Timms Review of Personal Independence Payment: call for evidence response

May 2026

About Marie Curie

Marie Curie is the UK's leading end of life charity. We are here for anyone with an illness they're likely to die from, and those close to them. We bring 75 years of experience and leading research to the care we give at home, in our hospices and over the phone. We are the largest charitable funder of palliative and end of life care research in the UK and campaign inside and outside Parliament for the policy changes needed to deliver the best possible end of life experience for all.

Summary of recommendations for the Department for Work and Pensions

- Ensure PIP adequately covers the costs associated with having a terminal illness.
- Empower more clinicians to use the SR1 form, including by making them aware that doing so does not come with professional consequences if a patient lives for longer than 12 months.
- Undertake an awareness campaign about the Special Rules for End of Life among clinicians likely to interact with terminally ill people and track uptake.
- Introduce a more flexible definition of terminal illness, that isn't time limited. This could be modelled on the approach taken by Social Security Scotland, where a person is considered to be terminally ill if they have a progressive disease from which death may reasonably be expected.
- Automatically provide people who have qualified for PIP via the Special Rules route with the Enhanced Mobility component of PIP.
- Work to reduce the time it takes for a PIP MR and appeal to be cleared, so people can get a timelier resolution when challenging their PIP claim.
- Make the default assessment process a review of existing documentation rather than a preference for in-person or telephone assessments and give individuals more choice about how they are assessed for PIP.
- Provide people who qualify for PIP under Special Rules with a lifetime award of the higher rate of PIP Daily Living and Mobility that will not be reviewed unless their circumstances change.
- Provide anyone who isn't covered by Special Rules, but who has a progressive life-limiting illness and is on the highest award rates for both Daily Living and Mobility, with a lifetime PIP award.
- For people with progressive life-limiting conditions who are on the lower rates of PIP Daily Living and/or Mobility, compulsory reassessments should be replaced with 'light-touch' reviews to check whether they have become eligible for a higher award.
- If at a PIP assessment it has been identified that someone has a condition that is expected to cause death, but they don't qualify for Special Rules, investigate whether they might subsequently be eligible for an SR1 form at future reviews.
- As discussions about the abolition of the Work Capability Assessment progress, take this opportunity to consider how the Severe Conditions Criteria or equivalent could be implemented in PIP.

1. The role and purpose of PIP

Our Dying in Poverty report reveals the ‘double burden’ of income loss and increased costs brought on by a terminal illness. This can leave those who were previously comfortably-off, struggling to make ends meet. It can also push those who were already on lower incomes or struggling to get by below the poverty line. This increase in costs due to a terminal diagnosis leaves many people needing to access PIP, often for the first time.

PIP can provide a vital contribution to supporting with the additional costs associated with terminal illness. In addition to new costs like paying for medications, travel to hospital appointments and the cost of care, perhaps the sharpest cost that many families affected by terminal illness face is rising energy costs. New and higher energy needs brought on by terminal illness – the need to keep the home warmer or cooler for longer in order to stay comfortable and healthy, using mobility aids and assistive technology, or storing medications at the right temperature – can lead to a dramatic increase in energy bills.

When people are dying, the most important thing is being able to spend the last months of life focusing on what really matters – making memories with their families and loved ones, living as well as they can for as long as they are able. A strong social security system that gives people the financial support they need to die in dignity without having to worry about their finances is key to supporting that.

However, as our Dying in Poverty report makes clear, our social security system is failing to protect people at the end of life. More than 100,000 people die in poverty every year in the UK. This is particularly true for people of working age, who face significantly higher rates of deaths in poverty than people over pension age. Being in the last year of life is associated with a 32% greater risk of poverty for working-age people, and a 23% greater risk for pensioners. A major contributor to this is the working age benefits system, which provides hundreds of pounds a month less to someone who is working age, compared to pension age.

There are a range of different policy interventions beyond increasing PIP that are needed to address this, but ensuring PIP adequately covers the costs associated with having a terminal illness is an important part of the picture. As it stands, too many terminally ill people are still struggling to cover the costs associated with having a terminal illness, despite being in receipt of PIP.

