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Welcome... we will start soon

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Welcome…

GMCDP Consultation Series

PIP Consultation - Response Session

Host: Kayla, GMCDP Project Worker

Note: GMCDP is run by and for disabled people

- We ask you about your access needs so that we can support you.
- You do NOT need to share your impairment or condition with us.

Any technical problems - please raise hand / wave for help

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Structure of this meeting

- Introductions
- Share information about the current UK PIP Consultation (not Social Model - prepare yourselves!)
- Discuss ideas for how to respond - quick response (20 minutes) & government form (rest of meeting)
- Closing questions and comments

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Introductions - please share:

1. Name & pronouns
2. General location (optional)
3. What’s the key thing you want from this meeting?
4. Nominate next person… (or Kayla can)

About the PIP Consultation

- Title: “Modernising support for independent living: the health and disability green paper” - 107 pages of information + spreadsheet
  - Complete this online form - 39 questions in 4 chapters
  - Email: consultation.modernisingsupport@DWP.GOV.UK
  - Write to: Disability and Health Support Directorate, Department for Work and Pensions, Level 2, Caxton House, Tothill Street, London, SW1H 9NA
- **Deadline: 22nd July 2024**

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About the PIP Consultation

In a nutshell, PIP will be changed (to a very medical model approach):

- a list of qualifying medical conditions (like USA)
- must be diagnosed by a recognised medical professional
- Paid in one or more of:
  - vouchers
  - a one-off grant
  - equipment from a catalogue
  - claiming back expenditure from DWP

Quick Response - post or email your views

consultation.modernisingsupport@DWP.GOV.UK

Subject:

Modernising support for independent living: the health and disability green paper

- I completely object to this reform and I think all the proposals should be abandoned
- Any proposals to reform PIP should be undertaken in genuine co-production with Disabled People and have our safety and dignity at its core.

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Quick Response - could also include:

- I am concerned that the calling of the General Election has redirected attention away from this consultation and will negatively affect the response rate, especially as it is against rules to promote consultations during a General Election period. I believe that this and all other similarly affected consultations should be cancelled and the incoming Labour government should abandon the proposals, and if reform is still a priority, then commit to co-producing new ones with disabled people.
- I am concerned that the face-to-face engagement events promised with this consultation have not taken place due to the general election.
- I am concerned that the documentation for this consultation is too dense, long and technical. This makes it difficult for those who are at risk of being negatively affected by the proposals to engage fully or at all with this process. Many disabled people are scared to engage with any kind of communication with the DWP for fear of being targeted for any benefits application they may need to make. Those who have been previously harmed and traumatised by the process of applying for PIP will be unlikely to engage at all. These factors combined means that those whose voices should be centred in any proposed reform will be silenced by the process chosen for consultation.
- The introduction of any of the policies in this green paper would increase barriers in multiple areas of life for disabled people.
- PIP needs to remain a non-means tested cash benefit, based on the functional impact of health conditions, taking into account the need for aids, appliances, prompting and more across all the current PIP activities.
- PIP should be assessed in a way that centres the dignity of the disabled person, with reviews only when absolutely necessary (and much longer than typical at present). By definition of being disabled, many people’s conditions and their functional impairment will be permanent.
- This green paper fails to address the clear reasons why PIP claims have increased, such as the changes to the WCA, the cost-of-living crisis, housing crisis, in-work poverty, and the NHS crisis. These should be addressed urgently and before any reform to PIP for this reason.
- I am responding to this consultation by email as I object to the premise of the questions in the online form, which violate the dignity of disabled people. I also believe that the questions are formulated to encourage answers that support the proposed reform, rather than collate genuine, fully informed responses to this consultation. Any reform needs to be co-produced with disabled people and our organisations before being put out to consultation. This is supported by the UN Committee on the Rights of Disabled Persons who have publicly stated that the UK government does not consult with Disabled people and our organisations as it is obliged to and uses a “rhetoric that devalues disabled people and undermines their human dignity”.

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End of Quick Response

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Detailed Response options for this online form

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Structure of this meeting

Forewords

Chapter 1 – PIP – Overview and assessment reform Q1-8

Chapter 2 – PIP – Eligibility reform Q9-17

Chapter 3 – PIP – What do we provide support for? Q18-27

Chapter 4 – PIP – Aligning support Q28-38

Q39

Credits:

- Benefits and Work consultation responses included
- DPO Forum
- GMCDP Members

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Ministerial foreword - Mel Stride, Secretary of State for Work and Pensions

- "… we are reforming the Work Capability Assessment to better reflect the modern world of work, with the Office for Budget Responsibility (OBR) confirming that this will reduce the number of people assessed as not needing to prepare for work by 424,000 by 28/29."

Note: Intention is to reduce costs of benefits in general by reducing the number of people eligible.

- "It is not clear at present that the very large scale of government expenditure on PIP translates into support targeted where disabled people and people with health conditions need it most; nor that it is providing value to the [taxpayer]"

Assumption: disabled people are not taxpayers (we are!); PIP is unfair to taxpayers (links to public opinion)

- "I am determined to find ways of making the system work better for those with the most severe disabilities and health conditions, including through improved models of assessment, treatment and support as this consultation sets out."

