillan. Cancer's hidden price tag: revealing the costs behind the illness. 2013.
- 8. The sample for special rules is quite small so caution is advised and findings are purely indicative.
- 9. The time taken to receive and submit the PIP2 claim form varied. 43% of those who submitted the evidence gather form but had not progressed further had submitted this form in less than three months, over a third (35%) had taken at least three months but less than six and just over one in five (22%) had taken six months or longer. The varying amount of time it took to submit the form may reflect varying degrees of difficulty that individuals were experiencing in filling the form in or getting an appointment with an advice agency.
- 10. For a full list of passported benefits see gov.uk/government/uploads/system/uploads/attachment_data/file/304507/pip-handbook.pdf
- 11. National Audit Office. Personal Independence Payment: early progress. 2014.
- 12. Department for Work and Pensions. Personal Independence Payment: Management Information. 2014.
- 13. Net positive impacts are the result of a positive answer minus the negative answer.
- 14. There were 27 respondents who stated that they had made the claim under special rules. Of these, 21 claimed that they had submitted a claim form, six that they'd been invited to an assessment and/ or two had been to a face-to-face assessment. This may be down to respondent confusion about special rules and due to the sensitivities involved these respondents were not re-contacted.
- Macmillan 'Macmillan Cancer Support pleased that PIP waiting times have been reduced to 10 days' www.macmillan.org.uk/Aboutus/News/Latest_News/ MacmillanCancerSupportpleasedthatPIPwaitingtimeshavebeenreducedto10days.aspx (date accessed 13 May 2014)
- 16. Due to the small base size of special rules claims, these findings are only indicative.

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Dan Rattigan, Policy Analyst Macmillan Cancer Support drattigan@macmillan.org.uk When people have cancer, they don't just worry about what will happen to their bodies, they worry about what will happen to their lives. At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support people through. From help with money worries and advice about work, to someone who'll listen, we're there. We help people make the choices they need to take back control, so they can start to feel like themselves again.

No one should face cancer alone. We are all Macmillan Cancer Support.