> “*My husband had terminal liver cancer. I'm disabled myself and struggled to care for him, the costs were enormous whilst waiting for help that often didn't materialise. PIP doesn't anywhere near meet needs when end of life care is needed.*” Marie Curie campaign supporter

More generally, there is evidence to suggest that PIP does not fully cover the additional costs that come with a long-term health condition or disability. Research from Scope suggests that, on average, disabled households need an additional £1,095 a month to match the standard of living of non-disabled households, a figure more than double the average PIP monthly payment of £465 a month. Instead of threatening to strip back the already limited social security support provided to disabled people, which has been the government’s rhetoric in recent consultations, the government should be considering how social security support like PIP can better enable disabled people, including those with a terminal illness, to have their financial needs met and live in dignity.

2. Eligibility, fairness and equity in the award of PIP

Take up of PIP

PIP can be an important lifeline for people with a terminal illness. However, as it stands, too many people with a terminal illness aren't accessing the support that they're entitled to.

Recent research has shown that just over one third (34.1%) of people who died from a chronic illness did not take up the non-means tested benefits available to all people with a terminal diagnosis in their last year of life. This includes PIP.

There are some noteworthy take-up level insights, according to characteristics such as condition, and where in England and Wales someone lives.

The take up rate of benefits varies between people with different chronic conditions, with the lowest being those with liver disease (44%), HIV (46%) and heart failure (52%), and the highest those with dementia (75%) and neurodegenerative diseases (90%). This may be because neurodegenerative diseases and dementia are associated with a long period of low function and disability which may mean that people have both a greater need, and more time, to claim benefits. Comparatively, deaths from cancer often have a shorter period of low function before death, and deaths from heart failure are characterised by episodic decline in function and an unclear prognosis.

Take-up rates are higher in more deprived areas located in Wales and the North of England. However, substantial proportions of people in the most deprived neighbourhoods did not receive non-means-tested benefits – 34% in the most deprived quintile group and 37% in the second-most deprived - indicating that lack of need for financial support is unlikely to be the only factor driving the take-up deficit.

Overall, it's clear that as it stands, too many people with a terminal illness are failing to access PIP.

Accessing the Special Rules route

Further work is needed to ensure that people with a terminal illness can quickly and easily access the disability benefits they are entitled to, enabling them to spend the last months of life focusing on what really matters. The Special Rules for End of Life route is an important mechanism for achieving that.

> *"If my mum wasn't classed as terminal, we could have lost our home as it's the only reason we are still able to afford to live, as terminal are automatically given PIP payments without the stress of horrible assessments*." Marie Curie campaign supporter

However, not everyone with a terminal illness is currently able to access PIP via this Special Rules route.

62% of seriously ill people on PIP who died between February 2025 and January 2026 did not have a claim under the Special Rules. And more generally, over 200,000 people die each year from a life-limiting illness but are not correctly identified as suitable for referral for Special Rules.

To qualify for Special Rules, someone needs to have an SR1 form - a medical report from a healthcare professional that says someone has a terminal illness. For a healthcare professional to provide an SR1 form, a patient needs to have a progressive disease, and as a consequence of that disease, the healthcare professional needs to not be surprised if the patient was to live for less than 12 months. However, some people with a terminal illness can struggle to get an SR1 form and therefore qualify for Special Rules.

Firstly, and crucially, the Special Rules are not designed to identify everybody living with a terminal condition. These rules are intended to identify people who are likely to be in the last year of life. This means that, for example, people with a terminal condition who are likely to die in, say, 18 months or two years do not qualify. This pen portrait of Laura - which isn't a case study, but a realistic scenario based on Marie Curie's clinical expertise – helps demonstrate this.

> *Around 90% of people diagnosed with Stage 4 bowel cancer will die in the following five years. Laura has incurable Stage 4 bowel cancer. She has had previous surgery to remove the cancer, but it has now spread to one of her lungs. She has abdominal pain, and some mild shortness of breath, as well as difficulties with fatigue.*
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> *However, at the moment, Laura doesn't qualify for the Special Rules for End of Life, because her clinicians don't expect her to die in the next 12 months.*

Other people who should qualify under the Special Rules might also miss out because they and their clinicians are unaware of the Special Rules altogether, or of the change from six months to 12 months.