TRANSLATION: I will set out a list of 'severe disabilities' and only these people will qualify.

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Executive Summary

- “This Green Paper will explore changes we could make to the current PIP system to ensure support is targeted where it is most needed. These options include:
    - Making changes to eligibility criteria for PIP.
    - Redesigning the PIP assessment to better target it towards the individual needs of disabled people and people with health conditions.
    - Reforming the PIP assessment so that it is more linked to a person’s condition.”

TRANSLATION: We will bring in a list of qualifying conditions (and exclude mental health). Only people with medical evidence of one of these conditions will qualify.

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Executive Summary

- “The Green Paper will also explore whether we should make fundamental changes to the way we provide support to disabled people and people with a health condition…
- These include:
  - Moving away from a fixed cash benefit system so people can receive more tailored support in line with their needs.
  - Moving towards a better join up of local services and a simpler way for individuals to access all forms of support and care, whilst reducing duplication, to better meet the needs of people with health conditions and disabilities.
  - Exploring alternative ways of supporting people to live independent and fulfilling lives. This could mean financial support being better targeted at people who have specific extra costs, but it could also involve improved support of other kinds, such as physical or mental health treatment, leading to better outcomes.”

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Chapter 1 – PIP – Overview and assessment reform Q1-8

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Chapter 1: Green Paper Information

- “whether we should consider a new or hybrid [assessment model] based entirely or partly on… diagnosis.”
- “We need to understand how we would choose the conditions that would be eligible for support, whether this approach would be fair and if it would help us ensure support goes to people with the highest needs and those who have extra costs associated with their condition.”
- “We want to understand if evidence of a clinical diagnosis made by a healthcare professional could provide a more objective assessment of need than the current functional assessment. This would mean that people could receive entitlement to PIP… without undergoing an assessment.”
- “We want to understand how we could account for the variation in the severity of the disability or health conditions and the effect on the individual if we moved to a full or hybrid condition-based approach. We also want to understand how claimants could provide clinical evidence for this approach.”
- “We would need to carefully consider… whether it would be the best use of [NHS] resource.”

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Question 1:

What are your views on an assessment that places more emphasis on condition rather than the functional impact of a condition on the person?

Please explain your answer and provide evidence or your opinion to support further development in our approach.

TRANSLATION: Do you agree we should have a list of eligible conditions as the only way to qualify for PIP?

We think this is a very bad idea, as the same condition can have a very different impact on different people.

Equally, the same condition can affect the same individual very differently at different times, especially if it is a condition that is known to deteriorate.

It could only result in a league table of qualifying conditions with fixed entitlements and not reflect the disability-related costs of individual PIP claimants.

Any assessment process needs to put dignity front and centre and be co-produced with Disabled People. The proposed changes are dehumanising to Disabled People.

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Question 2:

What are your views on people receiving PIP without an assessment if they have specific health conditions or a disability as evidenced by a healthcare professional?
Please explain your answer and provide evidence or your opinion to support further development in our approach.

TRANSLATION: If you have medical evidence that you have a condition on the list, is this enough to qualify for PIP?

We think this is a very bad idea. Because it is likely that the award rate would also be fixed. So, for example, people with ME/CFS might always get an award of standard care and standard mobility, no matter how the condition affects their needs.

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Question 3:

What are your views on PIP claimants not being subject to an award review if they have a specific health condition or disability as evidenced by a healthcare professional? Please explain your answer and provide evidence or your opinion to support further development in our approach

TRANSLATION: If you have medical evidence that you have a condition on the list, is this enough to qualify for PIP indefinitely?

Where a condition is very likely to remain the same, or can only deteriorate and the claimant is already on the highest rates of PIP, then not having award reviews is sensible.

At present, PIP claimants with the longest awards of PIP are subject to an automatic review of their award after ten years. This wastes the DWP's time, money, and resources; it is undertaken without evidence of any likely change in the claimant's daily living or mobility needs. In addition, it causes completely unnecessary worry and stress to the claimant.

Many claimants are already receiving the highest rates of PIP with long-term or permanent impairments, yet they are given a short award of 18 months to 2.5 years until a review is required. This wastes the DWP's time, money, and resources; it is undertaken without evidence of any likely change in the claimant's daily living or mobility needs. In addition, it causes completely unnecessary worry and stress to the claimant. This also impacts their ability to access passports benefits, especially when there may be very short (a year or less) extensions to their award while their renewal is processed. It also fails to take account that claimants are required to report any changes to the DWP, and that DWP figures show that fraud by PIP claimants fell from 0.2 per cent in 2022-23 to 0.0 per cent in 2023-24.

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Question 4:

Do you agree or disagree on making provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP?

- ○ Agree
- ○ Disagree
- ○ Don’t know

Disagree

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Question 5:

In relation to Question 4, please explain your answer and provide evidence or your opinion to support further development of our approach.

Disagree, because for many conditions – for example, ADHD, ASD - a claimant may have to wait years for a formal diagnosis and so be prevented from claiming PIP.

