To: **1. Minister for Social Security and Disability**

          2. Secretary of State

From: ███████████████████████████

SCS Clearance: ███████████████████

Date: 9 August 2024

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Summary

1. ██
   ██, this
   submission provides the headlines and a detailed review of 1,600 individual consultation
   responses for you to consider.

2. It also sets out ███████████████████████████████
   █████████████████ timelines on when you can expect a summary of the
   responses received from charities and other organisations (of which there have been 115).

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Key information

5. In total we have received over 16,000 responses via email, online and post, from disabled
   people, Disabled People's Organisations (DPOs), charities, and others, 6,000 of which
   were received after 5 July. The consultation included 39 questions; therefore, responses
   are often lengthy ████████████████████████████████

6. The main headlines from the review of 1,600 individual consultation responses are
   provided below, with a thorough review included at Annex B.

7. Given the volume of charity, DPOs and other organisation responses received, 115 in
   total, we plan to send you a summary of the most influential (c.25) charities in w/c 12
   August and then a further summary once the analysis is complete in w/c 26 August.
   Staggering our work in this way means you can see the emerging results of our analysis
   more quickly ██████████████████████████████████

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9. As you are aware, the online consultation closed at 11.59pm on 22 July. We have however received several hundred responses via email and post after that deadline. We suggest that we draw a clear line and not include any responses submitted after the 2.8 deadline in our response analysis. ████████████

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2.10 ██████████████. We are aware of at least 2 charities who submitted their responses after the deadline.

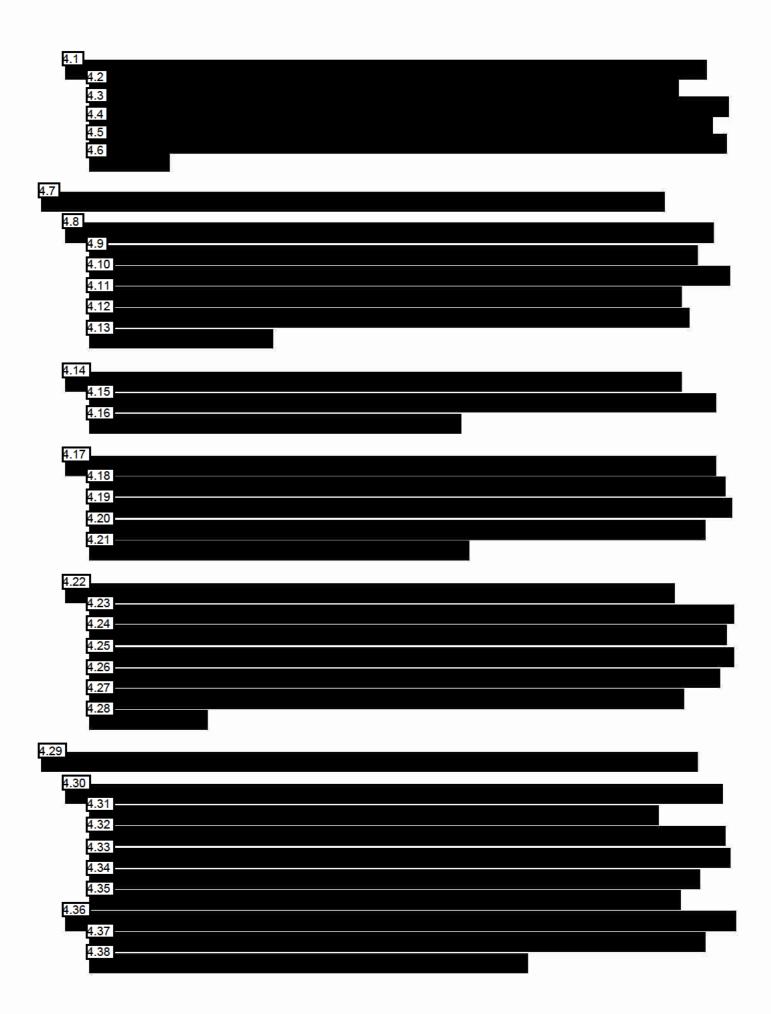## Review of 1,600 individual consultation responses – main headlines

10. We have reviewed 1,600 responses from individuals for which there are several headlines to bring to your attention within this note and a more thorough analysis provided in Annex B. Certain questions asked whether respondents agree or disagree to a certain idea or 2.11 statement, and for these we have included data from all 14,344 online responses. ████

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11. The main headlines from Chapter 1 include general sentiment against placing more emphasis on condition for assessments and PIP eligibility, although sentiment was broadly positive towards people receiving PIP without an assessment if they have specific health conditions or a disability as evidenced by a healthcare professional. Feedback on PIP eligibility reform in Chapter 2 was mixed, particularly concerning entitlement thresholds, PIP qualifying periods and the use of aids and appliances as an indicator of extra costs.