Clinicians might also be unwilling to submit an SR1 form due to misunderstandings about the Special Rules – for example, that they could face professional consequences if the patient lives for longer than 12 months.

The SR1 form does not require an estimation of prognosis and the DWP are clear in their guidance that payments under the Special Rules are made for three years before they are reviewed and that there are no repercussions for healthcare professionals if their patient lives for longer than expected. Yet, upcoming qualitative work from The Take-up Study with healthcare professionals indicates that worry about repercussions is common and prognostic uncertainty remains a key barrier to completing SR1 forms.

We also know that for rarer terminal conditions, people may find it difficult to get a specific diagnosis, or it may be harder for clinicians to assess whether they meet the criteria for the Special Rules.

Other people may already qualify for the relevant benefits due to their health conditions before receiving a terminal diagnosis. In these cases, there is currently little reason for someone to report their terminal diagnosis to the Department.

All of this means that "people with a claim under the Special Rules" is not and cannot be treated as synonymous with "people living with a terminal illness". Such people whose condition is only going to worsen in coming years but have not received a prognosis of having less than a year to live, are clearly still in need of additional protections and support within the benefits system. Yet, as it stands, these people are facing unacceptable delays and inappropriate assessment mechanisms to getting the support they need.

> "*My friend was denied PIP after filling in all his details to be told 'he wasn't ill enough'. He died the week after the letter arrived telling him he was not eligible*." Marie Curie campaign supporter
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> "*My best friend died from leukaemia before 50. I only heard her cry twice, both times about the benefits system. They kept saying she wasn't ill enough for PIP. Even when dying, she still couldn't get fast tracked. She died still trying to claim*." Marie Curie campaign supporter

There are several practice and policy changes, that would help ensure more people with a terminal illness are captured by the Special Rules.

First, is empowering more clinicians to feel able to use the SR1 form, including by making them aware that doing so does not come with professional consequences if a patient lives for longer than 12 months. There has been positive work undertaken by Kings College London, where bite-sized training videos were produced for clinicians on helping patients to access benefits via the Special Rules, by helping them understand their role in completing SR1 forms. The DWP should build on this work and undertake an awareness campaign about the Special Rules for End of Life among clinicians likely to interact with terminally ill people and track uptake.

We would also like the DWP to introduce a more flexible definition of terminal illness, that isn't time limited. Given the high levels of people in the last year of their life who continue to miss out on the Special Rules mechanism, prognosis may not be the best means for determining eligibility for Special Rules. Instead, a different approach should be taken that is modelled on Social Security Scotland's, where a person is considered to be terminally ill if they have a progressive disease from which death may reasonably be expected.

Feedback from qualitative research suggests this approach taken in Scotland has resulted in more people being reached under Special Rules than may have previously been the case when the same terminal illness definition as in the rest of the UK was being used. There is consensus (especially among support workers) that the new Scottish rules are assisting both in reaching more patients and benefitting them more quickly.

Ensuring people with a terminal illness can better access the benefits they are entitled to – including via the Special Rules route - is the focus of an upcoming briefing from Marie Curie that we will be glad to share and discuss with the Review team when published.

Entitlement under the Special Rules route

For people who do qualify for the Special Rules route, we also believe they should automatically be entitled to the mobility component of PIP. Currently in England and Wales, someone who receives PIP via the Special Rules route is automatically entitled to the Enhanced rate for the Daily Living component, but not necessarily the Standard or Enhanced rate of the Mobility component. The policy rationale for providing access to the Enhanced Rate of the Daily Living Component is presumably that, regardless of function on the day of application, the applicant will at some point in the next 12 months qualify for the Daily Living component, so it is humane and appropriate to guarantee access to it. Yet this is also true for the Mobility component.