Disagree, this will bar support for those who have a disabling condition that has yet to be medically identified. Mind reports that around two million people are sitting on waiting lists for mental health support. Many of these people will be awaiting a formal diagnosis.
ADHD UK reports that waiting times for a diagnosis can be 18 months.

Women and people in racialised groups would disproportionately disadvantaged by this proposal - conditions affecting predominantly women can take significantly longer to be formally diagnosed, e.g. fibromyalgia and endometriosis, where on average it takes 8 years 10 months from the first GP visit to get a diagnosis (Endometriosis UK Diagnosis Report 2024). PCOS can take more than 2 years to be diagnosed. Conditions (predominantly) affecting women and minority groups are under-researched and underfunded, and often go undiagnosed - for example, 50% of women with PCOS are undiagnosed*. People who are diagnosed in childhood, such as for sickle cell often do not have access to documentation from their childhood medical professionals to confirm their diagnosis. People who have moved areas and/or GP since NHS records were digitised may find that their pre-digitisation records have been lost and therefore cannot access proof of diagnosis from a medical professional.

- * https://www.pcosdietsupport.com/how-long-does-it-take-to-be-diagnosed-with-pcos/

Any reform has to go through formal consultation after being designed by Disabled People and Disabled People's Organisations (those led by disabled people)

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Question 6:

How could we prevent the provision of evidence or a formal diagnosis by a medical expert from impacting the NHS?
Please explain your answer and provide evidence or your opinion to support further development of our approach.

We don’t think you could prevent it from impacting on the NHS. This would be disastrous for both the NHS and for claimants. Either medical experts would be diverted from caring for patients because they had benefit claims to deal with or they simply wouldn’t prioritise benefits applications and claimants would wait many months for the necessary evidence. It would harm patients, further demoralise NHS staff and disadvantage PIP claimants.

People with childhood diagnoses or those who have changed GP or area since the NHS digitisation of records may not have any access to documentation confirming their diagnosis from a medical professional.

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Question 7:

Do you agree or disagree that eligibility for PIP should be based more on condition?

- ○ Agree
- ○ Disagree
- ○ Don't know

Disagree

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Question 8:

How could we determine eligibility for the following conditions?

- Conditions that fluctuate
- Conditions that vary in severity
- Conditions that might be cured or have access to better/new/novel treatments over time.

Please explain your answer and provide evidence or your opinion to support further development in our approach.

The most important factor in determining eligibility is the experience of individual Disabled people of their impairments or long-term health conditions

You can determine eligibility for conditions that fluctuate or vary in severity by collecting, and properly assessing, detailed evidence from the claimant.

You can determine eligibility for conditions that might be cured or have new treatments by requiring claimants to inform you if their needs change - as they are required to do now.

In other words, do what you do now but do it better. Inventing money saving short-cuts to avoid collecting detailed evidence will always lead to bad outcomes for claimants and wider society.

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Chapter 2 – PIP – Eligibility reform

Q9-17

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PIP Activities - recap

Daily Living:

1. Preparing food
2. Taking nutrition
3. Managing therapy or monitoring a health condition
4. Washing and bathing
5. Managing toilet needs or incontinence
6. Dressing and undressing
7. Communicating verbally
8. Reading and understanding signs, symbols, and words
9. Engaging with other people face to face
10. Making budgeting decisions

Mobility activities:

11. Planning and following journeys
12. Moving around

Award rates:

Daily Living:
Standard: 8-11 points - £72.65
Enhanced: 12 or more points - £108.55

Mobility:
Standard: 8-11 points - £28.70
Enhanced: 12 or more points - £75.75

(Maximum amount is under £800 per month)

Chapter 2: Green Paper Information

- “In this chapter, we look at the potential for… making changes to the PIP eligibility criteria, including whether changes should be made to activities, descriptors, points, and the required period condition.”
- “Entitlement to PIP considers the twelve activities relating to daily living and mobility”
- “Over time, following successful legal challenges, how we define certain elements within the activities and descriptors has changed and they capture the impacts of some health conditions or disabilities differently than was intended when the activities were designed.”
- “If a functional assessment is retained, we could consider partially or fully reviewing the PIP entitlement criteria to ensure they are working as intended. Our aim would be to ensure that the criteria are fair and that we focus support on people with the highest needs and significant ongoing extra costs.”
- “To be entitled to PIP, people have to satisfy a qualifying period of three months and meet a prospective test of nine months… the ‘required period condition’ and they help establish that the health condition or disability is likely to be long-term.”

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Question 9:

Do you think the need for an aid or appliance is a good/bad indicator of extra ongoing costs and why?

There is no alternative being offered in this consultation. Thus we can only conclude that the goal would be to reduce the number of successful claims made on the basis of taking aids and appliances into account. We therefore state that aids and appliances are perfectly reasonable indicators, the usage of which should not change.

It is a good indicator because it is one which has been used successfully for PIP since the benefit was introduced. The fact that no alternative is being suggested implies that the intention is simply to stop taking aids and appliances into account in order to reduce the number of successful claims.

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Question 10:

Do you think the need for prompting is a good/bad indicator of extra ongoing costs and why?

