



Response to the Timms Review of Personal Independence Payment: Call for Evidence

Submitted by the Foundation Exploring Skeletal Dysplasia Together (FEST)

May 2026

About FEST

The Foundation Exploring Skeletal Dysplasia Together (FEST) is a UK registered charity (Charity number 1215632) working to improve the lives of people affected by skeletal dysplasia (commonly known as restricted growth or dwarfism) and their families.¹ FEST works across advocacy, education, policy engagement, research awareness and community support, and is informed by engagement with individuals, families, clinicians and wider disability networks across the UK and Europe.

FEST is responding to this Call for Evidence as a national skeletal dysplasia advocacy organisation, representing the perspectives and lived experiences of people with achondroplasia and other skeletal dysplasias. FEST is a member organisation of the European Skeletal Dysplasias Alliance, a coalition advocating for improved recognition, healthcare, accessibility and social inclusion for people with skeletal dysplasias across Europe.²

About Skeletal Dysplasia

Skeletal dysplasias are a group of rare genetic conditions affecting bone and cartilage growth and development. There are over 400 recognised forms; achondroplasia is the most common, occurring in approximately 1 in 25,000 live births worldwide.³ There are an estimated 6,000 people with a restricted growth condition in the UK.⁴

The medical reality

Skeletal dysplasia is far more than short stature. For many, it means living with chronic pain from childhood, spinal stenosis (a narrowing of the spinal canal that can compress nerves and, in adulthood, often requires major surgery), fatigue, progressive joint degeneration, and neurological, hearing and respiratory complications. These conditions are lifelong, frequently progressive, and

¹ <https://www.myskeletaldysplasia.org.uk/>

² <https://skeletaldysplasias.org/about-sd-alliance/>

³ [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(07\)61090-3/abstract](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(07)61090-3/abstract)

⁴ <https://rgauk.org/what-we-do>

affect multiple body systems at once. They are also serious: adults with achondroplasia have an [overall life expectancy reduced by approximately 10 years](#) compared with the general population, with heart disease-related mortality more than 10 times higher in the 25–35 age group.⁵ There is also emerging evidence that some FGFR3-related skeletal dysplasias may be associated with higher rates of neurodevelopmental differences with around one in five children (21.6%) with achondroplasia showing developmental delay in one or more domains.⁶ Where these differences co-occur with the physical features of a skeletal dysplasia, the cumulative impact on daily functioning is greater still. This is not a cosmetic difference in height — it is a complex, demanding medical condition that requires lifelong management.

The environmental reality

The world is built around average-sized bodies, and this creates physical barriers to day-to-day essentials throughout the home and in public. An adult with achondroplasia typically has an arm reach extending to around mid-torso height on an average-sized person — meaning light switches, raised door handles, wall-mounted kitchen units, hobs, intercoms, public transport ticket machines, ATMs and supermarket shelves are routinely out of reach. Shorter limbs and reduced reach also affect the most personal of tasks: washing, toileting and dressing can require aids, adaptations or simply far more time and effort than for an average-sized person. Driving usually depends on adaptations such as pedal extenders and adjusted seating, because standard vehicles assume an average-sized driver. Each of these barriers, taken alone, may seem minor; cumulatively, they shape almost every hour of the day and require constant adaptation, planning and physical effort.

The social reality

People with restricted growth also navigate a social environment that few others experience. Visible difference attracts staring, unsolicited comment, photography without consent, and in some cases open harassment. People with dwarfism continue to be the subject of cultural ridicule and stereotype in a way that would be unacceptable for almost any other group. This shapes daily decisions — which places to avoid, when to travel, whether to use public transport or pay for a taxi — and carries a real psychological and financial cost. Living with restricted growth therefore means managing not only a demanding medical condition and a physically inaccessible environment, but also the persistent social burden of being treated as an object of curiosity rather than as an equal participant in public life.