Most people receiving PIP under the Special Rules route – 95% as of January 2026 according to Marie Curie's analysis of Stat-Xplore - do receive the Enhanced rate of the Mobility component. The fact that most Special Rules recipients do receive this, further raises the question of why it should not also be provided as standard in a Special Rules claim, as is the case for people in Scotland meeting their definition of 'terminal illness'. This figure also suggests that the lack of an automatic entitlement to the enhanced Mobility component is simply adding an administrative burden for Healthcare

Professionals and the Department, and unnecessary uncertainty to the terminally ill person and their family about their award.

3. Experience of claiming PIP

The time it takes to receive PIP

We support the method of assessment for people applying under the Special Rules for End of Life. This helps speed up the application process and minimise the administrative burden for people with a terminal illness.

When dealing with the additional financial, medical, and emotional impacts of a terminal diagnosis, no-one should be required to be completing complex and lengthy forms and attending assessments to receive the vital support they need. Ensuring more people with a terminal illness can access PIP via the Special Rules route – as outlined in our response to theme 2 - would help ensure more people with a terminal illness can access this payment in a more streamlined and less stressful manner.

It's important that beyond steps made to improve the number of people who are captured by the Special Rules route, the timescales for people receiving PIP via the normal route are also improved. This will help ensure that anyone with a terminal illness who is not covered by the Special Rules, is still able to get the vital support they need in a timely fashion.

> "*My wife was the main earner in our family at the time she was diagnosed with triple negative breast cancer...even as her condition deteriorated and she appealed for a reconsideration for PIP; she was still turned down. In her last 2 months before being admitted to hospital she no longer had the mental strength to go through that application process again, especially knowing that it would take months before she would receive any payment*." Marie Curie campaign supporter

A significant number of people who apply to PIP under normal rules challenge the initial decision made on their application. Over the last five years 17% of mandatory reconsiderations and 65% of those claims that were then taken to a tribunal hearing (equivalent to 3% of all claims) led to a change in award in favour of the applicant. However, the process for getting the right decision on a PIP claim can take a long time.

In January 2026, the median PIP MR clearance time was 79 calendar days for new claims. If an individual then goes on to lodge an appeal, this can take many more months.

This is time that someone with a terminal illness does not have. Many people with a terminal illness who are not covered by the Special Rules, may still only have a few months longer than a year to live. It's vital, therefore, that DWP and HMCTS work to reduce the time it takes for a PIP MR and appeal to be cleared, so people can get a timelier resolution when challenging their PIP claim.

The assessment process

We support the method of assessment for people applying under the Special Rules for End of Life. These applicants don't have to go to a face-to-face assessment. This helps minimise the administrative and emotional burden for people with a terminal illness. This is also why we would like more people with a terminal illness to be able to access PIP via the Special Rules route.

More generally, we disagree with the government's commitment to increase the number of PIP assessments taking place in person. We instead encourage an approach to be taken that better aligns with Social Security Scotland, where the default assessment process is a review of existing documentation rather than a preference for in person or telephone assessments. And ultimately, we believe that individuals should have more choice about how they are assessed for PIP. This will help ensure people with a terminal illness who are not covered by Special Rules have more autonomy over the assessment process, helping to improve their experience of it.

Award lengths

While few people who have been awarded PIP under Special Rules will live for 3 years – at which point a Special Rules claim can be reviewed – there are terminally ill people who are having their benefits reassessed because they reached the end of their three-year award period. This places an unacceptable and unnecessary strain on people with a terminal illness, who should have assured and constant financial support until they die.

> "*Hearing that you have 'lived too long' with a terminal illness and needing to renew PIP to keep a vital financially assisted car through the scheme - shocking that this is considered necessary on any level.*"
> Marie Curie campaign supporter

When it has been decided that someone's condition is terminal, they should have guaranteed access to fast-tracked, higher rate of PIP Daily Living and Mobility, enabling support with the additional costs that can come with that prognosis until the end of their life. That is why we would like the DWP to adopt the approach taken by Social Security Scotland, whereby an individual who receives ADP under the Special Rules route, is provided with a lifetime award that will not be reviewed unless their circumstances change.