It is a good indicator because it is one which has been used successfully for PIP since the benefit was introduced. The fact that no alternative is being suggested implies that the intention is simply to stop taking prompting into account in order to reduce the number of successful claims.

Prompting is a very good indicator and was successful used for Disability Living Allowance and then for PIP itself. It is a good indicator because it is one which has been used successfully for PIP since the benefit was introduced.   The law relating PIP, states that "prompting" means reminding, encouraging or explaining by another person.

The term "prompt" is relevant to the following PIP activities:

- Preparing food.
- Taking nutrition.
- Managing therapy or monitoring a health condition.
- Washing and bathing.
- Managing toilet needs or incontinence.
- Dressing and undressing.
- Reading and understanding signs, symbols and words
- Engaging with other people face to face.
- Making budgeting decisions.
- Planning and following journeys.

Without prompting and encouragement some Disabled people would be in danger of self-neglect and harm. The need for such support has never been questioned previously by Disabled People or our organisations. It is worrying that it is being so now as a consideration of how to reduce PIP eligibility.

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Question 11:

Do you think people who accumulate low points across activities have the same level of extra costs as those who score highly in one or more activities?

This is an unanswerable question. Someone who scores low points across a range of activities may struggle with virtually every aspect of daily living and therefore have considerable costs spread over numerous activities. Someone who scores highly for just one activity may have considerable costs just for that single activity. We think this question is designed to provide justification for removing low scoring descriptors altogether and reducing the cost of PIP.

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Question 12:

Do you think any of the PIP activities measure similar functions and could be merged?

No

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Question 13:

Do you think any of the PIP activities should be removed or re-written and why?

No. Because any removal or rewriting would be solely designed to reduce costs rather than improve PIP assessments.

No. We believe the impetus for this consultation is aimed at reducing the cost of PIP. Any meaningful or valid reforms cannot be considered in the absence of the active engagement by Disabled people and our organisations. Any future changes to the PIP system must be co-produced with Disabled people.

Many DLA claimants have only recently been moved to PIP - it is too soon to change the system again for these people in particular.

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Question 14:

Should we consider adding any new activities? If so, which activities should be added and why?

No. If new activities are added, this should be done on the basis of a proper, evidenced review and not on a questionnaire designed to justify reducing eligibility. Rather than new activities, there should be a detailed review of the lack of points available in the PIP criteria for needing supervision to stay safe.

No. The only way to add new activities would be by co-producing the entire application system with Disabled people, alongside a thorough evidenced review. This questionnaire cannot achieve those necessary goals.

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Question 15:

Do you think the current entitlement thresholds levels are set at the right levels to define the need for Government financial support and why?

Yes, because they are providing additional support to millions of people and any changes are likely to be aimed at reducing that support.

Any future changes to the PIP system must be co-produced with Disabled people.

Only a minority of Disabled People qualify for PIP (2.6 million out of 8 million Disabled People in England and Wales); there is no need to change entitlement threshold levels unless it is to increase the number of Disabled People who will qualify. Any changes should be done in co-production with disabled people and our organisations.

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Question 16:

What are your views on changing the length of the current three-month qualifying period for PIP which is used to establish that the functional effects of a health condition or impairment have been present for a certain time period before entitlement can start?

The qualifying period works effectively as it is and does not need changing.

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Question 17:

What are your views on retaining, removing, or changing the length of the current nine-month prospective test which is used to determine if the functional effects of a health condition or impairment are likely to continue long-term?

The prospective test works effectively as it is and does not need changing.

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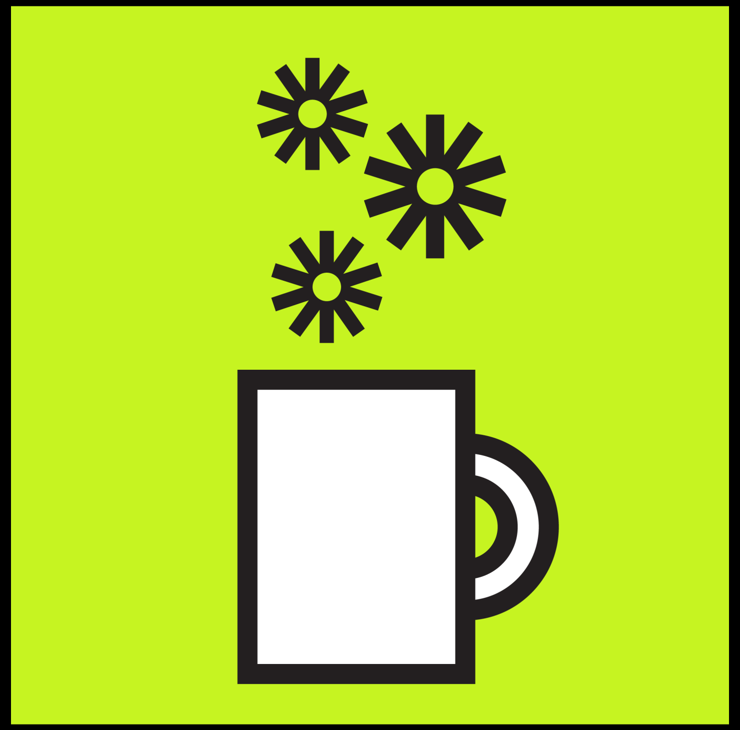
Back soon…