Executive summary

This submission asks the Review to recognise that skeletal dysplasia is not a single, mild mobility condition. It is a group of lifelong, rare, genetic and often multisystem conditions involving pain,

⁵ <https://pmc.ncbi.nlm.nih.gov/articles/PMC6972520/>

⁶ <https://www.endocrine-abstracts.org/ea/0110/ea0110oc7.3>

fatigue, restricted reach, spinal complications, psychosocial impacts and significant environmental barriers.

Our key messages are:

- **PIP is a contribution to the extra costs of disability, not an out-of-work benefit.** For many people with skeletal dysplasia it is an enabler of work, not an alternative to it — funding the adaptations, equipment and transport that make education, employment, parenting and community life possible.
- **Reassessment for lifelong genetic conditions should be substantially reduced.** Skeletal dysplasias are genetically determined, present from birth and do not improve — repeated functional reassessment serves neither the claimant nor the system.
- **The eligibility framework under-recognises cumulative disability.** PIP scoring is calibrated around the need for assistance from another person and on capability at a single moment in time, rather than on the effort, pain and slowness involved in completing tasks reliably across a typical day or week. Skeletal dysplasia, like many conditions characterised by reach limitation, cumulative slowness and reliance on adaptations, is systematically disadvantaged by this approach.
- **The proposed 4-point single-activity threshold would penalise this community.** Skeletal dysplasia typically produces broad cumulative restriction across many activities rather than one isolated catastrophic impairment, and a single-activity scoring threshold would systematically disadvantage this pattern of disability.
- **Use of aids and adaptations is evidence of underlying impairment, not its absence.** Adaptations are what makes participation possible — they should be weighted accordingly in assessment, not treated as a reason to reduce points.
- **The assessment process is in need of reform.** Generalist assessors lack expertise in rare conditions, lifelong adaptation can mask need, and 65–77% of appeals are upheld at tribunal — strong evidence of systemic problems with initial decision-making.
- **Rare skeletal dysplasia conditions are administratively and statistically invisible.** Most are absorbed into broad coding categories such as "Genetic disorders, dysplasias and malformations - Other / type not known", limiting assessor familiarity, policy attention and data-driven reform.
- **The wider context has changed significantly since 2013, but PIP has not kept pace.** Disability-related costs have risen, the built environment remains inaccessible for people with restricted reach and short stature, Access to Work is in crisis, and PIP's administrative coding still absorbs rare skeletal dysplasias into catch-all categories — out of step with broader UK rare disease policy.

Theme 1 – The role and purpose of PIP

1.1. PIP is a contribution to extra costs, not an out-of-work benefit

PIP plays a vital role in enabling people with skeletal dysplasia to live independently and participate in society. Independence for disabled people should not be narrowly interpreted as "coping alone" — in practice, independence depends on access to support, adaptations, transport, assistive equipment and the ability to participate safely and with dignity.

PIP's statutory purpose, under the Welfare Reform Act 2012⁷, is to provide a contribution towards the extra costs of disability. FEST is concerned that the Review's framing — including references to "meaningful activity, including employment" — risks conflating PIP with employment outcomes. Research has shown that disabled households need an extra £1,095 per month to have the same standard of living as non-disabled households, rising to £1,224 by 2029–30. The average PIP payment is £465 per month — leaving disabled households facing an average shortfall of £630 per month between the support PIP provides and the actual extra costs of disability. For people with skeletal dysplasia, these costs are particularly tangible.⁸

Ask: *The Review should reaffirm in its conclusions that PIP's statutory purpose is to contribute towards the extra costs of disability, and should explicitly reject any framing that conflates entitlement to PIP with capability for, or distance from, employment.*

