

Adult Disability Payment: Consultation on the Mobility Component

**Analysis of responses
Final Report**

August 2023

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Executive Summary

A public consultation on the eligibility criteria for the mobility component of Adult Disability Payment (ADP) ran between 31 January and 25 April 2023. The consultation aimed to gather a broad range of views on alternative approaches to the mobility component and identify any gaps, issues or unintended consequences of changes suggested by respondents.

In total, 210 consultation responses were received from 173 individuals and 37 organisations. Of these, 102 responses were received via a survey tool created, launched and promoted by MS Society Scotland. Six consultation engagement events were also organised by the Scottish Government, independently facilitated by The Lines Between and attended by 22 individuals and 12 representatives of stakeholder organisations.

Overarching themes

Across the consultation, many respondents suggested or called for broad improvements to ADP. The main request was for a holistic, person-centred and flexible approach to ADP decision-making, considering each application holistically, including the wider context of clients' lives and circumstances when making a decision. Some suggestions were raised repeatedly, including:

- Ensuring all aspects of mobility are considered, including a range of additional impacts reflecting clients' lived experiences before, during and after moving around.
- That the criteria should not judge movement in isolation from the reality of moving around and should consider the complexity of the circumstances people encounter when moving.
- Broadening the eligibility criteria to consider other conditions, including mental health conditions, and a wider range of mobility aids.
- That the eligibility criteria are not appropriate for those with fluctuating conditions.
- For the ADP criteria to consider, clarify and include additional aspects of mobility beyond simply the ability to move a certain distance or plan and execute a journey.

The moving around activity

Clarifying the language or meaning of the moving around activity criteria was requested by many respondents, for example by using examples and real life scenarios. Several also argued that the criteria would benefit from a clearer definition of what moving means. While there was appreciation of, and support for, the visual examples now included in the ADP application form, the need for clearer images was mentioned by several respondents.

There was positive feedback on changes made to the ADP application guidance. Respondents thought the changes would lead to more accurate decisions, allowing clients to receive benefits that fit their needs. A more individual approach was also thought to be more understanding, fairer and truer to life. Several also approved of the move from Department for Work and Pensions (DWP)-style face-to-face assessments to only using a consultation with a practitioner when there is no other practicable way to understand a

client's needs. However, concern about the application process was raised by some and reiterated at events, including that the application form is long, intimidating and confusing.

Changing the distance measure in the moving around activity was frequently suggested as another opportunity for improvement. These responses ranged from eliminating the 20-metre measurement in the criteria – the '20-metre rule' - to not using any distance measures. Respondents argued that 20 metres is an unrealistic and limiting distance. They suggested a system that focuses on the qualitative aspects of movement, i.e., how people move, captured through open-ended questions and a flexible approach dependent on people's real life experiences. Several suggested that these changes would improve ADP clients' circumstances and independence and positively impact those with fluctuating conditions as the decision-making process would be more inclusive, holistic and nuanced.

Planning and following journeys activity

Many respondents repeatedly criticised the term 'overwhelming psychological distress', which they found to be limiting, subjective and unclear, and suggested it should be defined, amended or removed. Several also noted confusion about the meanings of 'orientation aids', 'planned', 'unplanned', 'familiar' and unfamiliar', while a few suggested 'journey' could be confusing. Conversely, many also felt the criteria were easy to understand.

Several respondents called for greater consideration of mental health in relation to this activity. These comments often focused on clients' experiences during the journey, such as impacts on mental health if the journey does not go to plan or anxiety related to specific types of journeys but not others. Some respondents requested that the definition of orientation aids include technology like satellite navigation tools and mobile phone map applications, which respondents noted as being crucial to their ability to move around.

The effectiveness of the planning and following journeys section of the ADP application form was noted by many. Several noted that the form was clear, while a few noted it was an improvement on the PIP form. Some others suggested the form was more inclusive of those without physical disabilities and clearly spoke to those with mental health conditions. There was also positive feedback about removing assessments and support for the decision to use professionally trained practitioners instead of assessors for ADP.

Support for people with fluctuating conditions

Many commented on their difficulty understanding the criteria for fluctuating conditions, which they felt were unclear and overly complex. Respondents highlighted the formal, overly complicated language, including using fixed or confusing statements and the lack of examples or sufficiently detailed guidance. A common theme was calls to simplify or clarify the criteria. However, some individuals and organisations felt the criteria were clear, easy to understand, and comprehensive.

Another recurring theme was that the 50% of the time criterion – often referred to as the 50% rule - was not a useful measure and that it should no longer be used. Several commented on using the 'good day, bad day' criteria, either stating that it was impossible for clients to average their symptoms or advocating for a client's experiences on a 'worst day' to be used as a basis for decision-making. It was felt that doing so would simplify the

process and make it easier for people to describe their experiences compared to trying to measure and record their fluctuating conditions.

Respondents also called for a more open-ended approach to allow clients to express themselves in their own way. A key concern was for the application form to allow sufficient space to adequately describe conditions, particularly for those with multiple conditions. However, several respondents gave positive feedback about the fluctuating conditions section of the application form, stating they welcomed the broader range of conditions, found the contextual information helpful or felt it improved the previous application form.

Other considerations

When considering alternative approaches to a points-based system, several respondents advocated a move away from the medical model of disability that underpinned the previous system to a social model. It was argued that moving away from this narrow approach was necessary to help facilitate a more rights-based approach in Scotland, which could benefit disabled people's wellbeing through increased trust in the system and reducing stress and anxiety during consultations. Respondents called for an adequate budget, used equitably, to be allocated to achieve this, with several emphasising the need to ensure sound financial planning to determine the required budget.

The negative impact of the existing system on client wellbeing was highlighted; for instance, a perceived need to mask abilities or the disappointment experienced when awards were not made. Changes to build trust in the system and avoid loss of entitlement were considered a priority by some. Respondents commented on making the system more compassionate, enabling and supportive for disabled people, minimising any distress during the application process. A prevalent theme covered the decision-making approach, mainly that case managers should receive sufficient training to understand different disabilities. Some raised the need to provide independent support and advice to clients.

Regarding passporting benefits, prevalent themes were for the Scottish Government to work in partnership with the DWP to ensure a smooth transition to a new Scottish social security system, and that the independent review should not be constrained by passporting considerations when determining the criteria for devolved benefits, including ADP. Several argued that changes should not disrupt or adversely affect clients i.e., clients should retain their existing entitlements regardless of any changes made to ADP, and none should become worse off.

Conclusions

Many individuals and stakeholders with detailed knowledge and lived experience participated in this consultation, providing their opinions and insight on various aspects of the ADP mobility component. Their views will assist the independent review and the Scottish Government in deciding and delivering on further improvements to ADP.

1. Introduction

Adult Disability Payment (ADP) is a social security payment which launched on 29 August 2022. Delivered by Social Security Scotland and replacing Personal Independence Payment (PIP) in Scotland, it is provided to disabled people between the ages of 16 and state pension age and aims to mitigate the additional costs of living with a disability or health condition. The ADP consists of two parts, called components: a daily living component and a mobility component. A person may qualify for one or both components.

The Scottish Government and Social Security Scotland are committed to ensuring that people receive the support that they are entitled to by reducing stigma and seeking to positively encourage take-up of all social security payments. Several improvements have been made to ADP compared to PIP, including to the application, information gathering, consultation and decision-making processes, to make the benefit easier to access.

Over the next few years, people in Scotland who currently receive PIP will see their payments transferred from Department for Work and Pensions (DWP) to Social Security Scotland. Their entitlement to PIP will end, and they will become entitled to ADP. In light of significant stakeholder feedback on the risks associated with making changes to the eligibility criteria during the transitional period, the eligibility criteria for both PIP and ADP are broadly identical. However, the Scottish Government committed to an independent review of ADP one year after its launch. They also committed to considering possible alternative approaches to the mobility component eligibility criteria, including the '20-metre rule', which is a priority for some disabled people and stakeholders.

[A public consultation](#) ran between 31 January and 25 April 2023. The consultation aimed to gather a broad range of views on alternative approaches to the mobility component and identify any gaps, issues or unintended consequences of changes suggested by respondents. The consultation contained 13 closed and 40 open questions covering:

- The moving around activity
- The planning and following journeys activity
- Support for people with fluctuating conditions
- Other considerations for the Independent Review

The Scottish Government organised six consultation engagement events with stakeholders to provide a more accessible opportunity for disabled people to contribute to the consultation. These were independently facilitated by The Lines Between.

This analysis of responses to the consultation will be presented to the independent review for consideration later in 2023. Full responses to the consultation, where permission for publication was granted, can be found on the Scottish Government's website.

Respondent profile

In total, 210 consultation responses were received. Of these, 108 were submitted via the Citizen Space online consultation platform, or in an alternative format, for example, an email or PDF document, which was reviewed separately by analysts. The other 102 responses were received via a survey tool created, launched and promoted by MS Society

Scotland. People with lived experience of Multiple Sclerosis were asked eight questions, and their responses were automatically entered into Citizen Space. Some of these questions were different to the consultation questions and further information on this is provided below and in Appendix B.

A total of 173 individuals and 37 organisations provided responses to the consultation. To aid analysis, organisations were grouped based on the nature of their work. The table below shows the number of each category of respondent.

Table 1: Respondent classification

Sector	n=	%
Organisations	37	18
- Third sector	27	13
- Specific health/disability focused organisation	17	8
- Campaigning/umbrella bodies	7	3
- Disabled people's organisation	2	1
- Information and advice	1	0
- Public and representative bodies	10	5
- Local authority	4	2
- Representative body	3	1
- Statutory body	2	1
- Parliamentary body	1	0
Individuals	173	82
- Responding through Citizen Space	71	34
- Responding through MS Society tool	102	49

The analysis included notes collated by The Lines Between from the six consultation events facilitated on behalf of the Scottish Government. In total 34 people attended these events – 22 individuals and 12 representatives from stakeholder organisations. Due to participant preference, five events took place virtually, and one occurred in-person in Glasgow. The events were structured around the consultation themes and the open forum allowed participants to expand on areas of their interest.

Following standard data checks, two duplicate responses were identified. One respondent completed both the Citizen Space survey and the MS Society Scotland survey tool. Their Citizen Space response was included in the analysis as it included responses to more questions. Two responses from another individual were combined into one response.

Analysis approach

The Lines Between was commissioned to independently facilitate the six engagement events and provide a robust, independent analysis of the responses to the public consultation. The main purpose of analysis is not to quantify how many people held particular views, but to understand the full range of views expressed. This report provides a thematic analysis of responses using the approach outlined below.

Quantitative analysis

There were 13 closed consultation questions. Those using the MS Society tool are excluded from the quantitative analysis as they were not asked the closed questions directly; the tool automatically populated Q2a and Q12a as 'Yes'.

As not all respondents answered each closed question, the quantitative analysis is based on those who answered each question. We show the number and percentage response **among those who answered the question**, broken down by individual and organisation responses. Figures may not add to 100% due to rounding.

A full breakdown of the number and percentage response to each question, including a breakdown by organisation type, can be found in Appendix A.

Qualitative analysis

Qualitative analysis outlines the key themes identified in responses to each question. The analyst team coded responses against a framework which was developed based on a review of the consultation questions and a sample of responses. Through an iterative coding process, new codes were created if additional themes emerged.

Notes from the consultation events were reviewed to identify any differences in opinion compared to the main sample and to identify any new themes. The themes evident in the events typically aligned with those evident in the main sample, but any additional or unique perspectives are noted in this report.

In four instances where alternative format responses contained information that did not align to specific questions, analysts exercised judgement about the most relevant place to include this material for analysis purposes.

Where appropriate, quotes are included to illustrate key points and provide useful examples, insights and contextual information.

Reflecting the large number of people who took part, it is not possible to detail every response in this report; a few organisations shared lengthy submissions which reflect their specific subject matter expertise. These responses are referenced where possible.

When reviewing the analysis in this report, we ask the reader to consider:

- Public consultation of this kind means anyone can express their views; individuals and organisations interested in the topic are more likely to respond than those without a direct or known interest. **This self-selection means the views of respondents do not necessarily represent the views of the entire population.**
- It is possible that some respondents have not fully read or engaged with the consultation paper, leading to answers which do not directly address the questions. These answers have been noted in the report.
- Similarly, many respondents repeatedly raised the same issues or suggestions at multiple questions, regardless of the specific focus of the question. These views are all included in this report, but analysts exercised judgement about the most relevant place to include each theme to avoid repetition.

- Social Security Scotland and the DWP use different terminology for their respective ADP and PIP processes. For example, PIP has face-to-face assessments with a healthcare professional, whereas ADP may involve a consultation with a practitioner. However, as respondents typically used DWP terminology, it is often unclear if they are referring to past experiences with PIP or to ADP decision-making. This report uses Scottish Government and Social Security Scotland terminology; however, the language in respondent quotes is unchanged.

The MS Society Scotland's Survey Tool

The six open questions asked in the MS Society Scotland tool were different from those in the consultation paper, but were relatively closely aligned to consultation questions 2a, 3, 5, 5a, 12a, and 15. Appendix B compares the two sets of questions.

Responses to open questions received via the tool have been included in this analysis. For consistency and to allow comparison, answers were coded using the codeframes created for each of the above questions. However, the views expressed by those using the MS Society tool are presented separately for each question. This allows the reader to have a clear understanding of the views of those using the tool compared to those responding directly via Citizen Space.

While no closed questions were included, the tool automatically answered questions 2 and 12 with Yes. These responses have not been included in the quantitative analysis / tables.

Weight of opinion

Throughout this report, the themes identified in responses are listed from most to least commonly mentioned. All themes, including those mentioned by a small number of respondents, have been included either in the report or in Appendices C to F. Additional quotations to illustrate some of the key themes discussed in the main body of the report are also included in the Appendices.

Qualitative analysis of open-ended questions does not permit the quantification of results; an insightful view expressed by a very small number of participants is not given less weight than more general comments shared by a majority. However, to assist the reader in interpreting the findings, a framework is used to convey the most to least commonly identified themes in responses to each question:

- The most common / second most common theme; the most frequently identified.
- Many respondents; more than 20, another prevalent theme.
- Several respondents; 10-19, a recurring theme.
- Some respondents; 5-9, another theme.
- A few / a small number of respondents; <5, a less commonly mentioned theme.
- Two/one respondents; a singular comment or a view identified in two responses.

2. Overarching themes

Across the consultation, many respondents suggested or called for broad improvements to ADP. The main request was for a holistic, person-centred and flexible approach in ADP decision-making and many of the themes evident throughout this report relate to this principal aim. There were frequent calls for the ADP criteria to consider, clarify and include additional aspects of mobility beyond simply the ability to move a certain distance or plan and execute a journey.

Some suggestions were raised repeatedly, regardless of the specific focus of the question asked. These are: moving to a more flexible and holistic approach, ensuring all aspects of mobility are considered, that the criteria should reflect experiences of moving in the built and natural environments, and broadening the eligibility criteria. Concerns were also raised repeatedly that the eligibility criteria are not appropriate for those with fluctuating conditions.

To avoid repetition, we detail these themes below before examining the specific comments on each element of ADP in the following chapters.