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Chapter 3 – PIP – What do we provide support for? Q18-27

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Chapter 3: Green Paper Information

Alternatives to a cash transfer system

- DWP could continue to contribute to people's extra costs through alternative models which could include:
  - Catalogue/ shop scheme: in this kind of scheme, there would be an approved list from which disabled people could choose items at reduced or no cost. This would likely work better for equipment and aids rather than for services.
  - Voucher scheme: in this kind of scheme, disabled people could receive vouchers to contribute towards specific costs. It could work for both equipment/aids and for services.
  - A receipt-based system: this would involve claimants buying aids, appliances, or services themselves, and then providing proof of their purchase to claim back a contribution towards the cost. This could work in a similar way to Access to Work, which provides grants for equipment, adaptations, and other costs to help disabled people to start and stay in work.
  - One-off grants: these could contribute towards specific, significant costs such as for home adaptations or expensive equipment. It could involve a person supplying medical evidence of their condition to demonstrate the need for equipment or adaptations.
- We would like to understand whether some people receiving PIP who have lower, or no extra costs, may have better outcomes from improved access to treatment and support than from a cash payment.
- We would also like to know whether there are specific groups of people who have a need of a greater level of support than they currently receive, and whether this support should be financial or take a different form, such as improved access to healthcare (such as mental health provision or physiotherapy) or enhanced local authority support (such as care packages, respite or home adaptations).

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Question 18:

PIP provides a contribution towar[illegible]abled people are the most important for a new scheme to ad[illegible]order of importance:

- Equipment and aids
- Medications and medical produc[illegible]
- Personal assistance (costs arising [illegible]d physical and/or e[illegible] support within and outside the home, eg. help with household tasks or ass[illegible]with transportati[illegible]
- Health and personal care (including p[illegible]erapies, talki[illegible]ies, massages, etc. Also includes greater spending on personal hygiene or appea[illegible]
- Extra transport costs (from reliance on ta[illegible]essib[illegible]ospital parking fees, vehicle adaptations, etc.)
- Additional energy and utility costs arising fr[illegible]th condition (including digital access)
- Additional food costs arising from disability o[illegible]n
- Additional spending on clothing, footwear, and[illegible]s arising from disability or health condition
- Higher costs of insurance
- Additional housing costs arising from disability or [illegible] condition, including home adaptation costs

Question 19:

In relation to Question 18, please explain your answer below and tell us about any other important kinds of cost not listed above.

We very strongly object to the presence of the rigged question above. if we engage with the question then we are being obliged to decide whether food, medication, heating transport or a range of other things are the most important for disabled people. This is a cruel and uncivilised judgement to be asked to make.

Nobody should have to choose between these things, but their relative importance will vary depending on the individual, which is why people are free to spend their PIP in the ways most important to them.

Someone who depends on a specialised diet to stay well, will clearly consider this a priority. Someone who needs energy to power vital, disability-related equipment will prioritise paying for this. Someone who needs medication not available on the NHS to prevent a deterioration in their health will put this before other costs. And someone who depends on taxis to get to vital therapy or hospital appointments because they cannot use public transport will consider this a vital expense.

It is crass and unreasonable to ask respondents to this questionnaire to make a judgement on what is most important to other people.

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Question 19:

In relation to Question 18, please explain your answer below and tell us about any other important kinds of cost not listed above.

It is offensive for the DWP to produce a questionnaire which asks us to decide between food, medication, heating and other vital costs that Disabled people have to make. Being Disabled is not a homogenous experience – there are at least 16 million of us, and we have different impairments, backgrounds, hopes and aspirations and lead different lives. It is impossible and grotesque to choose or rank which costs are more important than others in the way outlined in question 18.

Many disabled people have needs in multiple areas and their needs may vary with seasons / time / wider circumstances. It is impossible to choose between the options presented here as they are all fundamental to wellbeing. It is a violation to the dignity of disabled people that we are being asked to make this choice. This reflects the findings of the UN Committee on the Rights of Disabled Persons, which has found in 2016 that UK welfare policies were leading to grave and systematic violations of Disabled People's Human Rights. The UN Committee in 2024 did not see any progress in addressing those violations, moreover, it documented evidence of retrogression.

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Question 20:

What are the benefits and disadvantages of moving to a new system for PIP claimants?

A catalogue/ shop scheme

- Benefits
- Disadvantages
- Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

This is a terrible idea, there are no benefits whatsoever. Claimants would be forced to choose from a limited range of probably substandard products, whilst the company running the scheme would be free to rack up vast profits with no competition.

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Question 20:

What are the benefits and disadvantages of moving to a new system for PIP claimants?

A catalogue/ shop scheme

All of these are completely unacceptable.

These measures would remove the independence and autonomy of Disabled People to decide what to spend their cash PIP benefit payments on. With a shop scheme, the DWP would also likely impose a spending limit for specified items, likely to be the cheapest available regardless of the claimant's actual suitability. Disabled people would be forced to choose from a limited range of probably substandard products, whilst the company running the scheme would likely be able to free to rack up vast profits with no competition.