1.2. PIP is frequently the mechanism that enables work

Around one in five PIP recipients are in employment.⁹ For people with skeletal dysplasia, PIP often funds the adaptations, equipment and transport that make this possible. Research suggests that many adults with restricted growth are highly qualified but remain underemployed or experience career limitation due to inaccessible workplaces, height discrimination, social prejudice and deteriorating musculoskeletal health.^{10 11} Any reform that treats PIP receipt as evidence against working capability would penalise precisely the people who use PIP to remain in work. Given that 28% of disabled people live in poverty and disabled people make up approximately one in three food bank users, alongside evidence that work is good for health and wellbeing reinforces the importance of PIP acting as a work enabler.^{12 13 14}

Ask: *The Review should recognise PIP as an enabler of employment and reject any reform that uses PIP receipt as evidence of incapacity for work. Any future alignment between PIP and out-of-work benefit assessments must preserve PIP's distinct role in funding the adaptations, equipment and transport that allow disabled people to enter and remain in work.*

⁷ <https://www.legislation.gov.uk/ukpga/2012/5/contents>

⁸ <https://www.scope.org.uk/campaigns/disability-price-tag>

⁹ <https://www.turn2us.org.uk/about-us/news-and-media/latest-news/timms-review-recommendations>

¹⁰ <https://sjdr.se/articles/10.1080/15017410902909118>

¹¹ <https://sjdr.se/articles/10.1080/15017419.2015.1063542>

¹² <https://webarchive.nationalarchives.gov.uk/ukgwa/20130703133719/http://www.dwp.gov.uk/docs/hwwwb-working-for-a-healthier-tomorrow.pdf>

¹³ <https://www.turn2us.org.uk/about-us/news-and-media/latest-news/timms-review-recommendations>

¹⁴ <https://www.bigissue.com/opinion/timms-review-pip-assessment-disability-rights-uk/>

1.3. The distinctive extra costs of skeletal dysplasia

People with skeletal dysplasia often incur high costs due to the nature of the condition. These include:

- Vehicle adaptations and driving modifications (pedal extenders, adjusted seating, steering adaptations, specialist vehicle configurations)
- Adapted clothing and footwear — body proportions associated with restricted growth often mean standard clothing does not fit appropriately, requiring expensive alterations or specialist adaptation. Appropriate footwear in particular is essential as poorly fitted shoes can contribute to pain, mobility difficulties, fatigue and musculoskeletal deterioration over time
- Specialist seating, furniture and step stools
- Home adaptations (lowered worktops, accessible kitchens and bathrooms)
- Taxis and private vehicle use where public transport is inaccessible, unsafe or hostile
- Replacement of unsuitable mass-market equipment (seats, toilet aids, shoes etc.)

Ask: *The Review should recognise that the extra costs faced by people with rare conditions, including skeletal dysplasia, are often distinctive, recurring and not adequately captured in standard disability cost analyses. Future PIP rate-setting and uprating decisions should be informed by condition-specific cost evidence drawn from rare disease communities, not solely by aggregate disability cost averages.*

1.4. Socio-cultural costs of disability

Disability-related costs for people with skeletal dysplasia are not solely medical or mobility-related. Research demonstrates that people with skeletal dysplasias experience distinct socio-cultural barriers linked to stigma, infantilisation, harassment and public scrutiny. High rates of staring, verbal harassment and feeling unsafe in public spaces directly influence transport choices, social participation and reliance on private vehicles or taxis — creating real, financially material disability-related costs that are rarely recognised in functional assessments.^{15 16}

Ask: *The Review should recognise that the additional costs of disability include socio-cultural costs — such as reliance on taxis and private transport to avoid harassment and public scrutiny — and ensure that future assessment frameworks and supporting guidance acknowledge these as legitimate disability-related expenditure.*

Theme 2 – Eligibility, fairness and equity

2.1. Assessments measure capability at a moment in time, not reliably over time

¹⁵ <https://sjdr.se/articles/10.1080/15017410902909118>

¹⁶ <https://www.researchgate.net/publication/320773858> Through a filtered lens unauthorized picture-taking of people with dwarfism in public spaces

Legislation already specifies the assessment of a claimant's capability to undertake daily activities safely, repeatedly, to an acceptable standard and within a reasonable time period.¹⁷ For skeletal dysplasia, this is precisely the test that should capture the disabling effects of chronic pain, fatigue, spinal compression and slower task completion. In practice, however, assessments tend to focus on whether a claimant *can* complete a task, not whether they can do so reliably across a typical day or week.