A flexible and holistic approach to the eligibility criteria

A prevalent theme across responses was the desire for a flexible, person-centred approach to ADP. Several mentioned the importance of considering each application holistically, including the wider context of clients' lives and circumstances when making a decision. Many felt people do not fit neatly into boxes and noted conditions impact mobility differently between individuals and, often, over time.

The criteria were viewed as overly simplistic by many respondents, who argued that more person-centred and holistic criteria could allow clients to develop a clearer understanding of the criteria and demonstrate how moving around relates to their daily experiences. Respondents did not feel a points system in the mobility component for specific activities was helpful; they preferred a focus on understanding day-to-day living with a disability.

It was repeatedly stressed that 'yes/no' questions were limiting and respondents called for a more person-centred approach to considering how clients move during the day, the pain, fatigue, mental distress of those movements and journeys on following days. They argued such an approach could change how the ADP process speaks about and understands the needs of disabled people; one respondent noted that a flexible approach would "allow for a true picture of mobility issues across a range of complex conditions."

"A more holistic view may be a better approach - what does the condition mean to the person - what does it stop them doing and so on? It doesn't treat people as individuals - a person who scores 7 points needs help yet gets nothing. A person who gets 11 points gets less than someone who gets 12 points and in the case of mobility prevents them getting access to a Motability vehicle. One of the main issues with points-based system is that it doesn't really tell you about the person - you are trying to fit in a myriad of people into boxes." – Individual

“A shift from the fixation on numerical distance walked, to a more person-centred approach of how someone moves (whether aided / assisted or independently and what the impact of moving around is on each individual) would yield a more accurate representation of someone’s level of disability.” - Neurological Alliance of Scotland

“Mobility isn’t just how far you can walk, it’s about the freedom to do things independently... A more holistic approach is need remembering not every person is the same. Mobility should be based on the individual person and their overall disability challenges” - National Carer Organisations

A few others suggest that a greater understanding of specific conditions by practitioners and case managers in Social Security Scotland will allow for a more accurate understanding of their needs in the application process. It was argued that a more flexible, individualised approach would avoid disparities caused by the universal application of an arbitrary points system. Event attendees highlighted the importance of assistance and advocacy if there was a switch to open questions, as some clients may not know what to include or how to best represent their condition.

In relation to the planning and following journeys activity, ENABLE Scotland explained how a holistic approach could be put into practice. They argue for a more binary approach to the planning and following journeys activity.

“An award for the standard rate could be made if the person can manage local journeys that are known to them but unable to manage journeys to unfamiliar areas. An award of the enhanced rate could be made for those unable to manage local journeys. This would mean that decision-makers/tribunals do not need to differentiate between planning/following a journey but instead could take a more holistic approach basing their decision on the impact of the claimant’s disability in carrying out all aspects of a journey. The exception to this would be an award of the enhanced element for those unable to use public transport even when assisted by another person/guide dog etc to a familiar or unfamiliar area. This exception would seek to protect those who would, in real terms have the highest transport costs as taxis/car use may be required as public transport is not an option.” – ENABLE Scotland

In responses to Q16, which considered alternatives to a points-based system, respondents gave examples of situations not currently considered, but that could be impacted by mobility. For instance, a joint response from three organisations noted the current exclusion of social interactions, household cleaning, and food shopping. A few suggested incorporating more information from the client’s perspective would allow a greater focus on what people need to participate fully in civic life.

“In our experience, people often use the benefit to pay for cleaners. This can be a key issue for people with mental health conditions and can also be a good indication of the severity of a condition. Hoarding can have an impact on people’s ability to access their kitchen, bathroom etc. but there is no scope for that within the criteria.” - The Action Group & VOCAL & Grapevine at Lothian Centre for Inclusive Living

Considering all impacts of mobility

A common overarching theme was a call to include a range of additional impacts reflecting clients' lived experiences of before, during and after moving around. Respondents suggested considering:

- The planning needed, both physical and mental, to prepare for moving around.
- Lingering physical and mental impacts, including pain and fatigue associated with moving around or journeys not going as planned, that can last for days, weeks or longer or have a delayed onset.
- That clients may need to pace themselves because the impact of moving could be long-lasting.
- People may avoid certain journeys to ensure they do not feel the impacts of those movements in the hours, days or weeks that follow.
- How often the distance can be repeated safely alongside everyday activities.

“It also focuses HEAVILY on physical ability rather than limitations set by pain. I can't move at all without being in pain, but I can still walk for miles - it just means I'm often in bed for a few days afterwards and I can't handle the other parts of my life. What would I put to indicate that?” – Individual

Others mentioned that consideration should be given to hidden disabilities where moving is possible, but the effect of moving can range from pain and fatigue to dizziness, breathlessness and abdominal pain. As noted in the introduction, this is an example of where it is unclear, whether participants were referring to these considerations based on their experiences of PIP or in response to clarifications to the ADP application guidance.

“The consultation document also notes that “whilst a person may be able to stand and move a few metres, they may not be able to achieve all the things they want to in life due to their mobility needs”. We agree that the moving around activity does not take account of the impact of walking the stated distance in terms of exertion or concentration, and the limits this may then place on their ability to partake of the activity to which they are journeying, or to enjoy activities later that same day because of consequent exhaustion.” – Law Society of Scotland

Criteria should reflect experiences of moving in the built and natural environments

Several respondents argued that the criteria judge movement in isolation from the reality of moving around and should consider the complexity of the circumstances people encounter when moving.

While the ADP criteria is currently identical to PIP, several suggested situations which should also be considered within the ADP criteria. These included:

- Walking on a gradient or slope, as well as on stairs and a variety of surfaces.
- How people move around their house functionally, i.e. they can walk to the kitchen, but cannot bend over to put things in the oven.

- The purpose of travel and subsequent difficulties faced at destination, such as the need for aids in both hands for long walks to bus stops or corner shops making use of hands impossible in the shop or destination impossible.
- The needs of those with hidden disabilities who may be unable to travel from home due to the availability of specialised supports and resources, such as toilets or resting places.
- Road closures or roadworks that complicate familiar journeys.
- Navigable access at destinations, such as ramps, lifts, and braille signs.
- Differences between rural and urban environments.
- Access to necessary community facilities, such as shops, schools and healthcare.
- Navigating environmental hazards like crowds or furniture.
- Weather.
- The impact of certain medicines on movement.

“The distance doesn't matter as much as the environment. Things that should be considered more are ability to walk uphill or downhill, taking stairs and other issues with moving around.” – Individual

Broader criteria

Some respondents provided examples of where they believed the criteria were too narrow. These included comments about the need to consider mental health conditions, conditions that require the surrender of a driving license, and conditions where movement in general is affected, not just mobility, such as getting from sitting to standing. Some suggested broadening the criteria to include the experiences of those with fluctuating conditions and mental health concerns would make the moving around activity criteria more inclusive.

Others suggested that the criteria include a wider range of aids, such as mobility suits, mobile phone map applications, while another suggested that the cost of some aids needed to move around should be considered.

Fluctuating conditions

Throughout the consultation, respondents commented on the lack of representation for people with fluctuating or variable conditions. This included consideration within the moving around activity as well as the planning and following journeys activity. In Chapter 4 we provide further analysis of responses to questions on the fluctuating conditions criteria, including the ‘50% rule’ and feedback on the ‘good’, ‘average’ and ‘bad day’ language.

However, in response to other consultation questions, it was often unclear if respondents were sharing their direct experiences of the moving around and planning and following journey criteria in relation to their condition, or making more general comments about the need for ADP to better support people with fluctuating conditions.

“Our view is that people with conditions that cause fatigue or chronic fatigue or conditions which are fluctuating like MS and epilepsy, cannot accurately answer the questions about the moving around element of the adult disability payment form. People with ME may well be able to walk 20 metres one day, but one of the features of ME is post-exertional malaise. This means that having walked 20 metres, someone with ME may well then be incapacitated for hours, weeks, or longer. Many people with progressive neurological conditions also suffer from constant fatigue which often worsens as the day goes on. This means that they may be able to walk 20 metres at the start of the day, but this would be impossible later on in the day. Furthermore, the moving around criteria is hard to define for conditions like epilepsy where mobility is affected by whether or not you have a seizure, but you are at risk of a seizure 100% of the time.” - Neurological Alliance of Scotland

Respondents frequently criticised the idea of an average day measurement as not representative of, or applicable to, specific conditions. A few respondents and some engagement event attendees argued that certain conditions, even if mobility is limited on one or two days a week, the limitations to mobility and the cost of aids and supports required on those days still need to be considered. Others pointed out that conditions like epilepsy or anxiety can affect mobility all the time.

3. The moving around activity

The moving around activity considers a person’s ability to stand and move specific distances without severe discomfort. While this considers movement on flat and outdoor surfaces, such as pavements and kerbs, it does not consider walking up slopes or stairs. The criteria consider how easily a person can stand and then move up to 20m, up to 50m, up to 200m and above 200m. Application guidance asks clients to consider factors that affect their experience of moving around. These include: how quickly a person can move; the risks of falling or injury; breathlessness, pain or fatigue; the way a person moves; and symptoms or side effects from moving around. Clients are scored on a 0-12 point scale depending on how far they can stand and move.

Respondents were asked to consider the clarity of the moving around activity criteria, to comment on evidence available about the activity, and to suggest changes to criteria.

The criteria for the moving around activity

1. Do you agree or disagree that the moving around activity criteria for Adult Disability Payment are easy to understand?

Base	n=	% Agree	% Disagree	% Don't know
All answering	100	35	50	15
- Individuals	68	41	46	13
- Organisations	32	22	59	19

1(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

Around eight out of 10 responded to Q1a. The most prevalent theme across comments was to consider the additional impacts of moving around alongside distance measures. Several argued the criteria are inappropriate for those with fluctuating conditions. As these are described in the previous chapter, we do not discuss this again in this section.

Clarity of the criteria

Clarifying the language or meaning of the criteria was the second most common theme, mentioned by many. Some stressed the importance of using examples, such as distances applied to real life scenarios or a specific number of steps, as clients could find it hard to imagine what walking the distances meant for their mobility and health.

A few consultation respondents and event attendees also suggested using videos. Others highlighted confusion around the wording on aided and unaided moving and indicated that the first part of the criteria measures only unaided movement, while the introduction of ‘aided’ in Criteria C creates further complexity. Some requested further clarity around specific factors that may inhibit movement to ensure consistent application of the criteria.

“This assessment has to consider the ability of an applicant to be able to move around ‘safely’, ‘to an acceptable standard’, ‘repeatedly’ and ‘within a reasonable time period’. The determination of how these factors affect a claimant’s ability to move around provides significant discretion in how a Social Security Scotland assessor understands and assesses a claimant’s individual ability to walk around which sets the conditions for disparity in decision-making assessments.” - Alzheimer Scotland

Positive comments about the criteria wording and other changes

Positive, supportive comments were provided by several respondents, two thirds of whom were individuals, about the criteria wording, the examples provided, and changes from PIP to ADP. Respondents described the criteria as straightforward, easy to understand, and clear, with one respondent stating the criteria benefitted from the added context provided.

“The way it was explained in the accompanying information seems clear. It's plain English and seems to try to explain more complicated questions clearly.” – Individual

Less commonly mentioned themes

- Each of the overarching themes described in Chapter 2 were mentioned by some respondents in relation to the moving around activity.
- The ‘20-metre rule’ was mentioned as unfair and limiting by some respondents. Their views are included and presented in the analysis of Q5 below.
- A few respondents mentioned specific points which are summarised in Appendix C.

1(b). How could we make the moving around activity criteria easier to understand?

Around two thirds answered Q1b. The most common theme was calls for a flexible, holistic approach to the application and decisions. There were also frequent requests for a clearer definition of mobility and better examples, to make the criteria easier to understand.

Clearer definition of mobility

The second most prevalent theme, raised by several, was that the criteria would benefit from a clearer definition of what moving means. A few respondents specifically requested clarity on the difference between ‘aided’ and ‘unaided’ movement. Respondents suggested using open questions that ask about movement, what people rely on to get around, and how people get around such as speed and with what aids. This was felt to help clients provide clarity or information than the current question allows. In contrast, a few respondents provided positive feedback on the clarity of the criteria.

Less commonly mentioned themes

The explanation for the distance measurement was described as confusing by some. There was support for including grounded, real-world examples, such as distances in relation to parked cars or buses, football pitches, length of a sofa or supermarket aisles. One respondent noted that older people might not think in metres, suggesting imperial measures also be included; another suggested making a video to provide examples. It

should be noted that a few of those raising this issue in Q1b later gave positive feedback on the example image now being used when presented with these in Q3.

Some called for greater consideration of the danger, fatigue and pain of moving around, as well as how reliably clients can move set distances consistently. A few acknowledged the change in the criteria, but others requested clarity about what levels of pain and fatigue are considered reasonable. An individual recommended changing the question wording that a person should be able to move around 'safely, confidently and without fear'.

Other themes raised in Q1b are summarised in Appendix C. These were primarily the overarching themes or points raised by a small number of respondents.

Evidence on the moving around activity

Research by the Scottish Government helped to inform the development of ADP and subsequent changes to the application and consultation. The research also provided greater understanding of issues with the moving around activity which are summarised in the consultation paper. Respondents were asked for their views on any additional issues.

2. Are there any other issues with the moving around activity that we have not captured above?

Base	n=	% Yes	% No	% Don't know
All answering	97	76	12	11
- Individuals	67	70	15	15
- Organisations	30	90	7	3

2(a). If you said 'yes' what other issues with the moving around activity do you think need to be considered?

Just over eight in 10 respondents answered Q2a. Reflecting the focus on improvements, the four most common issues raised were the overarching themes outlined in Chapter 2.

Improvements and considerations for the application process were suggested by some respondents. These included asking clients to keep a diary to provide greater detail on their mobility on a day-to-day basis, and providing independent advocacy services and advice to all clients. In response to Q2a, one anonymous respondent noted that there should still be an 'it varies' option, allowing people with fluctuating conditions to describe their experiences more accurately. Other suggestions included:

- SCoRRS (Scottish Campaign on Rights to Social Security) and Citizens Advice Scotland (CAS) called for transparency about the pros and cons of different assessment methods. They highlighted early evidence that remote assessment poses 'significant challenges to decision-making where direct observation and interaction with a claimant in person would be helpful'.

- CPAG in Scotland and a joint response from The Action Group & VOCAL & Grapevine at Lothian Centre for Inclusive Living asked for further clarification in the descriptors regarding movement that is aided and unaided in relation to case law¹.
- ENABLE Scotland called for an approach like the 'exceptional circumstances' regulation as part of the work capability assessment, which would treat a person as though they meet the required number of points.
- One Parent Families Scotland recommended using open ended questions to gather a better picture of individual experiences.

Suggestions to improve the application process were shared by some respondents. These included: reducing the length of the application, providing options for those who are unable to fill out the form, and considering alternatives options to address digital exclusion.

A few respondents endorsed the proposed changes, highlighting positive features such as support for the person-centred approach, or suggestions that practitioners receive further training. Some highlighted why this is important by giving past examples of where their supporting information had been dismissed or they were not listened to.