12. In Chapter 3, sentiment was consistently negative on moving PIP away from a monthly cash payment to either a catalogue, voucher, receipt or one-off grant-based system. Sentiment was also negative within Chapter 4 regarding the alignment of PIP support within local authorities and the NHS.
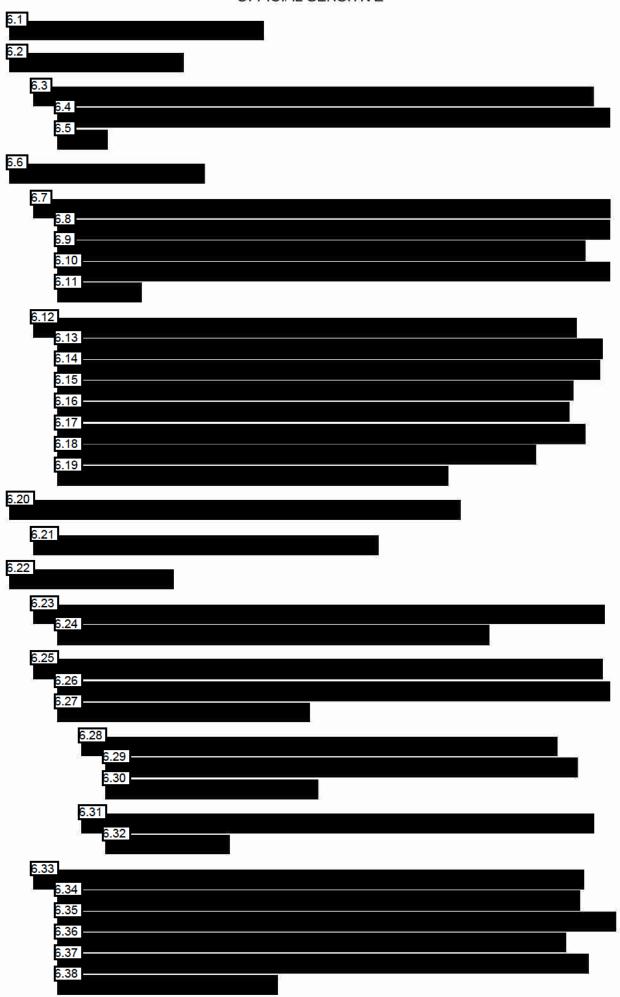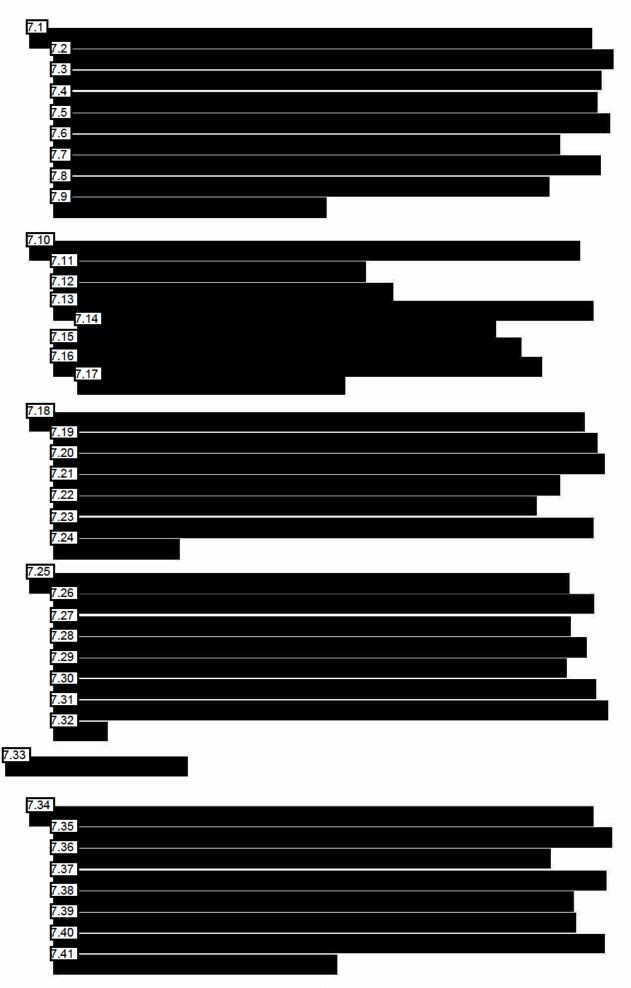
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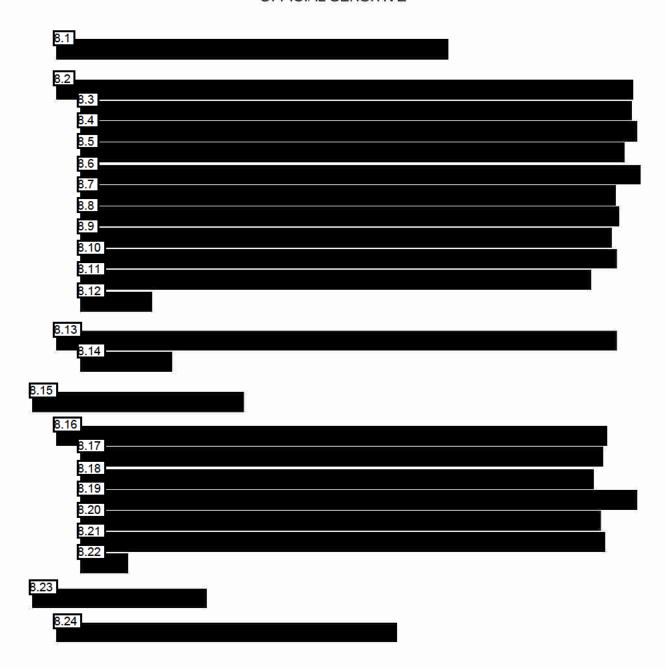
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29. We plan to send you a summary of the most influential (c.25) charity and organisation responses in the w/c 12 August and then a further summary once the analysis is complete in the w/c 26 August.