The 20-metre walking descriptor is a good example of this. People with skeletal dysplasias may be able to walk 20 metres, but often with pain, and repetition across a day can have a compounding impact on fatigue.^{18 19}

Ask: *The Review should strengthen the operation of the reliability test in regulation 4(2A) through revised assessment guidance and assessor training, requiring explicit consideration of pain, fatigue, time taken and repeatability for every descriptor.*

2.2. The scoring framework focuses on the need of assistance and does not recognise effort required to complete everyday tasks

The PIP descriptors and points framework is constructed primarily around the need for assistance from another person. For many people with skeletal dysplasia, the more common reality is that tasks are completed independently but at materially greater cost in time, pain and fatigue, and through reliance on aids such as reach extenders, step stools, adapted fixtures and specialist equipment. The current points framework awards relatively low scores for aid use, which systematically understates the cumulative daily burden of completing ordinary activities in an environment designed around average-sized bodies.

Ask: *The Review should examine whether the current descriptor and scoring framework — which is calibrated primarily around the need for assistance from another person — adequately captures the cumulative burden of conditions characterised by reach limitation, slower task completion, chronic pain and heavy reliance on adaptations.*

2.3. Use of aids and adaptations should not be characterised as independence

People with skeletal dysplasia face an extensive list of adaptation needs covering clothing, driving, education, employment, home adaptation and personal care, illustrating the scale of the burden faced.²⁰ The ability to complete an activity *with* aids or adaptations should not be treated as evidence of minimal need. Adaptations are evidence of substantial daily impairment and they are what makes participation possible.

Ask: *The Review should make explicit in revised assessment guidance that use of aids, appliances and adaptations is to be treated as evidence of underlying impairment, with appropriate weight in scoring decisions, rather than as a reason to reduce points.*

¹⁷ <https://www.legislation.gov.uk/uksi/2013/377/regulation/4>

¹⁸ <https://pubmed.ncbi.nlm.nih.gov/32450891/>

¹⁹ <https://pubmed.ncbi.nlm.nih.gov/37758167/>

²⁰ <https://rgauk.org/resources>

2.4. The proposed 4-point single-activity threshold would systematically disadvantage cumulative conditions

Skeletal dysplasia typically produces broad cumulative restriction across many activities — aids in the kitchen, reach extensions in the home, longer time taken across washing and dressing, fatigue affecting mobility — rather than one catastrophic impairment in a single activity. The current framework legitimately awards multiple 2-point descriptors across activities for precisely this pattern of disability. The 2025 Pathways to Work Green Paper proposal to require at least 4 points in a single activity would penalise those living with skeletal dysplasias.²¹

This risk is greater still for those with co-occurring neurodevelopmental differences. Where a skeletal dysplasia is accompanied by autism, developmental delay or a learning disability — which emerging evidence suggests is more common in achondroplasia and hypochondroplasia — needs are spread across both physical and cognitive activities, making the cumulative pattern more pronounced and the single-activity threshold even more likely to exclude someone with substantial need.

Ask: The Review should reject the 4-point single-activity threshold and reaffirm that cumulative impairment across multiple activities is a legitimate and intended basis for entitlement.

Theme 3 – Experience of claiming PIP

3.1. Remove the need for repeated assessments for those living with skeletal dysplasias

The process of claiming PIP is often stressful, overwhelming and exhausting for claimants.^{22 23} People describe needing to repeatedly "prove" lifelong genetic conditions that will not improve. Reassessments can feel intrusive and demeaning, particularly where there is little understanding of the condition involved.^{24 25}

We welcome the recent announcement that PIP claimants with "severe and long-term conditions" will receive longer awards with reduced reassessment frequency. Skeletal dysplasias are genetically determined, present from birth and do not resolve, so repeated functional reassessment serves neither the claimant nor the system efficiently.