MS Society Scotland's Survey Tool Responses

The survey tool automatically populated Q2 as Yes for all respondents, followed by the question: "What issues have you experienced with the 20m rule and the ADP/PIP application process?"

Almost all those using the survey tool provided an answer to this question. The responses were included in the overall analysis of the question and while the question wording was different, many of the responses provided via the tool aligned with the views of those who responded to Q2a via Citizen Space. However, the prevalence of these themes varied. The most common themes in response to this question in the tool are summarised below:

Comments about fluctuating conditions: Given the variable nature of MS symptoms, there were frequent calls to clarify how the criteria consider and include clients who may be able to walk a certain distance one day but not the next.

Critique of distance measures: Many criticised the '20-metre rule' as limiting and unfair:

"I can walk 20 m sometimes, but that's all well and good, but I cannot guarantee to be able to get back. Therefore it means that I am, in reality restricted to 10m or less, particularly if I'm going to a shop and have to stand in a queue. The 20m is a farce." – Individual

Consider all aspects of mobility: Many noted the impact of moving could be felt for hours, days or weeks and called for this to be considered in the moving around criteria.

Personal experience: Several described their own circumstances or experiences at this question, either in relation to their previous applications or in relation to daily life.

¹ They cite: [2016] UKUT 326 (AAC), [2015] UKUT 612 (AAC), [2015] UKUT 529 (AAC), and [2016] UKUT 501 (AAC). These are instances where rulings have established different precedents in relation to the application and assessment procedures with PIP.

2 (b). In your view, what are the positive aspects of the moving around activity that we have not captured above?

Respondents were asked to reflect on the research on the proposed changes to the criteria for the moving around activity. Just under half provided an answer to this question. The most common theme, raised by several, was that there were no positive aspects.

“We acknowledge the Scottish Government have made an attempt to mitigate the impact of using these eligibility criteria by introducing changes to the application and assessment processes. However, these changes will have minimal impact as applicants are being assessed against the same criteria. If you can walk 25 metres, you still won't be eligible for the highest number of points regardless of the changes to the application and assessment process. Ultimately if you ask the same questions, you will receive the same answers and these answers are assessed using the same criteria as PIP.” - MS Society Scotland

While not directly answering the question, some respondents highlighted that fear of the system has a negative impact on the mental and physical wellbeing of clients. Reiterating a point raised in the consultation paper, a few suggested that the criteria may deter people from attempting physical movement that could improve their mental wellbeing or the symptoms of their condition, which was also reflected in event discussions. Two respondents commented on the importance of practitioner and case manager training in maintaining a sense of trust and respect with clients.

Rather than providing positive aspects of the criteria, other respondents typically reiterated the overarching themes, for example, some requested a more flexible approach that acknowledges the unique circumstances of each client or recognition that not every client will fit into specific boxes.

Improvements

While the eligibility criteria for the moving around activity have not changed, the Scottish Government has sought to make the application form guidance clearer. Examples of these changes include the use of examples, images and prompts to help clients understand the criteria and help practitioners and case managers better understand clients' experiences. Social Security Scotland has changed the guidance for people applying for ADP and for the case managers. These changes are intended to consider environmental, cultural and social factors more fairly and consistently when making decisions.

3. How effective do you think the moving around section of the application form is at helping us understand a person's mobility needs? Please give reasons for your answer

Base	n=	% Very effective	% Effective	% Somewhat	% Not very effective	% Not effective at all
All answering	94	7	22	40	16	14
- Individuals	65	11	28	40	9	12
- Organisations	29	0	10	41	31	17

Support for changes to the application guidance

The most common theme in open responses from the nine in 10 respondents who answered Q3 was appreciation of, and support for, the visual examples in the application form. Many felt the images provided a real life context to what may seem an abstract distance to some clients. A few said prompts could help clients to provide a holistic view of their condition; a small number of others commented that the changes mean the ADP form is a clear improvement over PIP due to the improved guidance and the use of images.

“Simply showing distances compared to the spaces in a car park is a very good means of helping people judge how far they can walk rather than giving a distance such as “200 metres” which probably means nothing to the person filling in the application form.” – Individual

“The prompts are also a good addition - things can be easily forgotten in the stress of completing these forms.” – Individual

Overarching themes

In comments on the application form, several suggested there should be broader criteria to consider moving safely, mental health, use of different aids, and life in rural and urban environments, and more space for clients to detail the wider impacts of moving around. Some also noted that experiences of variable or fluctuating conditions felt excluded from the question guidance.

Critique of the images

The lack of clarity in images was mentioned by several respondents. Some referred to the overall image quality, others criticised the car park image as lacking relevance to non-drivers or suggested an overhead perspective would be clearer. CAS noted that the car park examples confused some clients. Event attendees suggested creating a video.

Suggested changes to the questions

Examples were provided by several respondents of factors they would like added or changed in the application questions. A few suggested moving away from yes and no questions and allowing free space for open responses that could add nuance. A few others suggested using a more holistic approach to decision-making.

A few respondents highlighted the need for clarity in aspects of the question, such as rephrasing unspecific language like “some or all of these things’ or ‘this can be done by yourself or with help’ i.e. what does ‘with help’ mean.

“OPFS would ask that the wording of the questions be reviewed, and more emphasis be placed on allowing claimants to provide details of their condition and the effect this has on their mobility as individuals rather than them trying to fit their circumstances around fixed narrow descriptors.” – One Parent Families Scotland

Suggested changes to the application process

Concern about the application process was raised by some and reiterated at events. Comments included that the application form is long, intimidating and confusing. A few argued that the process causes anxiety and may put clients off completing the process.

“Length of application (the combined application is 100 pages long and the section on Moving around is from page 90 near the end). There is the risk that people will be too tired, lack awareness or not have the support needed to either complete the application form or provide the necessary additional information, beyond the space in the application form. There is also the risk that people won’t complete an application, due to the level of anxiety that is caused by going through this process and the risk to their mental health being too high. The application was regarded as not easy to complete for those with a learning disability or difficulty and would result in excessive pain and impact for someone with a chronic pain syndrome.” - Experts by Experience Panel of the Poverty and Inequality Commission (EPPIC)

Negative feedback on the changes

Some respondents provided negative feedback on the changes to the question guidance. These included a feeling that the questions do not adequately cover or apply to all conditions; one suggested imperial instead of metric measurements should be used.

The MS Society Scotland’s Survey Tool Responses

The survey tool asked respondents to answer the question: ‘How effective is the ‘20-metre rule’ as a way to judge mobility?’ While this populated the answer space for Q3 in Citizen Space, the question asks respondents to concentrate specifically on the 20-metre criteria rather than the changed guidance as a whole. For that reason, the most common themes were different to those raised by other respondents in Q3. Almost all respondents answered this question.

Negative feedback on the ‘20-metre rule’: Many answered the survey tool question directly, with the most common theme being the ineffectiveness of the ‘20-metre rule’. Many described the criteria as poor, unsuitable and unreliable for judging mobility.

Consideration of fluctuating conditions: The ‘20-metre rule’ was disliked by many for not considering those with variable or fluctuating conditions. They noted that there were days when clients could walk more than 20 metres and others where they could not. Some suggested consideration of ‘worst days’ or ‘bad days’ rather than ‘average days’.

Lived experience of moving around: Many highlighted that the 20-metre criteria does not consider the impact moving around has on clients. As outlined at the start of this chapter, this can include the physical and mental toll of moving around, the preparation required to move, and a reluctance to move when the impact of doing so is extreme.

4. What impact do you think the changes to how we make decisions on the moving around activity have on understanding a person’s mobility needs? Please give reasons for your answer

Base	n=	% Significant Positive	% Positive	% Neither	% Negative	% Significant Negative
All answering	87	15	45	32	6	2
- Individuals	62	19	45	27	5	3
- Organisations	25	4	44	44	8	0

Support for changes to the guidance

Of the eight in 10 who answered Q4, the most common theme was positive feedback on the changes to the ADP application guidance. Respondents thought the changes would lead to more accurate decisions, allowing clients to receive benefits that fit their needs and said a more individual approach was more understanding, fairer and truer to life. A few argued it would make the process less stressful than previous experiences with PIP.

“As someone who has experienced both the PIP and ADP approaches, the ADP process blows the PIP process out into the stratosphere in regard to being far more humane. I don’t feel like I’m being asked trick questions, even if some are still weirdly phrased. I also feel like I’m much more capable of getting in contact with Social Security Scotland for any reason at all, without being judged or put off by negative attitudes or stereotyping by any of the staff, assessors, case managers, etc.” – Individual

Support for changes to the consultation process

Several approved of the move from face-to-face assessments to only using a consultation with a practitioner when there is no other practicable way to understand a client’s needs. Reasons for support included: that it makes the process less stressful; reduces clients’ mistrust of previous assessment processes; and addresses concerns that some clients attending a DWP-style assessment were being informally assessed without being made aware of it. Conversely, one individual preferred consultations as they could be more accurate than knowledge provided by GPs.

“The changes to guidance for decision-making processes is welcome, particularly in relation to assessors making observations and assumptions outside of consultations. We agree observations should only be made during the official consultation and the applicant must be informed as to when this has begun.” - Sight Scotland & Sight Scotland Veterans

Gathering information from professionals

Several were in favour of gathering supporting information from professionals who support those applying for ADP. They highlighted that it would provide a more rounded picture of clients and allow contributions from professionals who understand the client’s situation clearly.

“We support the positive shift in guidance around the collection of further supporting information on an individual before a decision is made. Information from a GP or a support worker may work to provide a more well-rounded view of an individual’s needs. Additionally, the inclusion of equal consideration given to information from a person’s family, carers, or friends weighing into the application decision is a positive move to recognise the knowledge unpaid carers and family members may have about a person’s needs.” - Age Scotland

However, several respondents noted issues with ADP case managers gathering information to support the application, in particular, from health professionals. Some noted concerns about the quality and accuracy of notes from GPs or social care workers who may only see clients occasionally or know little about their specific conditions. It was also noted that some people choose to not interact with medical or care professionals and so would not be able to source supporting information to support their application.

“For chronic conditions many patients see GPs and doctors rarely. This can make providing info difficult.” - Individual

A few others requested that supporting information be sourced from professionals who may be more aware of the condition of those applying, such as third-sector groups that assist with care, nurses, clinicians, and specialists. ScoRRS and CAS highlighted a concern about the lack of clarity in the application form about process for gathering supporting information. Glasgow City Council also had concerns that gathering supporting information may lead to delays in awards.

Other themes

A concern that the changes still did not reflect the lived experiences of those with fluctuating or variable conditions was mentioned by several respondents, specifically the ‘average day’ language, although it was unclear whether they were referencing previous PIP guidance or ADP.

Less commonly mentioned themes detailed in Appendix C include:

- The need to wait until more data about decision-making is available.
- Concerns about the training and qualifications of practitioners.
- Concerns about the application and consultation process.
- Technical and accessibility issues with the digital portal or uploading material.

5. If there was an opportunity to change the moving around activity criteria, what changes would you make (if any)?

Respondents were also asked to suggest their own changes to the moving around activity criteria. After changes to the distance measures, the three next most common themes in changes proposed were the overarching themes in Chapter 2.

Proposed changes to the distance measures

The most common theme among the nine in 10 respondents who answered Q5 was a desire to change the distance measure in the moving around activity. These responses ranged from eliminating the 20-metre measurement in the criteria – the ‘20-metre rule’ - to not using any distance measures. Respondents who supported eliminating or changing the ‘20-metre rule’ argued 20 metres is an unrealistic and limiting distance and that those who move only 50 metres have a high degree of immobility and deserve and need the highest level of ADP support.

“I would change the distance criteria from 20m for the highest level of support to 50m for the highest level of support, in recognition of the fact that a person who can only walk 50m is experiencing an extremely high level of impairment with respect to mobility, and that 20m is not sufficient to accomplish anything beyond moving a little around the home.” – Individual

“More important than the cost of the ‘20-metre rule’ to the Government’s budget was the cost in independence enjoyed hitherto by disabled people. Far too many people in the MS community have lost out because of the ‘20-metre rule’. Since PIP began to replace DLA in 2013, around one in three people with MS moving over to this benefit have had their support downgraded, including one in ten who have lost support altogether” - Cross Party Group on MS

“The restrictive element of the ‘20-metre rule’ has caused unnecessary stress and in most cases, has exacerbated their PPS symptoms... The recommendation is to increase the distance to a more realistic 100-200 metres, or indeed to take away the requirement altogether.” – Scottish Post Polio Network

Those who supported eliminating all distance measures wanted a system that focuses on the qualitative aspects of movement, i.e., how people move, captured through open-ended questions and a flexible approach to criteria dependent on people’s real life experiences.

“I would make the question much more open. Instead of asking people to choose an arbitrary distance, I would ask them how far they can move around and let them describe it.” – Individual

A few noted that decisions made about entitlement to ADP, specifically the 20-metre criteria, impact the receipt of other benefits. This includes disrupted access to the Accessible Vehicles and Equipment Scheme and termination of receipt of the blue badge benefit.

Other themes

In addition to the overarching themes, several respondents provided specific considerations or suggestions to include in the criteria. Some argued input from GPs, carers or other healthcare providers should be included in the decision-making process. Other suggestions each made by a few respondents are detailed in Appendix C.

Agreement with the existing criteria was expressed by some. This included support for the clarity of the new criteria as well as support for the current distance measures.

5(a). If you proposed changes, what positive impacts could these have, and for who?

Among the three quarters who answered Q5a, many highlighted the positive impacts of the changes they suggested in Q5, while others noted groups they believed would be positively impacted. Not all respondents answered both parts of the question.

Positive impacts of suggested improvements

Several suggested that the changes would improve ADP clients' circumstances. This was most often related to receiving awards, but a few also suggested it would improve independence among clients. One individual mentioned it would allow clients to access help sooner, such as paid support, and another thought it would stop discouraging clients from exercising to improve physical and mental wellbeing.

The outcome of improved treatment of clients was highlighted in several responses. This included a view that clients would be treated with dignity, empathy, compassion and respect. A few felt that the improvements would create a less stressful application process.

Some noted their recommendations would benefit family and carers of disabled people, the larger community and society. Two individuals felt that improved decisions would put less pressure on their family and carers. Inclusion Scotland and the Neurological Alliance of Scotland suggested it would allow people to lead more independent lives.

“As a consequence more would find it easier to participate in family, social, community and economic life - including work. This would assist disabled people in living healthier, more fulfilling lives and assist our society in achieving greater equality and in reducing disabled people's economic inactivity.” – Inclusion Scotland

Positive impact on different groups

Several believed their recommended changes would positively impact those with fluctuating conditions as the decision-making process would be more inclusive, holistic and nuanced. This would allow clients with fluctuating conditions to explain their situation more thoroughly and lead to more successful awards.

People who have Crohn's and Colitis, Multiple Sclerosis, fibromyalgia, chronic pain, and Parkinson's Disease were each mentioned by a few as groups who would benefit. A small number of other respondents also referenced hidden disabilities but did not specify which.

Some respondents noted that people with mental health conditions would benefit from the suggested changes due to either improved decision-making or broader criteria that took mental health into consideration.