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Annex B: Review of 1,600 individual consultation responses

1. The consultation included 39 questions, 32 open and 7 closed, across 4 chapters. Throughout the 12-week consultation period, we received over 16,000 responses online, through email and by post. The responses are from individuals, including disabled people and other members of the public as well as from disability charities and associated organisations.

2. We have now reviewed 1,600 responses from individuals for which there are several insights to bring to your attention within this Annex. Certain questions asked whether respondents agree or disagree to a certain idea or statement, for these we have included data from all those that responded online (there were a total of 14,344 online responses).

3. Please note that because most of the consultation questions are open questions, as opposed to 'Agree' / 'Disagree' type questions, we have captured the most common themes throughout the responses, rather than the proportion of people that either agree or disagree to a certain idea or policy. Therefore, for many responses there is often more than one theme raised by the respondent and this approach is reflected in the data and summary below.

4. We have received ~115 responses from disability charities and associated organisations, and we will provide separate submissions on the findings from these as soon as possible, beginning with the most high-profile of the organisations and charities.

Chapter 1 – Overview and assessment reform

5. For Question 1, there was strong sentiment against placing more emphasis on condition for assessments, with the most common theme, highlighted in 41% of responses, that the impact of a condition varies for each person and that there is no one-size fits all approach to a conditions-based assessment. However, Question 7 was more balanced. Of the 14,082 responses, 43% of responses disagreed that eligibility for PIP should be based more on condition, while 36% agreed, with the remaining 21% selecting 'Don't know'.

    a. *'I think it would be looking at things in totally the wrong way. Two people can have the same diagnosis but be affected in totally different ways. That's why it's more important to focus on how a condition impacts someone rather than the diagnosis itself.'* [Q1 Response No. 1,553]

6. When asked if making the provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP (Question 4), of the 14,153 responses from this question, 46% of responses agreed and 37% disagreed, with the remaining 17% selecting 'Don't know'.