Ask: That this Review ensure that lifelong genetic conditions including skeletal dysplasias are explicitly included within the "severe and long-term conditions" category.

3.2. Combat systems-generated trauma through getting decisions right the first time

²¹ <https://www.gov.uk/government/consultations/pathways-to-work-reforming-benefits-and-support-to-get-britain-working-green-paper>

²² <https://www.gov.uk/government/publications/claimant-views-on-ways-to-improve-pip-and-esa-questionnaires/claimant-views-on-ways-to-improve-pip-and-esa-questionnaires>

²³ <https://assets.publishing.service.gov.uk/media/6814b40da87f19ba7b3a82be/applicants-journeys-claiming-pip.pdf>

²⁴ <https://www.equallives.org.uk/post/no-reassessment-for-lifelong-disabilities>

²⁵ <chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://disabilitybenefitsconsortium.com/wp-content/uploads/2017/09/supporting-those-who-need-it-most-excecutive-summary.pdf>

Evidence demonstrates that hostile, repetitive and disbelieving institutional processes compound distress and reduce trust amongst disabled people and families seeking support.²⁶ Recent research has also found that the punitive assessment system has "created a culture of fear, leaving disabled people too afraid to try work", with assessors failing to apply rules correctly, medical evidence misinterpreted or ignored, and claimants' own accounts unfairly dismissed.²⁷ Considering that 65-77% of claimants have their appeals upheld at tribunal highlights systemic problems with initial decision-making and the unnecessary traumatic burden placed upon the claimant and their family.²⁸

Ask: *The Review should commit to a trauma-informed redesign of the assessment process, with the explicit aim of getting decisions right first time and reducing reliance on appeals as the route to fair outcomes.*

3.3. Coping strategies and normalisation can lead assessors to underestimate need

People with skeletal dysplasia develop extensive adaptive strategies from infancy, and assessors may misread these coping strategies as evidence of minimal impairment rather than of sustained effort, fatigue and cumulative disablement. Lifelong normalisation compounds the problem as claimants who have spent decades adapting to inaccessible environments may underreport difficulty, minimise distress, or struggle to identify which aspects of daily life are disability-related, because these barriers have become embedded within ordinary experience.²⁹ The psychosocial impact of visible difference, chronic public scrutiny and infantilisation also affects confidence, self-advocacy and willingness to disclose vulnerability — particularly within a system like PIP that relies heavily on self-reporting and verbal articulation of need.³⁰

Ask: *The Review should ensure that assessment processes actively probe beyond what claimants volunteer, recognising that lifelong adaptation can mask need, and that self-reporting alone is an inadequate basis for assessing people whose experiences of pain, fatigue and exclusion have been normalised since infancy.*

3.4. A lack of assessor expertise can lead to assumptions and inaccurate assessments

The rare condition knowledge gap amongst healthcare professionals is a recognised national policy problem.³¹ A UK survey of people living with rare conditions found that 88% reported limited knowledge of their condition amongst healthcare professionals, with not being believed or taken seriously identified as a significant emotional stressor.³²

²⁶ <https://cerebra.org.uk/download/systems-generated-trauma-report/>

²⁷ <https://z2k.org/pip-report/>

²⁸ <https://www.benefitsandwork.co.uk/news/seven-in-ten-pip-appeals-succeed.-latest-figures-show>

²⁹ <https://www.gov.uk/government/publications/additional-support-needs-in-the-personal-independence-payment-claim-journey/additional-support-needs-in-the-pip-claim-journey#common-challenges-people-face-in-their-pip-claim-journey>