5(b). If you proposed changes, what negative impacts could these have, and for who?

Half of respondents answered Q5b. The most common theme was comments that the suggested changes would have no negative impacts to clients. Respondents making this point did not provide further details.

However, several respondents noted the suggested changes could have a negative impact on the Scottish Government's budget. Some believed this would be due to increased cost as more clients would receive higher awards. Some others suggested the increased costs would be due to the additional workload needed to implement a more nuanced decision-making process.

A few highlighted that case managers could make poor decisions due to more open or subjective decision-making processes. Scotland Versus Arthritis suggested this could be mitigated, however, by outlining questions in more detail and including prompts as to the types of supporting information needed. CPAG in Scotland noted that alterations to criteria may benefit some but disadvantage others as some who had received higher awards under previous criteria may receive less, and vice versa.

MS Society Scotland's Survey Tool Responses

The MS Society Scotland tool asked the question: 'If you could change or remove the 20m rule, what would you do?' While this most closely aligns with Q5, it differs by prompting respondents specifically about the 20-metre criteria. Almost all respondents answered this question.

The most common theme in response to this question was that the '20-metre rule' should be abolished. A few respondents suggested that it should be changed. Other responses matched the themes and prevalence of responses received via Citizen Space. The only difference was that more respondents answering via the survey tool highlighted the need to gather supporting information from GPs, carers, family members or other health professionals.

In place of Q5a, the tool asked: 'Who do you think would benefit from getting rid of the 20m rule?' Almost all respondents answered this question. The most common response noted that those with fluctuating and variable conditions would benefit most. The second most common these stated generally that applicants and clients of ADP would benefit. Many stated that people with MS would benefit from changes to the 20-metre criteria.

4. Planning and following journeys activity

This chapter analyses responses to questions about the planning and following journeys activity. This activity is relevant for people whose mobility is affected by mental health, cognitive and sensory impairments, and physical problems. Cognitive impairment includes orientation (understanding where, when and who the person is), attention (including awareness of risk and danger), concentration and memory.

Section 2 of the consultation asked respondents to consider the clarity of the planning and following journeys activity, to comment on feedback received about the criteria through previous research, and to explain any suggested changes to the planning and following journeys activity.

Recurring themes

In addition to the overarching themes described in Chapter 2, two further themes were raised repeatedly in responses about the planning and following journeys activity: the criteria language and expanding the definition of orientation aids.

Criteria language

Many respondents shared concerns about the language used in the planning and following journeys criteria and suggested changes. Comments included criticism of the term 'overwhelming psychological distress', which respondents found to be limiting, subjective and unclear, and suggested it should be defined, amended or removed. Similarly, several noted confusion about the meanings of 'orientation aids', 'planned', 'unplanned', 'familiar' and 'unfamiliar', while a few suggested 'journey' could be confusing. Respondents explained that unclearly defined or overly simplistic language makes it difficult for those responding to describe their experiences accurately and makes the job of the case managers and practitioners more subjective.

"The planning and following journeys criteria are overly simplistic and open to interpretation. One person's understanding of a 'journey' is different to another person's. It would be helpful to clearly define what is meant by a 'journey', a 'familiar journey' and an 'unfamiliar journey' and whether travelling part or all the way by public transport is part of a journey. 'Overwhelming' (psychological distress) is also subjective and open to interpretation. These criteria should be clarified." - Neurological Alliance of Scotland

CAS also noted that the criteria do not make clear that equal emphasis is given to the mental health impacts of planning and following a journey as to the sensory impacts. Stirling Council suggested improving language to include specific conditions like agoraphobia which the criteria may exclude.

Expand the definition of orientation aids

Throughout this section, some respondents requested that the definition of orientation aids include technology like satellite navigation tools and mobile phone map applications that respondents noted are crucial to their ability to move around. This was also raised in stakeholder events, where discussion included the importance of aids in getting around.

A few others also suggested that a family member or carers travelling for support should also be included as an aid regardless of whether they are acting in a supervisory role or providing another type of support.

The eligibility criteria

The eligibility criteria are used to consider how a person plans a journey, embarks on a journey, follows the route and deals with unexpected changes to the journey should they arise. Consideration is also given to the safety risks associated with the journey. Case managers will consider if the person needs prompting, supervision or assistance. Assistance can include another person, an assistance dog or a specialist orientation aid.

6. Do you agree or disagree that the planning and following journeys activity eligibility criteria are easy to understand?

Base	n=	% Agree	% Disagree	% Don't know
All answering	95	39	44	17
- Individuals	64	50	34	16
- Organisations	31	16	65	19

6(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

Eight in 10 respondents answered Q6a, expressing mixed views on the criteria.

The most common theme was a desire for clearer eligibility criteria wording, as outlined above. Conversely, the second most prevalent theme, also raised by many respondents, was that the criteria were easy to understand, though no further detail was given to explain why they were clear. A few noted that while they understood it, they still disliked the criteria, and a small number of others compared it favourably to the moving-around criteria.

Several respondents suggested other factors to include in the criteria, such as references to confusion and brain fog, a change in the points-based system, further consideration of activities that cannot be done unaccompanied, and the inclusion of safety risks.

While not directly related to the activity, some respondents provided a critique of the application layout and accessibility. A few were concerned the photographic examples only represented people with physical conditions. A small number of others highlighted problems with the form length, and one noted that they could not access the forms online.

Both overarching themes mentioned at this question and less commonly mentioned themes about the criteria are in Appendix D.

6(b). How could we make the planning and following journeys activity eligibility criteria easier to understand?

Just over half of respondents provided an answer to Q6b. The vast majority raised themes described elsewhere in this report. These include improved language clarity, more holistic decision-making, broadening the criteria to include conditions such as such as autism, cognitive impairment and dementia, and expanding the definition of orientation aids.

Other suggestions each raised by a small number of respondents included:

- To collaborate with stakeholders to develop criteria which reflect their experiences.
- Criteria that acknowledge the safety and risks associated with the journey.
- Make the criteria more inclusive of those with fluctuating conditions, such as variable mental health conditions or cognitive fatigue. The stakeholder events also highlighted sensory issues that can vary depending on external conditions, such as poor weather or changing daylight hours throughout the year.

“We are calling for the application process to be modified to encourage a greater understanding of its application to those with mental health conditions, framed in a manner that elicits a complete picture account of a claimant’s mobility needs, not of “good day”, “bad days” or even “average” days. Such modifications must be developed through a genuinely inclusive co-design process.” - CAS

Evidence on the planning and following journeys activity

Research collected by the Scottish Government notes previous opinions and positions held by stakeholders about the planning and following journeys criteria. These include suggestions that overwhelming psychological distress is an overly strict way to measure a person’s ability to plan and follow a journey, as well as critiques of the ‘planned’ and ‘unplanned’ journey language. The consultation paper describes this research.

7. Are there any other issues with the planning and following journeys activity that we have not captured above?

Base	n=	% Yes	% No	% Don’t know
All answering	91	55	23	22
- Individuals	60	45	25	30
- Organisations	31	74	19	6

7(a). If you said “yes”, what other issues with the planning and following journeys activity do you think need to be considered?

Further consideration of mental health

Around half of respondents answered Q7a, with the most common theme, suggested by several, being a need for greater consideration of mental health in relation to this activity. These comments often focused on clients’ experiences during the journey, such as

impacts on mental health if the journey does not go to plan, or anxiety related to specific types of journeys but not others. Crohn's & Colitis UK noted that a sudden need to use a toilet mid-journey might lead to heightened anxiety about leaving the house in the future.

Other specific considerations

Some suggested specific issues not already captured by the research including:

- Inclusion of safety or steadiness measures.
- Adjusting the points system to allow higher scores for the descriptors in the criteria.
- Support in the application that explains mental health conditions are also considered alongside physical or sensory conditions.

Beyond this, most other comments reflected the overarching themes, and included giving further consideration to the additional impacts of planning and making journeys, reflecting the realities of the built environment in the criteria, expanding the definition of orientation aids and taking a holistic approach to criteria and decision-making.

7(b). In your view, what are the positive aspects of the planning and following journeys activity that we have not captured above?

A quarter of respondents answered Q7b. The most common theme in their comments was that there were no additional positive aspects that had not been captured in the consultation paper. However, a few respondents were positive about the changes to the application process, including the inclusion of carer perspectives and the support options for those applying.

Improvements

The Scottish Government has made improvements to the application form for the planning and following journeys activity. The guidance now includes photographic examples and more detailed prompts for certain questions. Changes have also been made to the decision-making process. These include removing the Mental State Examination, ensuring people conducting consultations are practitioners with two years of experience and providing guidance for case managers that focuses on building a more holistic evaluation of the impact of a disability or condition on a person's ability to plan and follow a journey. For complete details of all changes, please refer to the consultation paper.

8. How effective do you think the planning and following journeys section of the application form is at helping us understand a person's ability to plan and follow journeys? Please give reasons for your answer

Base	n=	% Very effective	% Effective	% Somewhat	% Not very effective	% Not effective at all
All answering	87	10	22	41	22	5
- Individuals	61	13	26	44	15	2
- Organisations	26	4	12	35	38	12

Support for the application form

Two-thirds of respondents commented at Q8a. The most common theme, highlighted by many, was support for the effectiveness of the planning and following journeys section of the application form. Several noted that the ADP application form was clear, while a few noted it was an improvement on the PIP form. Some others suggested the form was more inclusive of those without physical disabilities and clearly spoke to those with mental health conditions. Clarity around the definitions of familiar and unfamiliar journeys was welcomed by some, and others liked the use of photographic examples. Some felt the application was compassionate and more representative of lived experiences.

“I’m relieved to read this. It’s much more representative of my daily struggles. It is so much more compassionate. Thank you.” – Individual

“The examples given of the difference between familiar and unfamiliar journeys are reasonably clear and useful if that distinction is to continue to be drawn. In addition, the prompt with a list of mental health conditions that may result in anxiety about travelling may help make clear to applicants that there are legitimate and understood reasons they would feel that way, although these could be supplemented with specific reasons people may feel anxious as outlined in our response to the previous question.” - Health and Social Care Alliance Scotland

Other themes

Most other comments aligned with the overarching and recurring themes described elsewhere in this report. In addition, a few respondents described the application form as inaccessible, specifically due to the length, and a few others called for access to advocacy and welfare rights assistance when completing the ADP application.

9. What impact do you think the changes to how we make decisions on the planning and following journeys activity have on understanding a person’s ability to plan and follow journeys? Please give reasons for your answer

Base	n=	% Significant Positive	% Positive	% Neither	% Negative	% Significant Negative
All answering	79	19	46	27	6	3
- Individuals	55	25	44	22	7	2
- Organisations	24	4	50	38	4	4

Support for removal of DWP-style assessments

Just over half of respondents gave an open comment at Q9. The most common themes were positive feedback about the removal of DWP-style assessments, and support for the decision to use professionally trained practitioners over assessors for ADP. A few caveated their support of the changes with further recommendations and suggested improvements, such as shortening the length of the application, and there was still a concern that while the application process may be more dignified, the criteria remained unchanged.

“Having someone who understands the condition is simply fair. Having suitably qualified people is a major step forward.” – Individual

“The changes to the criteria for planning and following journeys are welcome as evidenced in the consultation document. We welcome the removal of the mental state examination and where a review is necessary, for this will be conducted by a qualified professional. The application process is important in this regard as it must take a more holistic approach to the current UK Government Personal Independence Payment (PIP) application and ensure the principles of dignity and respect are upheld.” - Sight Scotland and Sight Scotland Veterans

Other positive feedback

Several respondents noted their approval of the new process, suggesting it is better, improved and “a good thing” compared to PIP. Some mentioned they found the application more inclusive and holistic, allowing case managers and practitioners to gain a well-rounded picture of those individuals applying. A few approved of the ability to include support from carers, family members and professionals. One anonymous individual suggested it was more understanding, and another noted their approval of the included photographic examples.

10. If there was an opportunity to change any specific aspects of the planning and following journeys activity, what changes would you make (if any)?

10(a). If you proposed changes, what positive impacts could these have, and for who?

10(b). If you proposed changes, what negative impacts could these have, and for who?

Six in 10 respondents answered Q10. The most common theme, proposed by several respondents, was a desire for a more flexible, person-centred approach to the application and review process. The recurring theme of clearer language was raised by some.

Other suggested changes

Specific suggestions were provided by some respondents, and these included: a desire to separate planning and execution aspects of journeys in the criteria; consideration of whether an individual can drive or if they depend on public transport; inclusion of more types of orientation aids; introduction of a discretionary “safety net” similar to that created in the Universal Credit Regulations 2013; and an extension of full points to an individual that requires prompting or companionship to undertake a journey.

A clearer consideration in the descriptors of those with mental health conditions was recommended by some. Respondents did not specify how they would adjust the criteria, though CAS suggested greater understanding could be achieved through reframing the discussion of mobility needs, moving away from the “good day”, “bad day”, and “average day” language. They also recommend that changes should be “developed through a genuinely inclusive co-design process”.

“Descriptors within the eligibility criteria continue to read as more relevant to an individual with physical disabilities. Wording or descriptors which better reflect the needs and challenges of individuals with mental health conditions and other impairments, including dementia, are encouraged. As alluded to, providing a clearer definition of “overwhelming psychological distress” could help with this.” - About Dementia, Age Scotland

Specific suggestions or comments, each raised by a few, are listed in Appendix D

Positive impacts

Just over one third of respondents answered Q10a, and just under one quarter Q10b. Several respondents stated there would be no negative impacts from their suggested changes but did not provide greater detail. Several others described the positive impacts of their proposed changes to the planning and following journeys activity. These included:

- An improvement to the wellbeing of those applying due to, for example, a more supportive, understanding, less bureaucratic process which reduces anxiety. Another respondent noted that their suggestion would limit the explanations those applying would have to provide, which can be upsetting.
- An easier application which provides greater clarity of language and a more manageable size.
- More supporting information being collected being data, which would help the client explain their conditions fully and allow case managers greater clarity in making an award.
- Improved outcomes for clients suggesting more would receive awards, or awards would be more fairly given. One individual suggested that Social Security Scotland could benefit from cost savings due to fewer appeals being lodged.

Respondents noted that their suggested changes would have positive impacts on specific groups. Some mentioned that those with mental health conditions would benefit, and a few others suggested improvements would benefit those with fluctuating conditions.

Respondents said the process would feel more supportive and inclusive for both groups and help clients receive a fairer award. Other groups mentioned included: neurodiverse people, those who cannot leave home, people with Crohn’s disease and ulcerative colitis, people with neurological conditions, and those whose conditions are unlikely to change.

Negative impacts

Few negative impacts were identified. A small number of respondents noted that the workload and costs for Social Security Scotland could increase due to amended application processes. A few others reiterated that any application process was overly bureaucratic and stressful for those applying, regardless of changes. One individual noted that those who can receive treatment which can improve the ability to plan journeys might feel penalised if the weighting of points for planning and execution of journeys are considered separately.