Innovation in disability aids would be disincentivised due to the reduced market if PIP as a cash benefit is withdrawn and it becomes difficult to be admitted to a catalogue/shop scheme as a supplier.

PIP must remain a cash benefit. Any future changes to the support provided via PIP should focus solely on increasing the already meagre financial support given to claimants and should be co-produced with Disabled people.

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Question 21:

What are the benefits and disadvantages of moving to a new system for PIP claimants?

A voucher scheme

- Benefits
- Disadvantages
- Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

This is a terrible idea, there are no benefits whatsoever. It would limit choice and push up prices, as not all outlets would accept vouchers and there would be likely to be restrictions on what the vouchers could be spent on. It would be stigmatising for claimants to have to present vouchers at the point of sale.

Claimants would likely lose money as change is unlikely to be given.

Question 21:

What are the benefits and disadvantages of moving to a new system for PIP claimants?

A voucher scheme

These measures would remove the independence and autonomy of Disabled People to decide what to spend their cash PIP benefit payments on. There are no tangible benefits to this proposed system. Disabled people would be forced to choose from a limited range of probably substandard products, whilst the company running the scheme would be free to rack up vast profits with no competition.

Any future changes to the support provided via PIP should focus solely on increasing the already meagre financial support given to claimants and should be co-produced with Disabled people. PIP must remain a cash benefit.

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Question 22:

What are the benefits and disadvantages of moving to a new system for PIP claimants?

A receipt-based scheme

- Benefits
- Disadvantages
- Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

This is a terrible idea, there are no benefits whatsoever. It means that claimants would need to already have the money to purchase the item they required or they simply would not be able to get it. The DWP is already massively failing to cope with its workload, it could not possibly cope with processing millions of receipts, even if it outsourced the process to a private sector company making millions from the contract. There would inevitably be huge processing delays. Receipts would be lost. Others would be challenged as either not containing all the necessary information, not being legible or being too high for the goods or services in question. Some sort of appeal system would be needed when receipts were refused, adding to costs and delays. And it is a system that would be open to huge levels of fraud by criminal gangs.

Many claimants would have to pay for a PA to complete and send the receipt-based scheme claims forms on their behalf, adding costs to the system and/or eroding the value of refunds received.

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Question 22:

What are the benefits and disadvantages of moving to a new system for PIP claimants?

A receipt-based scheme

This would take away the independence and autonomy for Disabled People to decide what to spend their cash PIP benefit payments on. With a shop scheme the DWP would also likely impose a spending limit for specified items, likely to be the cheapest available regardless of its actual suitability to the claimant.

With a receipt system, Disabled people would need to already have the money to buy the item they require, or they simply would not be able to get it, essentially reducing the support they get.

It would likely lead to lengthy reimbursement waits and the need for an appeal system. Any future changes to the support provided via PIP should focus solely on increasing the already meagre financial support given to claimants and should be co-produced with Disabled people. PIP must remain a cash benefit.

The DWP would likely impose a limited list of acceptable items and acceptable costs for reimbursement, the value of which would be eroded with inflation and which would not meet the needs of the wide range of disabled people.

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Question 23:

What are the benefits and disadvantages of moving to a new system for PIP claimants?

One-off grants

- Benefits
- Disadvantages
- Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

This is a terrible idea, there are no benefits whatsoever. The point of PIP is that it covers the ongoing additional costs of being disabled, week in week out, potentially for many years. It would be impossible to calculate a single, one-off payment that would do this. There are already grant schemes to help with large capital outlays, such as installing disabled access or a wet room.

Greater Manchester
Coalition of Disabled People

Question 23:

What are the benefits and disadvantages of moving to a new system for PIP claimants?

One-off grants

Grants would take away the independence and autonomy for Disabled People to decide what to spend their cash PIP benefit payments on. The point and value of PIP is that it provides needed help for disability-related costs on an ongoing basis.

A one-off grant cannot simply waive away these. Any future changes to the support provided via PIP should focus solely on increasing the already meagre financial support given to claimants and should be co-produced with Disabled people. PIP must remain a cash benefit.

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Chapter 3: Green Paper Information

Passporting

- PIP passports claimants to a wide range of benefits and services offered by DWP, other government departments and more widely by other organisations and schemes, such as the Motability Scheme.
- In Transforming Support: The Health and Disability White Paper published in March 2023, we set out our plans to remove the Work Capability Assessment (WCA), and introduce a new PIP-passporting model, where anyone in receipt of PIP and the UC Standard Allowance would receive a new UC Health Element.
- PIP is also used in the current system to determine whether a person's carer is entitled to Carer's Allowance.
- If PIP was replaced by an alternative model, we would need to consider the implications for how we determine eligibility to these linked benefits and services. We would like your views on how this should work.

Greater Manchester Coalition of Disabled People

Question 24:

If PIP could no longer be used to determine eligibility to passport to other benefits and services, what alternative ways could service providers use to determine disability status?

We have no idea and don’t see any reason to change to an alternative method. If the DWP can’t even offer any suggestions, it implies you have no idea either and hope that someone else will.

