

Personal Independence Payment (PIP) benefit for people with cancer

Thousands of people with cancer have had to wait six months or more for disability benefits since the Disability Living Allowance (DLA) was replaced by PIP

In June 2013, the UK government replaced the Disability Living Allowance (DLA) benefit with the Personal Independence Payment (PIP) benefit. PIP is designed to help cover the additional costs arising from long-term illness or disability for people of working age. Following anecdotal concerns that people with cancer are experiencing issues accessing PIP, Macmillan Cancer Support commissioned a survey of 210 people with cancer who have applied for PIP to investigate this further.

Using the results of the survey, Macmillan estimates that in the first year since PIP replaced the DLA, **around 4,500 people with cancer who have applied for PIP have had to wait at least six months** to find out if their application has been successfulⁱ. The average waiting time has almost doubled compared with the previous DLA application process and lengthy delays are leaving people with cancer saddled with financial difficulties and mental health problems.

Longer waiting times

Under the previous system, it took 11 weeks on average for an applicant to find out if their claim for DLA was successful or not. Our survey shows that people with cancer are now waiting **an average of 19 weeks from starting their application to receiving a decision**ⁱⁱ. Overall two in three (65%) people are waiting for at least three months from the start of their application to decision and more

than one in four (29%) are waiting for at least six months.

As people are not able to apply for PIP until they have been experiencing their symptoms for at least three months, this suggests that **two in three (65%) of people with cancer** are waiting for at least six months from the **point at which they start needing PIP** to the time they find out if they will receive it or not.

The proportion of people experiencing delays of six months or more after applying for PIP is higher for those who are still waiting to hear a decision compared with those who have already received a decisionⁱⁱⁱ, suggesting that the **average waiting time may be continuing to increase**.

Of the people we surveyed, around one in three (35%) are currently waiting to be invited for an assessment after submitting a claim, and of these around one in five (22%) have been waiting for at least six months since starting their application.

Impact of the delays

Almost six in 10 (58%) people with cancer who have received a decision find the PIP application process takes longer than they expected. A third (33%) of all those who apply for PIP experience more than six different negative impacts as a result of delays with their application. More specifically:

- Over half (56%) experience **financial worries**

- One in three (34%) experience **mental health problems** such as anxiety or depression

Many of the negative impacts are related to financial issues:

- Two in five (40%) can't afford to **heat their homes** adequately
- One in four (27%) have difficulties attending their **hospital appointments**
- One in four (27%) find it harder to maintain a social life, putting them at **risk of isolation**

In addition to helping cover the additional costs arising from long-term illness or disability, PIP also acts as a 'passport' benefit. This means that people are only eligible to receive a range of other benefits and support from national and local government, such as **higher rates of Housing Benefit and Employment Support Allowance (ESA)**, if they receive PIP. In addition, a carer is only eligible for **Carer's Allowance** if the person they are caring for receives PIP.

Delays in the PIP application process are therefore also causing delays in people with cancer and their carers receiving these other vital types of support.

Satisfaction with the process

Almost half (47%) of people with cancer are **dissatisfied with the overall experience** of making a claim for PIP.

Of those who had applied for DLA previously, over two in five (45%) say **claiming for PIP is a worse experience**. Fewer than one in

seven (14%) say the process is an improvement^{iv}.

About the research

In 2013 Macmillan commissioned IFF Research to conduct a quantitative and qualitative study that explored the impact of PIP on the financial status, standard of living and wellbeing of people living with cancer.

The study consisted of two phases: firstly, a qualitative phase that comprised eight in-depth telephone interviews, and secondly, a quantitative phase informed by the interviews that surveyed 210 people living with cancer, with 75 interviews carried out by telephone and 135 online.

The study was conducted from December 2013 to February 2014. Participants were recruited from across Great Britain from callers to the Macmillan Support Line and clients referred by Macmillan's face-to-face benefit advice services. The results therefore may actually underestimate the extent of the delays and issues being experienced by people with cancer in the UK, as the support and advocacy the participants received from Macmillan may have been helpful in progressing their claim.

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%). The majority (63%) of respondents had claimed benefits previously.

For the full results of the research, read the report [Waiting to benefit](#).

ⁱ Macmillan estimate has been calculated based on:

- DWP Personal Independence Payments: GB Official Statistics released on 5th June 2014 which show that as of February 2014, 3.88% of PIP cases in payment were classified under 'malignant disease' not under special rules. We assume this proportion can be used to estimate the minimum proportion of Personal Independence (PIP) claimants with cancer. (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/317425/pip-statistical-release-june-2014.pdf)
- DWP Personal Independence Payments: GB Official Statistics which show a cumulative total of 335,100 PIP claims from April 2013 to March 2014. Adjusting these figures to produce a 12 month estimate covering the period since PIP was rolled out nationally in June 2013, we estimate a total number of 405,866 claims.
- Applying the 3.88% to the total estimated number of claims since PIP was introduced we estimate approximately 15,747 of these claims are from cancer patients.
- Results from our research show that 29% of PIP claimants (at various stages of the claims process) had waited for at least six months from the start of their claim to either receiving a decision or hearing about the next step of the process (either to be invited to assessment, have the assessment, or receive a decision). Overall times taken will include time taken by the claimant to complete and return their form.
- Applying this 29% to the 15,747 we estimate over 4,500 PIP claimants with cancer have had to wait six months or more from the start of their claim to either receive a decision or to hear about the next step of the process (either to be invited to assessment, have the assessment, or receive a decision).

ⁱⁱ Average for study respondents who have applied under 'normal' rules (i.e. excluding those with a terminal diagnosis who applied under fast-tracked 'special' rules)

ⁱⁱⁱ One in three (33%) people who are still waiting to hear a decision have waited for six months or more, while around one in five (18%) people who have received a decision said this took six months or more

^{iv} These figures are based on a small subgroup of 22 people from the survey who had previously claimed DLA