5. Support for people with fluctuating conditions

As many conditions fluctuate on a daily or weekly basis, the Scottish Government recognises that offering support for people with fluctuating conditions is relevant to the moving around and planning and following journeys activities. However, as noted in Chapter 2, respondents frequently expressed a view that the criteria for the two activities are not applicable to, or representative of, those with fluctuating conditions, specifically a person's ability to always walk more than 20 metres or consistently execute a journey.

This chapter presents an analysis of responses to questions which asked respondents to: consider the clarity of the fluctuating conditions criteria, including descriptors of previous activities being satisfied 50% of the time; comment on feedback received about fluctuating conditions through previous research; and suggest changes to the criteria.

The eligibility criteria

A Social Security Scotland case manager decides for each activity which of the descriptors apply to the person and, therefore, how many points they receive. A case manager should consider that a person's ability to carry out mobility activities may change daily and, as a result, a person may satisfy several different descriptors for an activity at different times. More detail on the descriptors is shown in a table in the consultation paper.

11. Do you agree or disagree that the criteria for fluctuating conditions is easy to understand?

Base	n=	% Agree	% Disagree	% Don't know
All answering	94	33	50	17
- Individuals	65	35	42	23
- Organisations	29	28	69	3

11(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

11(b). How could we make the fluctuating conditions criteria easier to understand?

Although Q11a and Q11b were analysed separately, respondents' answers to Q11b often addressed the issues they outlined at Q11a. Given this overlap, we have presented the analysis of the two questions together in the section below.

Clarity of criteria

Two thirds of respondents answered Q11a, and many commented on their difficulty understanding the criteria which they felt are unclear and overly complex. Respondents highlighted the formal, overly complicated language, including using fixed or confusing statements and the lack of examples or sufficiently detailed guidance. Some said clients would find it challenging to describe their fluctuating condition effectively using these

criteria. Glasgow Disability Alliance reported members felt the following text was “wordy, over-complicated and difficult to apply to their personal experience”:

“If they meet some criteria on different days that add up to more than half their days, they get the number of points they score on the most days. Or, if they meet different criteria for the same number of days, they get the criteria that scores the highest number of points”.

Some commented on the use of descriptors, noting either the term itself was disliked, or the inclusion of descriptors caused confusion. For instance, the language of the third descriptor – “If no descriptor is satisfied on over 50% of days, but two or more descriptors when added together amount to more than 50% of days” - was considered harder to understand, with calls for definitions of the words ‘descriptor’ and ‘satisfied’.

“If there is more than one ‘descriptor’, then why would it matter if the one with the highest score was considered? Surely both should be considered in their own right and given equal importance. What if there are more than two descriptors?” - Individual

Conversely, some individuals and organisations felt the criteria were clear, easy to understand, and comprehensive. A few noted that while clients may struggle to understand the criteria and accurately describe their situation, specialist workers would not have difficulty due to their regular engagement with the criteria. CPAG in Scotland recommended clients have access to a trained welfare rights specialist and independent advocacy, where appropriate, to provide advice on entitlement.

“These criteria are now much clearer, and suffering myself from fluctuating conditions, I believe that they make it much easier for judging a person's state of health and realising that not every day is the same.” - Individual

Calls to simplify or clarify the criteria was the most common theme among the half of respondents who answered Q11b. Several suggested specific changes to the application form, such as providing more examples, tables, embedded videos or illustrations and simplifying the wording. Respondents felt more explanation would be helpful, particularly around definitions of descriptors, fluctuations and points, and clarity around the conditional ‘if X then Y’ rules. Suggested text improvements included simplifying the syntax, avoiding jargon and using clear language, and clear labelling in tables.

“The criteria around fluctuating conditions need to be more explanatory and illustrative to reflect the variation of symptoms of different conditions and the various experiences of those with one or more fluctuating conditions.” - Alzheimer Scotland

Use of the 50% of the time criterion

The second most prevalent theme was comments from several respondents about the 50% of the time criterion – often referred to as the 50% rule. Respondents felt the criterion was not a useful measure. A range of difficulties were noted, including:

- Clients unable to accurately record their fluctuating symptoms, e.g., due to extremely regular fluctuations making it difficult to quantify into overall percentages or ill-health preventing recording.

- Lack of clarity for clients about what information to provide, for instance, when fluctuating conditions can impact them in various ways at different times.
- External factors such as seasonal variability (light, weather) impact fluctuations in conditions.

A few organisations reiterated their preference not to use the 50% rule; for instance, SAMH highlighted the complexity involved in its use:

“SAMH has longstanding concerns about the adoption of the 50% rule... Mental health conditions can fluctuate, both in the short and long term. As such, accurately quantifying the impact of a mental health condition on someone’s functional ability... over time against a strict 50% mathematical criteria is incredibly challenging. Indeed case law (Case No UK/972/2015) has found that in the case of comorbid conditions, mathematical probability theory may be needed to calculate whether someone satisfies the 50% rule.” - SAMH

A few individuals queried why the 50% rule was being applied, and Crohn's & Colitis UK felt ‘50% of days’ was unclear and requested clarification as to whether it meant 50% of days in a week, month or year. Only one respondent, an individual, expressed support for retaining this criterion.

For the reasons outlined above, the second most prevalent theme at Q11b was several calls for the removal of the 50% rule.

“The simplest way to make these criteria easier to understand would be to stop using arbitrary measures such as 50% of the time and to look at the frequency, severity and impact of symptoms as an alternative.” - MS Society Scotland

Some suggested tools to improve supporting information collection or gave views on decision-making. Two suggested using diaries to collect supporting information, though members of the EEPIC considered and then discounted this option because recorded diary information would quickly become outdated. They preferred a face-to-face consultation with an empathic person with active listening skills. A few respondents felt the client’s worst day should be the key determinant for an award.

Other aspects of the criteria to consider

The third prevalent theme, raised by some respondents, covered other aspects the criteria should address. Points raised included that: the current criteria are too narrow to capture the nuanced range of impacts on mobility; clients could be disadvantaged if unable to decide which descriptor best fitted their situation due to fluctuations in their condition; and the challenge of experiencing and describing fluctuating conditions, such as when multiple conditions exists or due to the unpredictable nature of their condition.

People First Scotland also highlighted that whilst a learning disability does not change over time, people who have learning disabilities are still affected by fluctuations in their lives, such as mental health, support available, weather, accessibility, and transport.

“It is also challenging to consider the descriptors where a claimant has more than one fluctuating condition that affects their ability to manage an activity. If you have more than one fluctuating condition and these affect your ability to manage a particular activity independently of each other, you may be affected on more than half of the days during the period considered, even if each condition only affects you on a minority of days. This complexity needs to be addressed.” Alzheimer Scotland

A few commented on how case managers applied the criteria should be considered:

“There are issues where a claimant may have multiple/overlapping fluctuating conditions, and an assessor has to make a judgement about which descriptor is best satisfied. This is open to interpretation and variability depending on an assessor’s knowledge and understanding of a particular condition/symptom, and there may be a greater likelihood of awarding a lower-scoring descriptor if there is more evidence to satisfy this... For example, this may be the case for claimants who experience dementia alongside other conditions such as Parkinson’s.” - Individual

Less commonly mentioned themes

A wide range of other comments were made at Q11a and Q11b by small numbers of respondents. For completeness, these are listed in Appendix E.

Evidence

12. Are there any other issues with the fluctuating conditions criteria that we have not captured above?

Base	n=	% Yes	% No	% Don't know
All answering	87	46	29	25
- Individuals	61	38	33	30
- Organisations	26	65	19	15

12(a). If you said “yes”, what other issues with the fluctuating conditions criteria do you think need to be considered?

Around half of respondents answered Q12a, citing a range of other considerations.

Use of ‘good day, bad day’ criteria

Several respondents commented on using the ‘good day, bad day’ criteria. Over half either felt it was impossible for clients to average their symptoms or that the worst day should be used for decision-making.

“It would be more effective for applicants to be asked to consider how they are on a bad day or worst day instead of trying to work out whether their condition negatively impacts them 50% of the time to understand the support they need.” - Neurological Alliance of Scotland

However, a few respondents commented positively on the proposals. Crohn's & Colitis UK welcomed the point around “not relying on the 50% marker”, whilst one individual felt account should be taken of both good and bad days and then determine an award based on the severity of disabilities. MACS also advocated this approach:

“Allowing clients to describe their best and worse days and the frequency of these is probably the best approach. A client needs to feel that they have every opportunity to describe their disability/health.” - Mobility and Access Committee

Unpredictability

Another prevalent theme, mentioned by some, was that the unpredictable nature of fluctuating conditions needs to be further considered. These comments highlighted that fluctuating symptoms could occur suddenly or vary in a day or that no two days are the same. Inclusion Scotland highlighted that the current descriptors are based on past experiences and argued past symptoms are not a useful predictor of future incidence. A few noted unpredictability can worsen if multiple conditions exist. One Parent Families Scotland and CAS highlighted difficulties forecasting the effectiveness of medication and treatment on a person's condition should also be considered.

Providing supporting information

Some mentioned difficulties in adequately recording, describing and assessing fluctuating conditions. It was felt clients themselves would experience difficulties in relaying their symptoms accurately. A few noted that clients would struggle to compare their symptoms to the eligibility criteria, whilst others highlighted psychological factors that could impact the client's ability to provide supporting information. Psychological issues could include clients downplaying the impact of their disabilities due to limited mobility becoming normalised in the person's daily life or wishing to avoid memories of negative experiences. Others highlighted that certain groups, such as people with autism spectrum disorder, could experience difficulties accurately describing their symptoms or feelings due to the nature of the condition.

“...with a fluctuating condition, it is difficult to admit to yourself or others just how much you are affected on bad days. You tend to try to say you're better than you really are because you're holding on to the fact you still have some better days.” - Individual

Less commonly mentioned themes

Some respondents highlighted certain groups they felt needed to be better considered - people who have fibromyalgia, Crohn's disease, arthritis, POTS (Postural Tachycardia Syndrome), auto-immune illnesses and people with multiple conditions were mentioned. A few suggested consideration should be given to including all conditions, with two noting those without a formal diagnosis can still experience severe impacts.

Appendix E details other points raised in Q12, including requests for changes to the application form, and the role of professionals in providing supporting information.

MS Society Scotland's Survey Tool Responses

89 respondents answered the survey tool's equivalent question to Q12a: "What are the issues with the way the ADP/PIP application process currently takes account of fluctuating conditions?"

The focus of many comments was highlighting the fluctuating nature of MS symptoms, alongside the view that these variations, as well as other fluctuating conditions, are not adequately reflected in the eligibility criteria for the mobility component. Respondents gave examples of challenges in using mobility aids, fatigue, relapses, experiences of living with multiple conditions and attending social events.

Other prevalent themes emerging from responses received via the tool aligned with those outlined above, specifically:

A critique of the '50% of the time' criterion which was felt to be inadequate or too simplistic to accurately capture fluctuations.

The need to consider the unpredictable nature of fluctuating conditions:

"It is narrow-minded and doesn't reflect the true reality of such conditions. It is contradictory as variable means constantly variable; it doesn't follow a timetable, so it makes it inaccurate and extremely unfair." - Individual

The use of good and bad days as a measurement which was described as a flawed and unfair way to measure the impact on someone's life. Concerns were expressed about what would happen if a good day was described or a client was having a good day during their consultation, sometimes based on past experiences:

"In my experience, as soon as I said I have a few good days, they took it as my MS can't be that bad." - Individual

12(b). In your view, what are the positive aspects of the fluctuating conditions criteria that we have not captured above?

Just over one quarter of respondents answered Q12b. The most prevalent theme, mentioned by some, was the merit of adopting a more flexible approach to understanding client needs. Some of these comments agreed the proposed approach was more flexible, whilst some others felt it was important to build a complete picture of the person, and this would be challenging if the 50% of the time rule were used. Respondents made calls for a more open-ended approach to allow clients to express themselves in their own way.

Other than the prevalent theme, responses covered a range of issues including both support for the changes and a view that there are no positive impacts. These are summarised in Appendix E.

Improvements

To address concerns, the Scottish Government has provided a legal definition of what it means to carry out an activity to an acceptable standard, and amended the definition of what it means to complete an activity safely. Further improvements to the application form include clear guidance on how the eligibility criteria is applied. This helps to support people in providing relevant information about how they feel after completing an activity.

Bespoke consultation durations have been introduced to allow fluctuating conditions to be properly considered. A consultation only covers the areas of the application which are relevant to the person and on which the case manager has requested further information to make a decision. Practitioners take the time necessary to fully understand the impacts of a disability and/or health condition on a person. Guidance is available for case managers to ensure that environmental, cultural and social factors are considered.

13. How effective do you think the fluctuating conditions section of the application form is at helping us understand the needs of people with fluctuating conditions? Please give reasons for your answer

Base	n=	% Very effective	% Effective	% Somewhat	% Not very effective	% Not effective at all
All answering	84	13	30	26	21	10
- Individuals	59	15	37	32	14	2
- Organisations	25	8	12	12	40	28

Just under two thirds provided a reason for their answer to Q13, and the most common themes in comments were improvements to, and positive aspects of, the application form.

Suggested improvements

Suggested improvements were made by several respondents. These included requests to amend or clarify the form, comments that the form does not capture fluctuating conditions well, and requests to consider multiple conditions. A key concern was for the form to allow sufficient space to adequately describe conditions, particularly for those with multiple conditions. A few, therefore, called for even more open text boxes.

“It is our understanding that there is not a fluctuating conditions ‘section’ of the application form; instead, someone is asked how often they need help for each activity. This may not be sufficient to gather the information needed for case managers to understand the needs of people with fluctuating conditions.” - The Action Group & VOCAL & Grapevine at Lothian Centre for Inclusive Living

Linked to the calls for greater clarity of the criteria, some suggested that more examples of how a condition can fluctuate would be useful. Alzheimer Scotland argued that examples could be broadened to include other groups, such as those with cognitive impairment or mental health conditions, to help clients understand how these are relevant.

Further singular suggestions raised by organisations are listed in Appendix E.

Positively rated features of the section

Several respondents gave positive feedback about the fluctuating conditions section. In these comments, respondents welcomed the broader range of conditions, found the contextual information helpful or felt it improved the previous form. Singular comments from individuals included that the examples covered the main situations clients were likely to experience, that it gave space for explanations, the form conveyed a sense the client was being listened to, and that the use of the pink bubbles was helpful.

“That is exactly the kind of information which can help someone to contextualise the overall effect of moving around.” - Individual

Factors that may impact client information

Some felt clients could not adequately describe their situation using the form or might downplay aspects, and that the complicated nature of demonstrating the impact of fluctuating conditions would adversely affect take-up. Respondents cited people with learning difficulties, cerebral palsy, attention difficulties or pain as likely to experience problems, and one organisation highlighted how seasonal changes might impact client statements.

14. Thinking about the changes we have made to how we make decisions about fluctuating conditions, what impact do you think this is having on understanding the impact of a person’s fluctuating conditions? Please give reasons for your answer.

Base	n=	% Significant Positive	% Positive	% Neither	% Negative	% Significant Negative
All answering	80	18	50	29	3	1
- Individuals	57	18	56	21	4	2
- Organisations	23	17	35	48	0	0

Around half of respondents answered Q14. Comments were largely optimistic; the few negative comments centred on a perception that insufficient data was available to make a judgement or a small number who challenged the criteria.