We don’t see any reason to change to an alternative method. There no suggestions given so it is impossible to understand the goal of this question. Any future changes to the PIP system must be co-produced with Disabled people.

Allow self-assessment as a disabled person for passported benefits and services. DWP figures show that fraud by PIP claimants fell from 0.2 per cent in 2022-23 to 0.0 per cent in 2023-24, which indicates that self-assessment would be a reliable approach.

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Question 25:

If PIP could no longer be used as the eligibility criteria to additional financial support in Universal Credit, what alternative ways of determining eligibility should we use?

We have no idea and don’t see any reason to change to an alternative method. If the DWP can’t even offer any suggestions, it implies you have no idea either and hope that someone else will.

Additional eligibility criteria may exist, but these would need to be the subject co-production with Disabled people.

Allow self-assessment of eligibility for additional financial support. DWP figures show that fraud by PIP claimants fell from 0.2 per cent in 2022-23 to 0.0 per cent in 2023-24, which indicates that self-assessment would be a reliable approach.

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Question 26:

Are there specific groups of people whose needs are not being met by the current PIP provision and have a need for a greater level of support? What form should this support take (eg. help with specific extra costs, access to improved healthcare such as mental health provision or enhanced local authority support such as care packages and respite)?

There are undoubtedly people whose needs are not being met, but a cost-cutting review such as this one is not the place to consider them. Nor is it appropriate to try to sneak in supposed replacements for PIP – such as mental health provision – by the back door, by pretending you are providing additional support.

There are undoubtedly people whose needs are not being met, but these would need to be in addition to current provision and involve co-production with Disabled people.

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Question 27:

Instead of cash payment, are there some people who would benefit more from improved access to support or treatment (for example, respite care, mental health provision or physiotherapy)?

Absolutely not. Access to support or treatment should already be available from the NHS or local authority, regardless of whether you are a PIP claimant or not. In no circumstances should such support be seen as a replacement for a cash benefit. If PIP claimants were ‘awarded’ physiotherapy, would this be in addition to NHS support or would it involve some form of queue-jumping? In either case it would be utterly unreasonable and unacceptable.

PIP must remain a non-means tested, cash benefit, paid irrespective of work status. In-work poverty has increased over the past two decades* and 62% of those in poverty are from working families. Disabled people are six percentage points more likely to be in poverty than non-disabled people - this is an underestimate as benefits like PIP are counted as income in these calculations. Disabled people live in poverty at twice the rate of non-disabled people.** Government figures show that disabled people make up 26% of the UK population and 69% of people referred to Trussell Trust food banks***.

Disability and risk of domestic abuse and violence: Public Health England reported in 2015 that disabled people are at higher risk of violence, especially domestic abuse - at up to 7 times the rate of the general population. When it occurs, they also experience domestic abuse that is more severe, more frequent and lasts for longer periods. Disabled women experiencing domestic abuse having lower incomes than disabled women not experiencing domestic abuse. PIP being a cash benefit paid directly and only to the claimant is a literal lifeline for those who may have no access to other funds to leave unsafe living environments. Removing this would increase the already significant barriers to leaving an abusive situation.****

*Sources in notes

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Chapter 4 – PIP – Aligning support
Q28-38

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Chapter 4: Green Paper Information

- “We would like to explore how to better align existing services and offers of support available to disabled people and people with health conditions. We want to better understand if this could create greater opportunities to simplify the application process for disabled people and individuals with health conditions (who currently must apply nationally and locally for different types of support).”
- “Since local areas understand their local population and available health, care and local authority services, this approach could allow us to offer better joined up and streamlined support than the current system.”
- “We want to know if aligning the support offered by PIP with local authorities, the NHS and other partners could improve services and support for individuals. Local areas could have the flexibility to choose how best to support individuals based upon the needs they identify within their local population.”

Greater Manchester Coalition of Disabled People

Question 28:

Do people already receive support from local authorities or the NHS with the need/costs that come with having a disability or health condition?

- ○ Yes
- ○ No
- ○ Don’t know

No

(See next slide for reasoning)

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Questions 29:

In relation to Question 28, please explain your answer and provide evidence or your opinion to support further development of our approach.

No. We have chosen this answer because it would depend entirely on what your condition is, where you live and what support you have already received. Cash-strapped local authorities and NHS trusts will vary massively in the services they provide.

There is no way to answer this question other than by saying no. The experience of a Disabled person in regard to the support they receive from local authorities and the NHS will vary from authority and health trust. We know that both bodies are already massively underfunded and require much more investment to deliver high-quality services. This questionnaire offers no route to fix those issues.

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Question 30:

Which of the following do local authorities or the NHS help with?

- ○ Equipment and aids
- ○ Medical products
- ○ Personal assistance (eg. help with household tasks)
- ○ Health services
- ○ Social care
- ○ Respite
- ○ Transport
- ○ Utility costs
- ○ Other

None selected

(See next slide for reasoning)

Greater Manchester Coalition of Disabled People

Question 31:

In relation to Question 30, please explain your answer and provide evidence or your opinion to support further development of our approach.

