

SMA UK's Response to the Timms Review

In this summary report we highlight key recommendations for reforming the Personal Independence Payment (PIP) system, focusing on the ensuring the assessment criteria and award levels accurately reflect the real-world economic and functional impacts of living with Spinal Muscular Atrophy.

Theme 1: How effectively is PIP delivering on its intended role and purpose?

PIP is failing to meet its intended purpose as a non-means tested benefit designed to offset the extra costs of living with a disability. Whilst providing a vital financial baseline for individuals living with Spinal Muscular Atrophy (SMA), the current award rates are drastically different from the economic realities of managing a lifelong neuromuscular condition.

Our community highlights three critical areas where PIP falls short:

1. The Mobility and Equipment Deficit

Whilst PIP contributes toward general everyday expenses, it fails to cover the extreme maintenance costs of specialist disability equipment. Vital independence aids such as bespoke powerchairs or specialised vehicle adaptations frequently cost thousands of pounds. These are re basic requirements, yet individuals are often left to self-fund the vast majority.

2. The Inadequacy of the "Daily Living" Component for 24/7 Care Needs

For those requiring round-the-clock care, the highest rate of PIP covers only a fraction of the actual cost of securing safe, consistent support. When social care packages fall short, individuals are forced to use their PIP to top up care hours, leaving zero financial buffer for the other daily disability expenses.

3. The Direct Payment Funding Gap

The cost of employing Personal Assistants have escalated dramatically due to an increase in the National Minimum Wage. However, Direct Payment contributions have failed to increase in parallel, leaving individuals to use their PIP.

4. The Underestimation of Indirect Costs:

SMA incurs hidden daily premiums. Our community notes higher bills for accessible transport, specialised dietary requirements, and elevated home utilities to run respiratory equipment, charge wheelchairs, or use assistive technology. Ordinary costs, such as hiring help to maintain a house or a garden that the individual is physically unable to do themselves, is entirely unaccounted for.

Theme 2: Does the PIP assessment, including the assessment criteria, effectively capture the impact of long-term health conditions and disability in the modern world, and provide fair access to the right support at the right level across the benefits system?

The current PIP assessment framework is outdated, rigid, and failing to capture the reality of living with a progressive neuromuscular condition like SMA. Whilst the assessment may register a few high-visibility limitations, it often ignores the nuanced barriers that dictate true functional capacity. Our community highlights that the current test “understands some parts of my life but misses others”.

1. Failure to Account for the Toll of Fatigue and Pain

Assessments focus on whether a task can be completed once (e.g., preparing food or walking a short distance). It misses the exhaustion, pain, and prolonged recovery times associated with SMA. If an activity causes severe fatigue that compromises the individual’s ability to function for the rest of the day, the system should treat them as unable to do it.

2. Inability to Capture Dynamic, Long-Term Impacts

Despite the development of disease-modifying treatments for SMA, the functional impact on an individual's life remains complex. A brief assessment by a generic healthcare assessor cannot accurately capture how a condition manifests across weeks or months.

Theme 3: What is the experience of people claiming PIP and does this vary for different groups of people?

The experience of claiming PIP is highly inconsistent, varying drastically from straightforward to severely stressful. Whilst some find the process “easy and fair”, others face immense stress, particularly regarding physical assessment environments, complex evidence-gathering, and anxiety of repetitive reviews.

1. Inaccessible and Anxiety-Inducing Environments

Being forced to travel to and navigate “crowded, unfamiliar centres” induces high levels of anxiety and physical exhaustion.

2. Logistical and Financial Burden of Medical Evidence

Securing additional evidence remains a major barrier. Getting further information from GPs is increasingly difficult and many face an unfair financial burden where surgeries charge a fee for medical reports.

3. Over-Frequent Reviews for Lifelong Conditions

There is significant frustration regarding assessment frequency. As our community clearly states: “The assessment happens too often, my SMA isn’t going to go away, so I shouldn’t have to prove it every year”. Forcing individuals with a progressive condition to repeatedly prove their disability creates stress and financial insecurity.

Theme 4: What has changed in wider society and the workplace since 2013 (and might be expected to change in the future), and how has this impacted PIP and does PIP need to change accordingly?

The social and economic landscape has shifted dramatically since 2013, yet the PIP framework remains trapped in the past. Our community confirms that PIP “needs a big update to match life today”.

1. Physical Barriers of a Digital Society

Managing healthcare appointments, ordering prescriptions, banking, communicating and accessing essential utilities is now almost entirely online. For individuals with SMA, navigating touchscreens or typing with limited hand function requires specialised, costly assistive technology and software.

2. Evolution of Remote Working

The rise of remote and hybrid working represents a massive opportunity for the SMA community, allowing individuals to bypass traditional commuting barriers. However, working from home does not eliminate disability-related costs, it shifts them. Disabled professionals now face higher energy bills to run essential equipment during the day, alongside the costs of specialised home-office adaptations.

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