7. Sentiment was broadly positive towards people receiving PIP without an assessment if they have specific health conditions or a disability as evidenced by

a healthcare professional (Question 2). The most common theme, in 37% of responses, was that it made sense to remove assessments for people with specific conditions or disabilities if there was an appropriate health care professional available for diagnosis and there is appropriate evidence in place.

8. The second most common theme in Question 2, in 32% of responses, was also in favour of this change, but only for specific and life-long conditions.

   b. *'Absolutely agree, once a condition is proven why do we constantly need to be reassessment. My illness is life long and will only get worse and i will never "get better" so why am i constantly penalised.'* [Q2 Response No. 538]

9. However, another common theme, raised in 10% of responses, was that both diagnosis and functional impact are key factors to take into consideration, rather than just condition.

10. When asked for views on PIP claimants not being subject to an award review if they have specific health conditions or a disability as evidenced by a healthcare professional (Question 3), the most common theme, in 51% of responses, was in agreement for specific conditions and/or where an individual was not likely to get better.

Chapter 2 – Eligibility Reform

11. Feedback on PIP eligibility reform in Chapter 2 was mixed. For example, when asked if people think the need for an aid or appliance is a good/bad indicator of extra ongoing costs and why (Question 9), the most common theme, highlighted in 27% of responses, was that they are a good indicator because they can be expensive to buy, repair and replace.

   a. *'Getting the right equipment and keeping it in good maintenance is expensive, especially as costs rise. It is a good indicator.'* [Q9 Response No. 596]

12. However, 18% of responses, highlighted that they are a bad indicator because not all aids and appliances incur ongoing costs and some conditions do not require an aid or appliance.

   b. *'I feel this is a bad indicator as people with mobility issues are not the only ones with extra costs. Those with anxiety or depression have extra costs, treatment not provided by NHS, taxis, extra electricity as often stuck in the house more and higher use of heating in the winter.'* [Q9 Response No. 71]

13. For prompting (Question 10), the most common theme, recorded in 26% of responses, was that it is a good indicator of extra ongoing costs as the need for prompting has several costs associated with it, such as the need for support from a carer. In contrast, the most consistent common theme indicating that it is not a useful indicator, recorded in only 4% of responses, was that prompting is not applicable for every support need, such as invisible conditions, and is not the only way to determine the need for extra ongoing costs.

14. When asked whether people who accumulate low points across activities have the same level of extra costs as those who score highly in one or more activities (Question 11), there were mixed themes. The most common, recorded in 24% of responses, was that an individual's needs are person-specific and where one person may need more assistance in one activity, others may not and there should not be generalisations made on this topic. The second most common theme, in 21% of responses, was 'Yes', with no rationale provided.

   c. *'In some cases yes and in other cases no. I think it entirely depends what these activities are and what support a person may need from the difficulties of it. It is important to know how this financial help would provide better support for the person and what they would get out of it based on each activity to understand the costs of living with a disability.'* [Q11 Response No. 940]

15. On current entitlement threshold levels and whether they are set at the right levels to define the need for Government financial support (Question 15), there were again mixed themes. The most common theme, recorded in 23% of responses, was that the current threshold levels are set at the right level, but with no specific or common reason recorded. Whereas the second and third most common themes (in Question 15), recorded in 17% and 13% of responses, respectively, were that thresholds are too high and should be lowered and that current levels are not set at the right level, with no specific or common reason provided.

16. Themes related to changing the length of the current three-month qualifying period for PIP were also mixed (Question 16). While the most common theme, recorded in 32% of responses, was that the qualifying period should not change, there were other prevalent themes, such as making the qualifying period condition-based, with some conditions being exempt from this period, as recorded in 21% of responses.

   d. *'I agree with the 3 month wait as it gives amicable time to determine the needs of the individual in depth. It is not rushed.'* [Q16 Response No. 1,084]

   e. *'I think this should vary depending on the condition. For example if you are very suddenly impacted and cannot physically do daily living*

activities at all then you should not have to wait around to meet the time period.' [Q16 Response No. 1,112]

17. Another common theme (in Question 16), within 12% of responses, was to reduce the qualifying period, to between 1-2 months, for example. 13% of responses mentioned abolishing the qualifying period. However, 11% mentioned increasing it.