Staff training and knowledge

Several respondents emphasised that case managers and practitioners must thoroughly understand disabilities. However, negative reflections on previous experiences with the DWP’s PIP assessments were made by a few individuals. EEPIC welcomed case managers being advised to consider cultural, social and environmental factors and listen carefully, but felt more work was needed to improve the criteria or address legacy issues around trust. Crohn's & Colitis UK also welcomed the changes, but felt were more likely to result in a better client experience rather than directly improving staff’s knowledge and skills.

Improved client wellbeing

The second most mentioned theme, raised by several, was that any improvements which reduce stress and anxiety in clients are welcome. Respondents noted consultations could

be stressful for clients, and their emotions could easily be heightened, either by the process itself or by revisiting distressing symptoms. Putting people at ease, not rushing them, listening closely and believing clients were all considered helpful qualities of a practitioner during consultations.

More individualised approach

Several respondents supported the move towards a more individualised and holistic, all-encompassing approach to identify and understand people's circumstances. Comments included a practitioner discussion being helpful as clients could use their own words in their own time, that clients would better understand the process, and that focusing on impacts was helpful. A few cited the move away from face-to-face assessments as a positive development. The Scottish Association of Social Work also highlighted social workers are skilled at understanding the impact of conditions and that including social worker supporting information could reduce pressure on other professionals.

Flexibility within the consultation was considered helpful by some, such as only focusing on specific areas to avoid repetitive or unnecessary questions and prevent clients from retelling their story. However, Versus Arthritis warned against clients with curtailed consultations receiving limited or restricted awards. One organisation highlighted the similarities with tribunals, arguing for greater client support if such an approach were used:

“Generally, tribunals then limit themselves to questions on these activities saving the claimant having to answer questions which are not relevant. For this type of system to work, however, the claimant would need to have had good support to complete their application/understand the rules.” - ENABLE Scotland

Improved decision-making

Some commented on decision-making about fluctuating conditions, arguing that supporting information gathered through a more holistic decision-making process would lead to better decisions by case managers. However, it was noted:

“The litmus test would be the number of claims being made right the first time, which would result in an increase to the number of paper-based decisions and a reduction in challenges to a decision.” – Blesma

15. If there was an opportunity to change any specific aspects of the fluctuating conditions criteria, what changes would you make (if any)?

15(a). If you proposed changes, what positive impacts could these have, and for who?

15(b). If you proposed changes, what negative impacts could these have, and for who?

Just over half of respondents commented on Q15. The main themes that emerged were comments on the measurement of good and bad days and for the 50% rule to be replaced with a more flexible, person-centred approach.

Good days, bad days criteria

Several respondents commented on the measurement of good and bad days. Most frequently, respondents felt that decisions should be based on a person's worst day rather than good days. Doing so would simplify the process and make it easier for people to describe compared to trying to measure and record their fluctuating conditions.

Two noted clients might downplay the truth if asked about good days. A small number in this theme preferred a more holistic approach rather than this measure. The Scottish Association of Social Work suggested an enhanced person-centred approach could be achieved by creating an accurate measure of how people are impacted on their worst day and comparing it to their better days. They suggested social workers could become more involved in the application and decision-making processes given their expertise in people's social and interpersonal needs.

"This would not only build foundations to a more understanding and person-centred system but allows for a social model within the assessment as opposed to the current medical model." - Scottish Association of Social Work

More person-centred

Several respondents commented on the need for a person-centred approach that, in the words of Glasgow Disability Alliance, "trusts disabled people as the experts in their own lives". Most felt the existing measures should be replaced with an approach based on the impact limited mobility could have on a person's life, rather than the movement or journey in itself. For instance, one individual highlighted that if someone were bedridden for three days a week, they would not qualify, despite having a considerable impact on their lives. They argued allowing discretion in such cases would create a more person-centred approach.

"As an example, if a person is impacted less than 50% of the time, but a Motability car would allow them to get out, maintain a job etc. Perhaps this can be considered as some form of exception processing where the benefits to a person and society are justifiable." – Individual

Other themes

Respondents' comments ranged widely in answer to this question. Some requested greater use of open questions, some for more listening to clients and those who know them well, and some requested a greater understanding of conditions among staff. A small number felt the impact of the process, the interplay between mental health and conditions or the impact of having multiple conditions should be further considered.

Positive impacts

Around a third of respondents answered Q15a. Several highlighted how their suggested changes would positively impact those with fluctuating conditions. They described improved client outcomes from introducing a more person-centred approach, including a more stable income, a more supportive and understanding approach, and more people receiving awards or higher rate awards. A few suggested that income stability would

benefit a client's quality of life in other ways, such as being more independent and able to participate in society and improving wellbeing. Some respondents took a wider view and felt all clients would benefit from a more holistic approach, as this would help build a more understanding culture, build trust in the system and reduce client stress. A few noted more people might receive awards, or more higher rate awards could be made.

"To tackle legacy issues, it is important to build trust with disabled people, including evidencing a positive change in Adult Disability Payment." - EEPIC

A few respondents also felt the changes should improve decision-making which could result in more people receiving awards, with greater accuracy in awards made the first time, and a reduced number of appeals. One respondent noted that the ability to make discretionary awards would increase flexibility by extending options for decision-makers.

"The move to a more detailed, holistic assessment approach will have a range of positive impacts. Initially, these impacts will improve the decision-making process, which will help people develop trust in Social Security Scotland and support the stated aims for treating people with dignity, fairness and respect." - MS Society Scotland

Negative impacts

Around a quarter of respondents answered question Q15b. Half stated that no negative impacts would arise from their suggested changes. Some noted that their changes might lead to increased financial expenditure or workloads for staff. For instance, a person-centred process might be more time-consuming to complete. However, MS Society Scotland felt this would be offset by improved decision-making. Some highlighted negative impacts could occur if case managers were insufficiently trained or adopted poor practices.

MS Society Scotland's Survey Tool Responses

The MS Society Scotland tool asked the question: 'How could the ADP/PIP application process take into account your fluctuating symptoms?'. Around three quarters of those using the tool responded.

Respondents were more likely than those responding via Citizen Space to identify the need to involve other professionals. Several felt GPs should be more involved in providing information about a client's condition, but other suggestions included MS nurses and specialists, physiotherapists and occupational therapists.

Another prevalent theme was the need for better recognition of the lifelong nature of certain fluctuating conditions such as MS. Some raising this issue therefore argued that fluctuations should not be used as a measure or to have greater recognition of, or research into, fluctuating conditions.

6. Other considerations

The final section of the consultation asked respondents to consider alternative approaches to a points-based system, how the independent review can ensure its recommendations are deliverable, and the impact of any changes on passporting benefits.

Alternative approaches

16. If there was an opportunity to consider alternative approaches to a points-based system to understand disabled people's needs, what alternatives would you propose (if any)?

Almost one third of respondents answered this question. The three most common themes all focused on the need for a more holistic approach to ADP. Most common were the overarching themes of a more flexible, person-centred approach, and making sure that the criteria reflect real life; these are described in Chapter 2 and not repeated here. Another prevalent theme was adopting a social rather than medical model of disability.

Adopting a social model of disability

Several respondents advocated a move away from a medical model of disability that had underpinned the previous system to a social model. Respondents felt moving away from this narrow approach was necessary to help facilitate a more rights-based approach in Scotland, as it would incorporate social and environmental factors. For instance, a few highlighted the application process could feel like a test to determine disability levels leading to fears of a person seeming too able.

Respondents argued that adopting a social model focused on treating people with compassion and respect would allow the client to describe their mobility in their terms and more fully incorporate relevant factors. It was felt the focus should be on addressing any barriers to mobility to enable people to live meaningful and independent lives. MS Society Scotland noted a Scandinavian approach that supports people to meet additional costs associated with their disability. Similarly, CAS argued a vital feature of a human rights approach would ensure adequate financial support to offset such costs.

“It would also move away from a deficit model towards assessing the support that people may need to achieve the best possible quality of life across a range of parameters that are most relevant for them, rather than those defined by non-disabled people designing assessments.” Parkinson's UK Scotland.

Comments on the application process

Several respondents requested changes to the application process, mainly related to the use of a form, with a small number referencing broader issues. It was felt the points system might disadvantage those who complete the application form independently, e.g. individuals may fail to understand the descriptors and entitlement criteria or feel unable to describe themselves adequately in the boxes provided. Conversely, Inclusion Scotland believed many welfare rights workers liked the points-based system because they understood how to word the application to maximise points. A few argued against using a

form, as it could cause negative emotions. Suggested alternatives were to make the application process more visual or discussion based.

“I have friends who are dyslexic who would absolutely hate this approach, and I’ve seen someone reduced to tears having to fill out a two page form for a gym membership. But they expressed themselves visually quite well, and I imagine the option to supplement with videos and pictures would go a long way, even if there would need to be a fair bit of work done to set a standard for a review process for something like that.” - Individual

Other comments on the application process included the need to ensure equity of access e.g. by auditing award decisions regularly, minimising bias, having sub-scores which contribute to an overall score for each ADP category and the need to ensure joined-up information systems to avoid clients having to retell their story multiple times.

Another issue mentioned by some respondents was the emotional impact of applying for benefits, such as anxiety or frustration. They suggested a points system could compound this, for instance, when someone just falls short of receiving the required points for an award. Similarly, a small number argued the previous system had focused on reducing social security expenditure, and clients remained fearful this was the key driver for decision-making rather than a person’s needs.

Some suggested using alternative approaches to a points-based system to determine awards. These included using medical or other professional supporting information, passporting from Disability Living Allowance and a qualitative client personal statement.

Less commonly mentioned themes

Some suggested specific alternatives to the points system. Over half suggested using a sliding scale rather than points depending on the severity of the client’s disability. Comments varied as to how best to do this. For instance, the scale could be descriptive, e.g. not at all, sometimes, all the time, or more quantitative, e.g. high to low. Other specific suggestions included using a Lived Experience Panel to review anonymous applications.

Other themes detailed in Appendix F include:

- Some who highlighted the importance of taking a system-wide perspective.
- Examining examples of best practice from elsewhere.
- A few commented that indefinite awards should be made in relevant cases.

16(a). If you proposed changes, what positive impacts could these have, and for who?

This question was answered by one third of respondents. Some reiterated their support for a holistic and person-centred approach, arguing that adopting a human rights-based approach would have positive benefits for both individuals and society.

The most prevalent theme was the benefit to disabled people’s wellbeing. Some felt this would occur through increased trust in the system, reducing stress and anxiety during consultations. A more conversational approach could also help put people at ease.

“If we let go of this basic assumption that we can put people in boxes, rather acknowledging the uniqueness of our individual needs and then opening up the possibility of our being able to enrich our communities. This could be a direct result of our energy not being used up in preparing for and then completing forms that have previously been degrading. It also means using less pain medication saving that cost. When I talk about my experience it outrages people. If we work to improve things surely that benefits us all.” - Individual

A few highlighted longer-term health and wellbeing benefits arising from people living more actively such as are improved physical and mental wellbeing, a reduction in poverty, remaining in employment and the ability to live more independently.

Specific groups who would benefit were mentioned by some, including people with long-term, rare and specific conditions, those who are neurodiverse and those with learning or severe disabilities. Multiple Sclerosis and Parkinson’s Disease were explicitly mentioned. Two noted people with hidden disabilities would benefit, such as people with ME.

Some felt that in redesigning a more holistic, person-centred system, all disabled people would benefit. Two respondents reflected that a more flexible approach could help remove rigid lines between qualifying or not. ENABLE Scotland suggested discretion could be used to make awards for those who might not fit within existing parameters.

16(b). If you proposed changes, what negative impacts could these have, and for who?

The prevalent theme among the quarter who answered Q16b was that some respondents did not perceive any negative impacts from their proposed changes. However, the second most prevalent theme was a negative impact on clients when applying. Comments centred around the likelihood of the process being more time-consuming or overwhelming if more qualitative supporting information is required or if accessible formats are unavailable. A less commonly mentioned theme was that negative impacts could arise from using more qualitative data collection methods. For instance, fraudulent applications or manipulation by articulate people or more significant potential for inconsistencies in decision-making.

Glasgow City Council argued that whilst the system may ‘look’ more complicated, the complexity of the benefits system should not be a reason to avoid making changes. They believed rationalising age-related benefits into a single lifetime benefit could aid simplicity. The same criteria could apply across all three benefits, with slightly different rules initially for children and then older people.

A small number highlighted the potential for increased workloads, which could be more intensive initially. For instance, ENABLE Scotland felt a provision for exceptional circumstances could be open to a high level of interpretation and subject to challenge, but this would ease as case law and experience progressed. Two mentioned workload issues that would be ongoing. One suggested case managers would have more work reviewing less standardised information or a greater volume of supporting information.

16(c). If you proposed changes, which of these would you prioritise?

Addressing barriers to participation

Of the quarter of respondents answering this question, the most prevalent theme raised by some was the need to address barriers disabled people faced when engaging with the social security system. Some respondents noted the need to address obstacles when applying for or making awards. The negative impact of the existing system on client wellbeing was highlighted; for instance, a perceived need to mask abilities or the disappointment experienced when awards were not made. Changes to build trust in the system and avoid loss of entitlement were therefore considered a priority by some.

Similarly, the second most prevalent theme was that some felt the independent review should prioritise ensuring the system is fair and equitable for disabled people. One individual articulated that being disabled was challenging enough, and case managers should listen with empathy.

Many other suggestions to overcome barriers, all of which have been addressed elsewhere in this report, are noted in Appendix F for completeness.

Other priorities

Some felt that a priority should be revising the ADP application form to: fully capture the impact of mobility issues and accommodate a broader range of conditions; ensure greater accessibility, e.g. someone explaining to the client what the questions meant or offering alternative formats; and to ensure it treats people with dignity, fairness and respect.

A small number mentioned other priorities are outlined in Appendix F.

17. Other than changes to the eligibility criteria, are there any changes you think we could make to Adult Disability Payment to support people's mobility needs (if any)?

Over two thirds of the 52 respondents who answered this question shared comments on making the system more compassionate, enabling and supportive for disabled people.

The prevalent theme, mentioned by some, covered the decision-making approach, mainly that case managers should receive sufficient training to understand different disabilities. Other comments included a call for a shift to using different sources of supporting information, e.g. from unpaid carers and health and social care professionals, whilst two, including ScoRRS, preferred to reduce the use and scope of consultations.

“Mental health is not black and white. It is such a vast medical subject and totally under-resourced that unless the assessor is mental health trained it is not a fair assessment. OT and physio assessors should only cover physical cases with mild mental health conditions.” - Individual

The gap between ADP financial awards and the costs incurred by clients due to mobility issues was identified by some respondents. There was also a call for greater flexibility in

how awards are made to accommodate individual needs such as to make a contribution towards equipment or travel costs, or to enable clients to top up their payments.

Some respondents raised the need to consider independent support and advice to clients, with independent advocacy mentioned most frequently. Multiple singular points were shared on this issue which are summarised in Appendix F.