More generally, we also believe that anyone who isn't covered by Special Rules, but who has a progressive life-limiting condition and is on the highest award rates for both Daily Living and Mobility, should also be exempt from any fixed-length award. And for people with progressive life-limiting conditions who are on the lower rates of PIP Daily Living and/or Mobility, compulsory reassessments should be replaced with 'light-touch' reviews to check whether they have become eligible for a higher award.

Too many people with conditions that would classically be identified as life-limiting, are being put on fixed-term awards. According to Marie Curie's analysis of Stat-Xplore, between February 2025 and January 2026, 38% of people whose main condition is Parkinsons, 16% of people whose main condition is Dementia and 9% of people whose main condition is Motor Neurone Disease were put on fixed-term PIP awards. We also looked at how many PIP awards for these same conditions were then decreased at a planned award review. Only 2% of PIP awards where the main condition is Dementia, Parkinson's, and Motor Neurone Disease were decreased at an award review. This demonstrates the lack of value in the department reassessing people whose conditions are sadly only going to worsen. Especially when, as the latest figures show, each PIP assessment costs £282.

> "*I am disabled with severe Emphysema, it's not something I can recover from but PIP stopped my allowance for 10 months saying I wasn't as bad as I was saying...I had all the stress of trying to prove how my illness affects my life, eventually going to the tribunal. It was re-instated but now I face the same thing again in January. I am getting more and more anxious as the time gets nearer... Why aren't chronic illnesses exempt from these extremely stressful and nerve-wracking interviews? I am going to die through Emphysema, it doesn't magically get better...only worse*." Marie Curie campaign supporter

Finally, if at a PIP assessment it has been identified that someone has a condition that is expected to cause death, but they don't qualify for Special Rules, the DWP should investigate whether they might subsequently be eligible for an SR1 form at future reviews.

4. Changing context and the impact on PIP

Increasing number of people with a terminal illness

The number of people in England who need palliative and end of life care is increasing as our population ages and people live longer, often with multiple and complex conditions. The number of people needing end of life care in the UK will rise by almost 25% between 2025 and 2050.

We know that many of these people will also depend on the social security system, and in particular PIP, to meet the additional costs that are associated with having a terminal illness.

Increased energy costs

Across the UK, thousands of people living with terminal illnesses rely on medical devices that they use at home. Medical equipment – including ventilators, suction machines, and powered hospital beds – play a vital role in preserving people's health, comfort, and dignity in their own homes towards the end of their lives.

However, the cost of running these devices typically falls on terminally ill people and their household, rather than the NHS. Although people who use some medical devices (such as oxygen concentrators, and some forms of dialysis in England) receive a rebate or reimbursement for their costs, those who use other medical devices do not receive any help at all. The cost of running essential at-home medical equipment is yet another expense for those already under serious financial pressure.

With UK energy prices having risen substantially in the last few years and continuing to be historically high, we are concerned that some households affected by terminal illness are struggling to meet these unavoidable running costs. This is leaving some with an awful, and potentially life-threatening decision – do they cut back on other essentials like heating and food, or do they ration their use of their prescribed equipment?

Support provided by the likes of PIP to help with the additional costs associated with a terminal illness, is therefore more pressing than ever.

Implications of abolishing the Work Capability Assessment

In the Pathways to Work Green Paper, the government proposed replacing the Work Capability Assessment with the PIP assessment. The suggestion was that eligibility for the Health Element of UC would therefore depend on receiving the Daily Living component of PIP.

One of our main concerns with this is the potential loss of the Severe Conditions Criteria that exists within UC, which can provide an important protection for people who are not covered by Special Rules. Because this category is explicitly linked to the Work Capability Assessment, it will become obsolete as and when that assessment is abolished.

Concerns with this are especially pressing given that since April 2026, the Severe Conditions Criteria – alongside the Special Rules – are the only means that new applicants to UC can access the higher UC health rate. Given the challenges terminally ill people face qualifying for Special Rules, removing the Severe Conditions Criteria would just make it harder for terminally ill people to qualify for the additional support they need.

As discussions about the abolition of the Work Capability Assessment progress, we would like the government to take this opportunity to consider how the Severe Conditions Criteria or equivalent could be implemented in PIP.

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