18. Similarly, when asked for views on retaining, removing or changing the current nine-month prospective test for PIP (Question 17), there were mixed themes. The most common theme, in 24% of responses, was to not change this prospective test period. However, the second most common theme, in 15% of responses, was to make the prospective test period based on condition, similar to the views expressed in Question 16, above.

Chapter 3 – What do we provide support for?

19. The most common sentiment associated with moving PIP to a new system focused on either a catalogue, voucher, receipt or one-off grant-based system was negative (Questions 20-23).

20. The most common theme associated with the voucher scheme (Question 21), for example, and highlighted in 45% of responses, was that it would identify individuals as benefit claimants, potentially leading to discrimination, exacerbated health conditions and reduced independence.

   a. *'I hate the very notion of a voucher scheme for anyone, as it stigmatises people and restricts what they spend their money on. It's treating people like second-class citizens. I think the government should allow people (who are already stressed and ill) to spend their benefits on how they see fit.'* [Q21 Response No. 556]

21. For the catalogue scheme (Question 20), the most common theme, within 31% of responses, was that there are no benefits to this idea and/or that the current PIP system should remain in place. This theme was closely followed by, and within 29% of responses, the theme that the challenges and needs of disabled people are so diverse that individual choice as to how they use their money is really important and that a catalogue scheme would remove independence and trust.

   b. *"There is no benefits as being disabled isn't just about getting equipment it's paying for other things like carers etc and it's not means tested so it should be used on how you feel fit to help you. I see mostly disadvantages as many use it towards daily living costs to.'* [Q20 Response No. 1,076]

22. However, for the receipt-based system (Question 22), the most common theme, within 29% of responses, were concerns around the complexity and administrative burden it would entail and the impact this could have on individual stress levels and exacerbating existing health conditions. The most common theme regarding the one-off grant system (Question 23), highlighted in 30% of responses, was that it would not be suitable for ongoing, day-to-day or variable expenses.

> c. *'Most conditions that people claim PIP for are ongoing and potentially life long. A one off grant will cover some up front costs such as purchasing a wheelchair but wouldn't help with maintenance or with any of the regular day to day living expenses that are increased for those who have disabilities.'* [Q23 Response No. 51]

23. When asked if there are 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 (Question 26), the most common theme, highlighted in 24% of responses, was for people with mental health or psychological conditions. The second most common theme, present in 16% of responses, called for improved general treatment or support services, such as reducing NHS waiting times or increased funding, without referring to specific group or condition.

24. When asked if, instead of a cash payment, there are some people who would benefit more from improved access to support or treatment (Question 27), the most common theme, captured in 21% of responses, was that there should be no need for better access to treatment as the NHS and other organisations should be providing such access to all people already. The second most common theme, within 18% of responses, was that cash payments should be in addition to further support.

> d. *"NO. These & other options should be available AS WELL as the cash payment. The cash payments cannot be stopped, or even more people will be "tipped over the edge", due to being forced further into poverty.'* [Q27 Response No. 1,558]

Chapter 4 – Aligning Support

25. The general sentiment regarding the alignment of PIP support within local authorities and the NHS was negative. For example, when asked how conditions could improve for disabled people and people with health conditions if support offered by PIP was aligned into existing local authority and NHS services (Question 34), the most common theme was one of scepticism and recorded within 27% of responses. This theme relates to the negative impact this would have due to current system limitations in relation to funding, waiting times and an inability to absorb any further demand from support alignment.

   a. *'I think it would overwhelm the system with the most disastrous consequences. It's already buckling at the seams. Anything more and it will be more misery, more delays and more distrust.'* [Q34 Response No. 714]

26. When asked if respondents thought 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 (Question 35), the most common response, highlighted in 20% of responses, was 'No' with no reason provided. Another common theme, within 11% of responses, was that alignment would exacerbate existing strains on assessment capacity and waiting times. However, within 8% of responses, the theme 'Yes' was captured, but with no detail provided.

27. Another theme (in Question 35), and within 15% of responses, was that alignment could possibly reduce assessments. Some responses provided no further detail, while others did, including with regard to sharing data or information.

   b. *'Only if IT was developed to make health information accessible but obviously there are data protection issues to be considered.'* [Q35 Response No. 737]

28. Finally, of the 13,822 responses, 53% answered 'No' and 23% answered 'Yes' (and 24% 'Don't know') when asked if people already receive support from local authorities or the NHS with the need/costs that come with having a disability or health condition (Question 28).

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