³⁰ <https://committees.parliament.uk/writtenevidence/83245/html/>

³¹ <https://www.gov.uk/government/publications/uk-rare-diseases-framework>

³² <https://pmc.ncbi.nlm.nih.gov/articles/PMC9107210/>

This knowledge gap is amplified within PIP assessments where evidence has shown that assessments are often undertaken by healthcare professionals lacking appropriate expertise which in turn means there is a lack of knowledge about the problems a particular condition can cause.^{33 34}

For people with skeletal dysplasias, the knowledge gap is compounded by a documented cultural stereotype problem. Empirical research has shown that public beliefs about people with dwarfism are shaped by persistent cultural stereotypes rather than knowledge of the medical and functional realities of the condition.³⁵ This can result in assessors making assumptions and superficial observations rather than developing an informed understanding of how disproportionate limb length, reduced reach, spinal stenosis, fatigue associated with compensatory movement, and the cumulative musculoskeletal impact of living in environments not designed for short stature impacts an individual's daily life.

“In my experience, you're assessed on your appearance rather than your reality. The things that actually shape my day — chronic pain, limited reach, fatigue, the cumulative toll of an inaccessible world — are rarely understood and rarely asked about. A fair assessment has to start from knowledge of the condition, not assumptions about height.” **Adult with Achondroplasia**

Ask: *The Review should require assessors to be supported by specialist clinical input when assessing rare conditions, in line with the UK Rare Diseases Framework's commitment to increasing healthcare professional awareness, and should commit to assessor training that explicitly counters appearance-based assumptions and cultural stereotypes about visibly different bodies.*

3.5. Accessibility and evidence-gathering barriers

There are practical and accessibility issues in undertaking a PIP application which include:

- Completing lengthy forms — upper limb disproportion, pain, fatigue, reduced grip strength or joint complications can make handwritten forms physically difficult and exhausting;
- Gathering medical evidence across multiple specialties;
- Attending assessment centres — which are themselves frequently inaccessible for people with restricted growth;
- Navigating inconsistent communication.

Many adults with skeletal dysplasia also experience difficulty evidencing need through conventional medical documentation. Specialist adult skeletal dysplasia services remain limited across the UK, and many individuals are not under continuous specialist care unless receiving active treatment or surgical intervention. Assessment systems should recognise the realities of rare lifelong conditions where the absence of recent specialist medical care does not indicate an absence of need.

Ask: *The Review should ensure that the PIP process is accessible at every stage — including consistent digital submission options, physically accessible assessment venues, and clear pathways*

³³ <https://committees.parliament.uk/writtenevidence/83245/html/>

³⁴ <https://www.benefitsandwork.co.uk/news/assessment-dirty-tricks-to-be-urgently-investigated>

³⁵ <https://www.tandfonline.com/doi/full/10.1080/00224545.2012.711379>

for accepting evidence from highly specialised services — and should explicitly recognise that, for rare lifelong conditions, the absence of recent specialist evidence does not indicate the absence of need.

Theme 4 – Changes in society and the workplace since 2013

4.1. Cost of living

Since 2013, the cost of living has risen substantially and research shows that disabled households experience deeper and more persistent poverty.³⁶ For people with skeletal dysplasia, additional costs associated with disability have increased significantly across transport, heating, specialist equipment, adapted products, and private healthcare and therapies where NHS provision is delayed.

Ask: The Review should recommend that PIP rates are uprated to reflect the actual extra costs of disability faced by claimants today — closing, or at minimum narrowing, the gap between the average PIP payment and the £1,095 monthly disability cost identified by Scope, and ensuring future uprating keeps pace with the specific cost categories that disproportionately affect disabled households.³⁷

4.2. Accessibility remains a challenge

Disability-related disadvantage arises not solely from medical impairment, but from the interaction between impairment and environments which fail to accommodate human diversity. For people with skeletal dysplasia, this interaction is a daily reality. Many public spaces and transport systems remain inadequately accessible for people with restricted reach and short stature. "Accessibility" is too often interpreted narrowly through the lens of wheelchair access, without considering the needs of people with skeletal dysplasia. Self-service tills, contactless payment terminals, parking machines and public information screens are typically mounted at heights inaccessible to people with skeletal dysplasia, creating routine, daily exclusion.