Calls for the system to improve to minimise the distress during the application process were shared by some respondents, who used words to describe the existing process such as 'difficult', 'tortuous' and 'dread'. Two noted delays could cause stress, such as lengthy telephone waits or delays in awards. ScoRRS referred to Section 1 of the Care Act 2014 governing England and Wales which places a duty on local authorities to promote the wellbeing of clients during the assessment process, but did not explain further.

Less commonly raised themes, noted in Appendix F, included: calls for spot checks or an audit of decisions to maintain quality; a need to address delays in the system; suggested changes to the application form; and requests to co-design the criteria with clients.

17(a). If you proposed changes, what positive impacts could these have, and for who?

17(b). If you proposed changes, what negative impacts could these have, and for who?

17(c). If you proposed changes, how would you prioritise these?

Two main themes emerged on potential positive impacts based on 32 responses to Q17a. Some felt no adverse impacts would arise from suggested changes. However, a less commonly mentioned theme was that they could create a more positive experience for the client navigating the benefits system. Respondents suggested changes might reduce the need for appeals or reduce client financial hardship due to addressing delays.

Fewer than one in twenty respondents answered Q17b. Again, some felt there would be no adverse impacts, while a less common theme was that suggested changes could have workload or financial implications for Social Security Scotland. Two felt there might be more applications or improved ADP take-up; another thought it may take time to allocate cases to a practitioner leading to a longer wait for the client.

No consensus was identified across 17 responses to Q17c. Many singular suggestions were raised, all of which are covered elsewhere in this report.

Deliverability of recommendations

18. How can the independent review ensure that any recommendations it makes are both deliverable and affordable?

An equitable, human rights approach

Over a quarter of respondents answered Q18. The most common theme was prioritising a human rights approach, ensuring fairness and equity in the system and the benefits this could bring. Respondents called for an adequate budget, used equitably, to be allocated to achieve this. Some highlighted the Scottish Government should expect costs to increase in

a system based on human rights. A small number noted disabled people are more likely to live in poverty and that offering sufficient financial assistance could help address this.

"While we recognise the financial limitations the Scottish Government is operating under, we believe decisions on social security should be made on a people-centred, human rights basis. Social security should be there to support people in need and enhance dignity. Cost considerations must be balanced with the intent behind policy decisions to lift people out of poverty and help people who face associated costs due to disability or an unpaid caring role." - Age Scotland

Financial planning

Financial considerations were noted by several and mentioned in the stakeholder event discussions. The main emphasis was to ensure sound financial planning – identifying needs, forecasting costs, and determining the required budget. A few felt financial management could be improved, with the independent review having a role in scrutinising budgets. Other suggestions included allowing client contributions as part of an option to buy a vehicle or cost savings from making lifelong awards and reducing fraud. One respondent reiterated the Scottish Government's commitment to covering additional expenditure arising from more awards being granted under wider eligibility criteria.

Streamline services

Several argued the system could be streamlined, particularly by moving to indefinite awards for those whose condition is unlikely to improve; this was also mentioned in the event discussions. Others felt minimising fraud, better planning or management, or quicker processing rates could improve deliverability. One individual felt the independent review should develop a detailed plan and realistic timetable, with funding guaranteed.

Improved practice and decision-making

Several highlighted the need to improve decision-making and the use of supporting information for decisions. They argued there would be fewer appeals if the right questions were asked and better decisions made the first time. Cerebral Palsy Scotland noted case managers could only notice vital information if they understood relevant conditions well.

A number of suggestions for improved use of supporting information were made by very small numbers. These are detailed in Appendix F.

Broader social security system issues

Some highlighted the need to ensure affordability considerations do not constrain aspirations for social security in Scotland. The Health and Social Care Alliance Scotland stressed the importance of viewing social security as part of a whole government approach, while Parkinson's UK Scotland felt that as one of the Scottish Government's flagship programmes, the social security system provided a significant opportunity to improve people's lives and should not limit itself to an inherited 'broken' system. Half of the respondents mentioning this theme explicitly endorsed the recommendation of the Disability and Carer Benefits Expert Advisory Group that a reduction in expenditure should not be the purpose of this consultation and subsequent review. More detail on this theme is provided in Appendix F.

"Careful consideration should be given to how to best raise and maximise the revenues available for public services... We recognise that a comprehensive social security system must be adequately funded and would encourage the Scottish Government to approach budgets and revenue raising from the perspective of what services will promote wellbeing and human rights in society, rather than what level of taxation may be seen as "appropriate" and only then fitting public service provision to that arbitrary level." - Health and Social Care Alliance

Less commonly mentioned themes

A few specific comments about co-design and transparency were made by small numbers. These are detailed in Appendix F.

Considering the impact of recommendations on reserved benefits and entitlements – “passporting”

Disabled people receiving a specific rate of PIP or ADP may be entitled or passported to other means-tested benefits retained by the UK Government, including Universal Credit, Employment and Support Allowance and Housing Benefit. Changes to devolved benefits, such as widening the ADP eligibility criteria, could financially impact people receiving passported benefits. The Scottish Government wishes to ensure changes to ADP do not disadvantage or create barriers to receiving passported payments and is seeking views on what the independent review should consider about passporting issues.

19. How can the independent review consider the impact of any recommendations on existing “passporting” arrangements?

Just under a quarter of respondents answered Q19. While responses from organisations provided detail, answers from some individuals did not directly address the question.

Joint working between the Scottish and UK Governments

The most prevalent theme was calls for the Scottish Government to work in partnership with the DWP to ensure a smooth transition to a new Scottish social security system. Some felt this should be prioritised and start at the earliest opportunity. Respondents highlighted this would facilitate a more rights-based approach as it would allow the new system to be built on foundations of dignity, fairness and respect. Such work could involve:

- Undertaking impact analysis on potential options to aid decision-making.
- Social Security Scotland supporting transitioning clients to inform appropriate agencies and receive associated passporting benefits.
- Addressing issues anticipated from changes e.g., potential passporting issues caused by using entitlement to ADP to determine qualification for the health element of ESA and Universal Credit.
- Maintaining existing passporting arrangements whilst a new system is introduced e.g., to allow for renegotiation of contracts such as with the AVE Scheme.

Not being constrained by passporting arrangements

The second most common theme was that the independent review should not be constrained by passporting considerations when determining the criteria for devolved benefits, including ADP. There were calls for the Scottish Government to maximise its responsibilities for devolved social security benefits, ensuring it recognises and responds to the specific needs of Scotland's population.

"Consideration around the impact on passporting arrangements must start from a position of refusing to limit the ambition to deliver leading, transformative disability assistance in Scotland." - ScoRRS

Two respondents suggested that any decisions by the independent review to broaden the mobility component criteria should be based on need rather than being driven by financial considerations. EEPIC and one individual called for a distinct system in Scotland, whereby Scottish clients would not be dependent on passported benefits.

Impact on specific benefits

Another recurring theme was how changes to the ADP eligibility criteria could impact specific passporting benefits. These comments are detailed in Appendix F.

Financial implications

Some respondents commented on the financial implications of the proposals. Comments included the potential financial impact of changes to UK legislation and that the proposals would have little impact if criteria remained similar, as client numbers would be similar. A few argued clients should not have to re-apply for passported benefits:

"Any move away from automatic passporting would have a negative impact on take up of the passport reserved benefit. If claimants in Scotland need to undertake an additional assessment to be eligible for reserved benefits... this is unlikely to be in the best interest of claimants. Furthermore since presumably the cost of an alternative assessment process would fall on the Scottish government, this is also unlikely to be cost effective." - CPAG in Scotland

There were also calls for the independent review to address the needs of the population rather than focus on financial factors. Respondents argued that if that led to an increase in awards, then the Scottish Government should have further discussions with the UK Government over passporting benefits. Conversely, two argued that more independence for clients could lead to cost savings in health and social care, linked to lower staff hours for example, which should be considered when evaluating cost.

Support for passporting

Some participants explicitly supported passporting arrangements and felt these should continue. However, many others assumed that passporting is continuing and implicitly supported this in their comments.

19(a). How much of a priority to you is maintaining the current “passporting” arrangement?

19(b). Please explain why you chose this answer.

Base	n=	% Very high	% High	% Medium	% Low	% Very low
All answering	66	50	23	14	9	5
- Individuals	44	39	25	16	14	7
- Organisations	22	73	18	9	0	0

Just under a quarter gave reasons for their answer to Q19, though a third of these, mostly from individuals, did not directly address the question. The main reasons for high or very high priority ratings were not only to minimise the disruption for clients, but to enhance their quality of life. Other themes covered the need to work with DWP, information provision and the benefits of an improved approach.

The most prevalent theme, raised by several, was that changes should not disrupt or adversely affect clients i.e., clients should retain their existing entitlements regardless of any changes made to ADP, and none should become worse off. A small number highlighted many disabled people already found it challenging to navigate the system:

“Applying for social security has historically been a long and often challenging process, requiring people to large amounts of their personal life and speak about instances in their daily life when they are vulnerable. It is vital that people don't lose out on access to other payments, even if the changes to ADP mean a greater number of those in receipt of payments which would undoubtedly have a knock-on effect on other payments.” - Sight Scotland and Sight Scotland Veterans

The value of passporting arrangements in maintaining client wellbeing and a meaningful life was the second most prevalent reason given by some for prioritising passporting arrangements. These comments focused on the improved client quality of life that comes from maximising benefit take-up through automatic passporting, for instance, more secure or adequate incomes and better health and wellbeing. However, some also felt that maintaining passporting arrangements would reduce client stress and anxiety that might occur as a result of changes, especially those requiring a client to reapply.

Some respondents felt the existing system should be maintained or improved to aid the client journey, for instance, by retaining more compassionate criteria and decision-making processes, reducing waiting times and bureaucracy. Keeping the system simple and clear for clients was also highlighted by some respondents to ensure clients are given timely information about their benefit entitlements. RNIB specified this could include giving clients information about their awards, any changes and any action they may need to take.

Very few of the several respondents who rated maintaining passporting as a medium or low priority elaborated on why they felt this way. Most of those who commented indicated that they did not receive passporting benefits, or that they were not essential to them.

7. Conclusions

Many individuals and stakeholders with detailed knowledge and lived experience took part in this consultation, providing their opinions and insight on various aspects of the ADP mobility component. Their views will assist the independent review and the Scottish Government in deciding and delivering on further improvements to ADP. This report summarises the consultation responses; for more detail, [see individual responses](#) where permission was given for publication.

Respondents consistently highlighted their desire to see an application and decision-making process which takes a holistic, person-centred approach to understanding an individual's circumstances and needs. Several overarching themes were seen as vital in achieving this aim, including: ensuring all impacts of mobility are considered, that the criteria reflect the reality of moving around, broadening the criteria and ensuring the process adequately supports those with fluctuating conditions.

While these broad themes were raised throughout the consultation, specific constructive suggestions were also shared. There were calls for greater clarity of the language used across all the ADP eligibility criteria. Many argued for more opportunities to provide further information and add nuance to explanations of their condition and its impacts.

Respondents frequently argued that the '20-metre rule', or any use of distance measures, should be reformed or eliminated from the moving around activity criteria, and replaced with a focus on the quality and wider impacts of movement.

Many highlighted concerns about the wording of the planning and following journeys criteria and suggested making it easier to understand. In particular, respondents found the term 'overwhelming psychological distress' to be limiting, subjective and unclear and suggested it should be defined, amended or removed.

The 50% rule was frequently criticised as an unfair and inappropriate way to measure the impact of fluctuating conditions, as it is often impossible for clients to average their symptoms. This resulted in calls to remove the 50% rule or use a 'worst day' measure for decision-making. Respondents broadly welcomed the move to more flexible consultations with a practitioner only when there is no other way to understand a person's needs, and approved of gathering information from professionals.

Several advocated moving from a medical model of disability to a social model, helping to facilitate a more rights-based approach and improving clients' wellbeing through increased trust in the system. Respondents called for an adequate budget to be allocated to achieve this. There were also calls to ensure no clients lose existing entitlements to passported benefits and that the independent review should not be constrained by passporting considerations when determining the criteria for devolved benefits, including ADP.

The changes proposed by respondents were seen as important in ensuring ADP reflects the experiences of those with fluctuating conditions, hidden conditions or disabilities and people with mental health conditions. It was felt that taking these steps should improve client wellbeing by encouraging a more supportive and understanding process, aligned with a fair and equitable system.

Appendix A: Quantitative summary

The following tables outline the results for each of the 13 closed questions in the consultation. Please note that the row percentages may not add to 100% due to rounding.

For each question the following tables show:

- The number of respondents from the total sample of 108 Citizen Space respondents who selected each response, and the corresponding percentage.
- The number and percentage response among those **who answered each question**, broken down by:
 - Individual and organisation responses.
 - By sector².

² The 'Third Sector - Other' category includes two disabled people's organisations and one information and advice organisation. The 'Public / statutory bodies and local authorities' category includes four local authorities, two statutory bodies and one public body.

Q1. Do you agree or disagree that the moving around activity criteria for Adult Disability Payment are easy to understand?

Base	n=	% Agree	% Disagree	% Don't know	% No answer
All respondents (n=)	108	35	50	15	8
All respondents	108	32	46	14	7
All answering	100	35	50	15	-
- Individuals	68	41	46	13	-
- Organisations	32	22	59	19	-
- All third sector	24	17	67	17	-
- Health / Disability	15	13	67	20	-
- Campaigning / umbrella bodies	6	17	67	17	-
- Other	3	33	67	0	-
- Public / statutory bodies and local authorities	6	50	50	0	-
- Representative bodies	2	0	0	100	-

Q2. Are there any other issues with the moving around activity that we have not captured above?

Base	n=	% Yes	% No	% Don't know	% Yes
All respondents (n=)	108	74	12	11	11
All respondents	108	69	11	10	10
All answering	97	76	12	11	-
- Individuals	67	70	15	15	-
- Organisations	30	90	7	3	-
- All third sector	22	95	0	5	-
- Health / Disability	13	92	0	8	-
- Campaigning / umbrella bodies	6	100	0	0	-
- Other	3	100	0	0	-
- Public / statutory bodies and local authorities	6	67	33	0	-
- Representative bodies	2	100	0	0	-

Q3. How effective do you think the moving around section of the application form is at helping us understand a person's mobility needs?

Base	n=	% Very effective	% Effective	% Somewhat	% Not very effective	% Not effective at all	% No answer
All respondents (n=)	108	7	21	38	15	13	14
All respondents	108	6	19	35	14	12	13
All answering	94	7	22	40	16	14	-
- Individuals	65	11	28	40	9	12	-
- Organisations	29	0	10	41	31	17	-
- All third sector	22	0	0	45	32	23	-
- Health / Disability	14	0	0	50	29	21	-
- Campaigning / umbrella bodies	5	0	0	20	40	40	-
- Other	3	0	0	67	33	0	-
- Public / statutory bodies and local authorities	6	0	50	33	17	0	-
- Representative bodies	1	0	0	0	100	0	-

Q4. What impact do you think the changes to how we make decisions on the moving around activity have on understanding a person's mobility needs?