We have not answered question 30 because it is not possible to answer it accurately. As in relation to question 29 above, it would depend entirely on what your condition is, where you live and what support you have already received. Cash-strapped local authorities and NHS trusts will vary massively in the services they provide.

Greater Manchester Coalition of Disabled People

Question 32:

Which needs/costs that come with h eas help with further?

- Equipment and aids
- Medical products
- Personal assistance (eg. help with d tasks)
- Health services
- Respite
- Transport
- Utility cost
- Other

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Question 33:

In relation to Question 32, please explain your answer and provide evidence or your opinion to support further development of our approach.

None. Local authorities and NHS trusts are already overwhelmed by costs and do not have the resources to take on additional provision.

They shouldn’t have any. Because individuals should be able to decide their own priorities and have the resources, via cash payments of PIP, to meet them.

Greater Manchester Coalition of Disabled People

Question 34:

If we align the support offered by PIP into existing local authority and NHS services how could this improve things for disabled people and people with health conditions?

It couldn’t improve things, it would be a disaster. Funding from central government to local authorities and NHS trusts would inevitably be insufficient to meet the level of need and would be further squeezed over time. Central government would blame local authorities for inefficient use of funds and local authorities would blame central government for inadequate funding. Disabled people would be left powerless between the two parties. In addition, it would entirely remove disabled claimants’ opportunity to make their own decisions about what their priorities are and how to maintain their personal independence.

Greater Manchester Coalition of Disabled People

Question 34:

If we align the support offered by PIP into existing local authority and NHS services how could this improve things for disabled people and people with health conditions?

We categorically oppose this proposal – it would be a dangerous total failure. There is no recent precedent that suggest that a combining of two vastly different systems of support would work – with Disabled people inevitably left worse off. Fundamentally, it would also remove our agency, choice and control as Disabled people by removing our ability to make our own decisions about our own priorities and what we want to spend our money on to maintain our personal independence.

PIP is non-means tested; local authority support usually is means-tested. This would be disastrous for Disabled People who are already more likely to live in poverty. For example, 69% working-age people referred to food banks in 2023 were disabled. That alone is shocking, but when you understand that it is more than three times the rate in the general population it is damning.

The waiting time for NHS and/or Local Authority support is also horrendous - NHS waits of 70 weeks for a first appointment are reported in some areas; it can take over 2 years to get a ramp installed at your (owned/mortgaged) home and this may not be possible at all in private rented accommodation. The PIP process is substantially quicker than this and puts cash in the hands of disabled people to spend it how best meets their needs.

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Question 35:

Do you think aligning PIP with local authority and NHS services could reduce the number of assessments a person with a disability or health condition would have to undergo? Would this help to reduce duplication?

How could anyone possibly know the answer to this? Especially as different authorities would choose to meet people’s needs in different ways, leading to an utterly fragmented system. It might well be that in some areas you would have to undergo multiple assessments and in others very few.

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Question 36:

What disability support services in your community are the most important services or support to deliver?

This is another unanswerable question. All support services are important and their relative importance will depend upon the needs of any specific individual.

This again is another question that is impossible for us to answer. Our community is diverse, and every Disabled person has our own specific needs. There is no way to rank which services are most important, and this is a reductive framing from the DWP.

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Question 37:

How much flexibility should local areas have to decide their priorities in supporting people with disabilities and health conditions?

They shouldn’t have any. Because individuals should be able to decide their own priorities and have the resources, via cash payments of PIP, to meet them.

None. The goal of PIP is to allows individuals to decide their own priorities via the cash- payments they receive. This should not change.

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Question 38:

What capacity and capability would be required to better align PIP with local authority and NHS services?

It’s hard to know what this question is even asking. But we don’t believe that there should be any attempt to align PIP with local authority and NHS services as they are so variable around the country. It would, in any case, simply be an attempt to introduce cuts through the back door.

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Question 39: (Compulsory)

Are you an individual or an organisation supporting claimants applying for PIP?

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Green Paper Information - Conclusion

- “We will hold Green Paper events to hear directly from disabled people.”
- “We want to involve more disabled people and people with health conditions in shaping how we work.”

"Thank you for your interest in Modernising Support for Independent Living: The Health and Disability Green Paper. The consultation remains open but during the period in the run up to the General Election on 4 July 2024, we shall not be running any public face-to-face or virtual events. We shall provide an update on next steps for the consultation after the General Election.”

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Recap: Purpose of this meeting

- Share information about the current UK PIP Consultation
- Discuss ideas for how to respond - quick response (20 minutes) & government form (rest of meeting)

This meeting is repeated - first 20 minutes for quick response, rest for detail:

- Wednesday 17th July 12.30 to 2.30pm

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Next steps

- **Deadline: 22nd July 2024**
- **Modernising support for independent living: the health and disability green paper**
  - Complete this online form - 39 questions
  - Email: consultation.modernisingsupport@DWP.GOV.UK
  - Write to:

Disability and Health Support Directorate
Department for Work and Pensions
Level 2
Caxton House
Tothill Street
London SW1H 9NA

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Final questions?

Feedback Poll

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Thank you and good bye