Ask: The Review should recognise that the persistent inaccessibility of public spaces, transport and self-service infrastructure for people with restricted reach and short stature is a continuing source of disability-related cost and exclusion, and should ensure PIP descriptors and assessment guidance reflect the realities of navigating environments designed around average-sized bodies.

4.3. Workplace changes

Changes in working patterns have had mixed impacts. Remote working has improved access for some people with skeletal dysplasia by reducing commuting strain, fatigue and exposure to inaccessible environments. However, many workplaces still lack understanding of the condition and appropriate ergonomic adjustments. Remote working can also risk compounding social isolation where workplace inclusion and participation are already limited for many with disability.

³⁶ <https://www.irf.org.uk/uk-poverty-2025-the-essential-guide-to-understanding-poverty-in-the-uk>

³⁷ <https://www.scope.org.uk/campaigns/disability-price-tag>

Delays within the Access to Work scheme, recent evidence of cuts and potential future cuts are a real concern.^{38 39} For people with skeletal dysplasia, where relatively small ergonomic adjustments can significantly affect economic participation, prolonged delays create substantial barriers to employment retention and career progression.

Ask: *The Review should not be considered in isolation from the parallel reforms to Access to Work. Given the documented delays, cuts and uncertainty within the scheme, the Review should recommend that PIP and Access to Work are treated as complementary mechanisms supporting disabled people into and within employment — and that any reform of PIP is accompanied by clear commitments to address the Access to Work backlog and funding concerns.*

4.4. Statistical and administrative invisibility of rare skeletal dysplasias

One feature of the PIP system that has not kept pace with the development of UK rare disease policy since 2013 is the administrative coding of conditions. Although DWP coding guidance includes a small number of named skeletal dysplasia conditions (including achondroplasia, osteogenesis imperfecta, multiple epiphyseal dysplasia, hereditary multiple exostosis, Marfan syndrome and joint hypermobility syndrome), many other skeletal dysplasia conditions do not appear as distinct categories. Instead, they are absorbed into broad classifications such as "other genetic disorders/dysplasias/malformations".⁴⁰

This is significant because skeletal dysplasias are not a homogeneous condition group. The International Skeletal Dysplasia Society Nosology and Classification of Genetic Skeletal Disorders (2023 Revision) recognises hundreds of distinct entities with highly variable clinical and functional impacts.⁴¹

The UK Rare Diseases Framework commits government to improving rare disease data infrastructure and increasing healthcare professional awareness — both of which directly speak to the PIP coding and assessor knowledge problems set out in this submission.

Ask: *The Review should recommend that DWP improves the statistical and administrative visibility of rare conditions within PIP — moving beyond catch-all coding categories such as "Genetic disorders, dysplasias and malformations – Other / type not known" — to align the benefit system with the broader cross-government direction set by the UK Rare Diseases Framework.*

Summary of asks

- The Review should reaffirm in its conclusions that PIP's statutory purpose is to contribute towards the extra costs of disability, and should explicitly reject any framing that conflates entitlement to PIP with capability for, or distance from, employment.

³⁸ <https://www.nao.org.uk/press-releases/processing-delays-and-backlogs-in-access-to-work-affect-job-security-and-employer-finances/>

³⁹ <https://www.disabilitynewsservice.com/access-to-work-dossier-of-evidence-shows-real-harm-and-job-losses-caused-by-dwp-cuts-and-failings/>

⁴⁰ <https://www.gov.uk/government/collections/personal-independence-payment-statistics>

⁴¹ <https://pmc.ncbi.nlm.nih.gov/articles/PMC10081954/>

- The Review should recognise PIP as an enabler of employment and reject any reform that uses PIP receipt as evidence of incapacity for work. Any future alignment between PIP and out-of-work benefit assessments must preserve PIP's distinct role in funding the adaptations, equipment and transport that allow disabled people to enter and remain in work.
- The Review should recognise that the extra costs faced by people with rare conditions, including skeletal dysplasia, are often distinctive, recurring and not adequately captured in standard disability cost analyses. Future PIP rate-setting and uprating decisions should be informed by condition-specific cost evidence drawn from rare disease communities, not solely by aggregate disability cost averages.
- The Review should recognise that the additional costs of disability include socio-cultural costs — such as reliance on taxis and private transport to avoid harassment and public scrutiny — and ensure that future assessment frameworks and supporting guidance acknowledge these as legitimate disability-related expenditure.
- The Review should strengthen the operation of the reliability test in regulation 4(2A) through revised assessment guidance and assessor training, requiring explicit consideration of pain, fatigue, time taken and repeatability for every descriptor.
- The Review should examine whether the current descriptor and scoring framework — which is calibrated primarily around the need for assistance from another person — adequately captures the cumulative burden of conditions characterised by reach limitation, slower task completion, chronic pain and heavy reliance on adaptations.
- The Review should make explicit in revised assessment guidance that use of aids, appliances and adaptations is to be treated as evidence of underlying impairment, with appropriate weight in scoring decisions, rather than as a reason to reduce points.
- The Review should reject the 4-point single-activity threshold and reaffirm that cumulative impairment across multiple activities is a legitimate and intended basis for entitlement.
- That this Review ensure that lifelong genetic conditions including skeletal dysplasias are explicitly included within the "severe and long-term conditions" category.
- The Review should commit to a trauma-informed redesign of the assessment process, with the explicit aim of getting decisions right first time and reducing reliance on appeals as the route to fair outcomes.
- The Review should ensure that assessment processes actively probe beyond what claimants volunteer, recognising that lifelong adaptation can mask need, and that self-reporting alone is an inadequate basis for assessing people whose experiences of pain, fatigue and exclusion have been normalised since infancy.
- The Review should require assessors to be supported by specialist clinical input when assessing rare conditions, in line with the UK Rare Diseases Framework's commitment to

increasing healthcare professional awareness, and should commit to assessor training that explicitly counters appearance-based assumptions and cultural stereotypes about visibly different bodies.

- The Review should ensure that the PIP process is accessible at every stage — including consistent digital submission options, physically accessible assessment venues, and clear pathways for accepting evidence from highly specialised services — and should explicitly recognise that, for rare lifelong conditions, the absence of recent specialist evidence does not indicate the absence of need.
- The Review should recommend that PIP rates are uprated to reflect the actual extra costs of disability faced by claimants today — closing, or at minimum narrowing, the gap between the average PIP payment and the £1,095 monthly disability cost identified by Scope, and ensuring future uprating keeps pace with the specific cost categories that disproportionately affect disabled households.
- The Review should recognise that the persistent inaccessibility of public spaces, transport and self-service infrastructure for people with restricted reach and short stature is a continuing source of disability-related cost and exclusion, and should ensure PIP descriptors and assessment guidance reflect the realities of navigating environments designed around average-sized bodies.
- The Review should not be considered in isolation from the parallel reforms to Access to Work. Given the documented delays, cuts and uncertainty within the scheme, the Review should recommend that PIP and Access to Work are treated as complementary mechanisms supporting disabled people into and within employment — and that any reform of PIP is accompanied by clear commitments to address the Access to Work backlog and funding concerns.
- The Review should recommend that DWP improves the statistical and administrative visibility of rare conditions within PIP — moving beyond catch-all coding categories such as "Genetic disorders, dysplasias and malformations – Other / type not known" — to align the benefit system with the broader cross-government direction set by the UK Rare Diseases Framework.