Base	n=	% Significant Positive	% Positive	% Neither	% Negative	% Significant Negative	% No answer
All respondents (n=)	108	13	39	28	5	2	21
All respondents	108	12	36	26	5	2	19
All answering	87	15	45	32	6	2	-
- Individuals	62	19	45	27	5	3	-
- Organisations	25	4	44	44	8	0	-
- All third sector	18	0	44	50	6	0	-
- Health / Disability	11	0	27	64	9	0	-
- Campaigning / umbrella bodies	4	0	50	50	0	0	-
- Other	3	0	100	0	0	0	-
- Public / statutory bodies and local authorities	6	17	50	17	17	0	-
- Representative bodies	1	0	0	100	0	0	-

Q6. Do you agree or disagree that the planning and following journeys activity eligibility criteria is easy to understand?					
Base	n=	% Agree	% Disagree	% Don't know	% No answer
All respondents (n=)	108	37	42	16	13
All respondents	108	34	39	15	12
All answering	95	39	44	17	-
- Individuals	64	50	34	16	-
- Organisations	31	16	65	19	-
- All third sector	23	9	70	22	-
- Health / Disability	14	7	64	29	-
- Campaigning / umbrella bodies	6	17	67	17	-
- Other	3	0	100	0	-
- Public / statutory bodies and local authorities	6	33	67	0	-
- Representative bodies	2	50	0	50	-

Q7. Are there any other issues with the planning and following journeys activity that we have not captured above?					
Base	n=	% Yes	% No	% Don't know	% Yes
All respondents (n=)	108	50	21	20	17
All respondents	108	46	19	19	16
All answering	91	55	23	22	-
- Individuals	60	45	25	30	-
- Organisations	31	74	19	6	-
- All third sector	23	74	17	9	-
- Health / Disability	14	71	14	14	-
- Campaigning / umbrella bodies	6	67	33	0	-
- Other	3	100	0	0	-
- Public / statutory bodies and local authorities	6	67	33	0	-
- Representative bodies	2	100	0	0	-

Q8. How effective do you think the planning and following journeys section of the application form is at helping us understand a person's ability to plan and follow journeys?

Base	n=	% Very effective	% Effective	% Somewhat	% Not very effective	% Not effective at all	% No answer
All respondents (n=)	108	9	19	36	19	4	21
All respondents	108	8	18	33	18	4	19
All answering	87	10	22	41	22	5	-
- Individuals	61	13	26	44	15	2	-
- Organisations	26	4	12	35	38	12	-
- All third sector	19	0	0	42	47	11	-
- Health / Disability	11	0	0	45	55	0	-
- Campaigning / umbrella bodies	5	0	0	20	40	40	-
- Other	3	0	0	67	33	0	-
- Public / statutory bodies and local authorities	5	20	60	0	0	20	-
- Representative bodies	2	0	0	50	50	0	-

Q9. What impact do you think the changes to how we make decisions on the planning and following journeys activity has on understanding a person's ability to plan and follow journeys?

Base	n=	% Significant Positive	% Positive	% Neither	% Negative	% Significant Negative	% No answer
All respondents (n=)	108	15	36	21	5	2	29
All respondents	108	14	33	19	5	2	27
All answering	79	19	46	27	6	3	-
- Individuals	55	25	44	22	7	2	-
- Organisations	24	4	50	38	4	4	-
- All third sector	17	0	53	41	0	6	-
- Health / Disability	10	0	40	50	0	10	-
- Campaigning / umbrella bodies	4	0	50	50	0	0	-
- Other	3	0	100	0	0	0	-
- Public / statutory bodies and local authorities	6	17	50	17	17	0	-
- Representative bodies	1	0	0	100	0	0	-

Q11. Do you agree or disagree that the criteria for fluctuating conditions is easy to understand?					
Base	n=	% Agree	% Disagree	% Don't know	% No answer
All respondents (n=)	108	31	47	16	14
All respondents	108	29	44	15	13
All answering	94	33	50	17	-
- Individuals	65	35	42	23	-
- Organisations	29	28	69	3	-
- All third sector	21	19	81	0	-
- Health / Disability	12	17	83	0	-
- Campaigning / umbrella bodies	6	17	83	0	-
- Other	3	33	67	0	-
- Public / statutory bodies and local authorities	6	67	33	0	-
- Representative bodies	2	0	50	50	-

Q12. Are there any other issues with the fluctuating conditions criteria that we have not captured above?					
Base	n=	% Yes	% No	% Don't know	% No answer
All respondents (n=)	108	40	25	22	21
All respondents	108	37	23	20	19
All answering	87	46	29	25	-
- Individuals	61	38	33	30	-
- Organisations	26	65	19	15	-
- All third sector	18	72	17	11	-
- Health / Disability	10	80	20	0	-
- Campaigning / umbrella bodies	5	60	20	20	-
- Other	3	67	0	33	-
- Public / statutory bodies and local authorities	6	50	33	17	-
- Representative bodies	2	50	0	50	-

Q13. How effective do you think the fluctuating conditions section of the application form is at helping us understand the needs of people with fluctuating conditions?

Base	n=	% Very effective	% Effective	% Somewhat	% Not very effective	% Not effective at all	% No answer
All respondents (n=)	108	11	25	22	18	8	24
All respondents	108	10	23	20	17	7	22
All answering	84	13	30	26	21	10	-
- Individuals	59	15	37	32	14	2	-
- Organisations	25	8	12	12	40	28	-
- All third sector	18	0	6	17	56	22	-
- Health / Disability	10	0	0	30	50	20	-
- Campaigning / umbrella bodies	5	0	0	0	60	40	-
- Other	3	0	33	0	67	0	-
- Public / statutory bodies and local authorities	6	33	33	0	0	33	-
- Representative bodies	1	0	0	0	0	100	-

Q14. Thinking about the changes we have made to how we make decisions about fluctuating conditions, what impact do you think this is having on understanding the impact of a person's fluctuating conditions?

Base	n=	% Significant Positive	% Positive	% Neither	% Negative	% Significant Negative	% No answer
All respondents (n=)	108	14	40	23	2	1	28
All respondents	108	13	37	21	2	1	26
All answering	80	18	50	29	3	1	-
- Individuals	57	18	56	21	4	2	-
- Organisations	23	17	35	48	0	0	-
- All third sector	16	6	44	50	0	0	-
- Health / Disability	11	9	36	55	0	0	-
- Campaigning / umbrella bodies	3	0	33	67	0	0	-
- Other	2	0	100	0	0	0	-
- Public / statutory bodies and local authorities	6	50	17	33	0	0	-
- Representative bodies	1	0	0	100	0	0	-

Q19(a). How much of a priority to you is maintaining the current “passporting” arrangement?							
Base	n=	% Very high	% High	% Medium	% Low	% Very low	% No answer
All respondents (n=)	108	33	15	9	6	3	42
All respondents	108	31	14	8	6	3	39
All answering	66	50	23	14	9	5	-
- Individuals	44	39	25	16	14	7	-
- Organisations	22	73	18	9	0	0	-
- All third sector	17	76	24	0	0	0	-
- Health / Disability	10	80	20	0	0	0	-
- Campaigning / umbrella bodies	5	100	0	0	0	0	-
- Other	2	0	100	0	0	0	-
- Public / statutory bodies and local authorities	4	50	0	50	0	0	-
- Representative bodies	1	100	0	0	0	0	-

Appendix B: MS Society Scotland Survey

Tool

A total of 102 responses were received via a survey tool created, launched and promoted by MS Society Scotland.

The table below presents the questions asked in the survey tool compared to those asked in the consultation. Responses given via the tool were automatically sent to the Scottish Government, via email, to include in Citizen Space as answers to the questions in the left-hand column.

Consultation question	MS Society survey tool
Question 2 - Are there any other issues with the moving around activity that we have not captured above?	No question asked. Automatically responds to question 2 as “yes”.
Question 2(a) - If you said “yes,” what other issues with the moving around activity do you think need to be considered?	What issues have you experienced with the 20m rule and the ADP/PIP application process?
Question 3 - How effective do you think the moving around section of the application form is at helping us understand a person’s mobility needs?	How effective is the 20m rule as a way to judge mobility?
Question 5 - If there was an opportunity to change the moving around activity criteria, what changes would you make (if any)?	If you could change or remove the 20m rule, what would you do?
Question 5(a) - If you proposed changes, what positive impacts could these have, and for who?	Who do you think would benefit from getting rid of the 20m rule and why?
Question 12 - Are there any other issues with the fluctuating conditions criteria that we have not captured above?	No question asked. Automatically responds to question 12 as “yes”.
Question 12(a) - If you said “yes”, what other issues with the fluctuating conditions criteria do you think need to be considered?	What are the issues with the way the ADP/PIP application process currently takes account of fluctuating conditions?
Question 15 - If there was an opportunity to change any specific aspects of the fluctuating conditions criteria, what changes would you make (if any)?	How could the ADP/PIP application process take into account your fluctuating symptoms?

Appendix C: The moving around activity

1(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

Clarity of the criteria

This theme is discussed in main report but additional quotes are included below.

“People who are new to the benefits system do not realise - and the form doesn’t tell you - that the issue is not just how far you can walk, but whether you can do it “reliably” i.e. safely, to an acceptable standard, repeatedly and in a reasonable time. While the form highlights pain, fatigue and breathlessness, it does not mention speed, issues with gait or uncontrolled movement which may mean that people are not moving to “an acceptable standard”, or the need to be able to repeat the distance - all of which are common for people with Parkinson’s.” - Parkinson's UK Scotland

To be made easier to understand, panel members felt that the system and criteria needed to be made more distinct from the existing DWP assessment, which does not reflect enough about what real life is like as a disabled person, so the questions in the criteria need to be re-written... Linked to this, the questions in the eligibility criteria, which are based on statements such as “Can stand and move more than ...” are also focused on very prescriptive, yes and no answers and not descriptive ones, thus do not seem to be a genuine attempt to gain an understanding of the needs of the individual.” - EEPPIIC

Less commonly mentioned themes

A few respondents each mentioned the following points:

- Specific changes to the criteria, including universal access to advocacy to assist with the application and regulations in line with case law, which are addressed more in Q2b.
- Critique of the criteria as it relates to ‘aided’ or ‘unaided’ movement, with respondents noting that those who move unaided should not be considered the same way as those who need an aid to move.
- The negative impact of not being entitled to ADP and therefore not able to access other passported benefits, such as the blue badge scheme and the Accessible Vehicles and Equipment Scheme.
- Negative comments about the training, attitudes, and skills of DWP assessors, including poor advice given during DWP-style assessments and a lack of understanding about the experiences of disabled people or those with health conditions that impact mobility.
- Generally negative comments about ADP, without providing specific details.

1(b). How could we make the moving around activity criteria easier to understand?

Some respondents each raised the overarching theme of considering the wider impact on clients of moving around, or called for the language used in the eligibility criteria to be simple, unambiguous and consistent but did not provide any further detail.

A few respondents each raised overarching themes of ensuring the criteria are more reflective of real-life situations or recommending other considerations to broaden the criteria.

Other points made by a few respondents included:

- Negative comments about the training level, attitudes, and skills of practitioners, though it was unclear whether respondents were referring to DWP assessors or Social Security Scotland practitioners
- A critique of the use of distance measures, in particular, the '20-metre rule'.
- One respondent suggested the Scottish Government should further engage stakeholders when amending or changing the criteria.

2 (b). In your view, what are the positive aspects of the moving around activity that we have not captured above?

"We note that you have talked about disincentives to physical activity, and we want to highlight that this is a particular issue for our community... There is increasing evidence that physical activity can help people to live better with their Parkinson's, including managing mood and even some motor symptoms. But many people have told us that they are scared that they will be seen as scamming the system if they take part in physical activity - creating a barrier to keeping well." - Parkinson's UK Scotland

"Adult Disability Payments should be based around the principle of enabling someone to live as independently as possible with a good quality of life and discouraging people to be active may have a negative impact on health and wellbeing." - Sight Scotland and Sight Scotland Veterans

"It was particularly concerning within the consultation document to see that two-fifths of respondents to a survey were effectively discouraged from being active due to the fear they would lose their entitlement to social security. The health benefits, both physical and mental, arising from exercise or otherwise being active are well known." - Health and Social Care Alliance Scotland

4. What impact do you think the changes to how we make decisions on the moving around activity have on understanding a person’s mobility needs? Please give reasons for your answer

Support for change

“This can also reduce the stress and anxiety on applicants by removing the automatic requirement for a consultation, therefore creating a more dignified approach to assessments.” – Scottish Association of Social Work (SASW)

Other themes

Some organisations reserved judgement on the changes until they can collect more data on the process, impacts on clients and the decisions being made.

The practitioner, particularly the training and professional qualifications of the practitioner, was a concern for some respondents. A few acknowledged that the change to consultations improved upon the otherwise subjective nature of DWP-style assessments. However, a few others highlighted that supporting information would add little to the process if the practitioner is not trained to read and understand it.

“Will the team assessing the applications have medical knowledge and be in a position to be able to interpret the information provided? There is no point in being given a copy of a prescription if the person assessing for the award has no medical training.” - Individual

Some noted continuing concerns over the application and consultation processes. These included a fear that people who do not deserve ADP will be awarded it and that the changes do not go far enough. CPAG in Scotland raised concerns about a legality that allowed Scottish Ministers to refuse to undertake a determination without application (DWA) if a client requests a review of their award. As CPAG notes, “in this situation the individual would have no right of appeal against this decision.”

The overarching themes of considering the wider impact of moving around and broadening the eligibility criteria were repeated by some respondents at Q4.

A few respondents each mentioned technical and accessibility issues such as issues with the digital portal or problems with uploading material, and that they found the application itself to be overly long and repetitive to complete.

5. If there was an opportunity to change the moving around activity criteria, what changes would you make (if any)?

Specific suggestions or changes to the criteria

- A consideration of the length of time taken to move was suggested by a few to get a clearer picture of a person's ability to move.
- Two respondents recommended further consideration be given to the application process for people with incurable or progressive conditions.
- An individual suggested home visits be included for consultations, while another recommended an option to upload a video.
- Health and Social Care Alliance Scotland provided rewritten criteria that expanded on the distance measures to include other factors, such as a person's ability to move around their own home, local area, and "other places they may frequent in daily life such as their place of education or employment, shopping and leisure facilities, and healthcare services."
- MS Society Scotland acknowledged the improvements to the criteria but called for future changes to be co-designed with clients.

5(a). If you proposed changes, what positive impacts could these have, and for who?

Positive impacts of suggested improvements

"Mostly this type of change would affect those like myself who are wheelchair users, even those with a Zimmer. It would help those affected in this way feel like every aspect is being looked at and considered, and those with the most need do truly receive the help needed. As a wheelchair user from birth, I've learnt tricks and skills in managing to get around, and due to this I do try to continue working with adjustments to be an effective contributor within my community. During these assessments it feels like this goes against you; the fact you're trying to find ways around barriers excludes you from getting this award whereas those who don't try seem to pass the assessment much easier, which to me seems the wrong way round. Minimizing an individual's life instead of maximising it, which this benefit can and should support, so I agree with the studies that disabled people can feel very afraid to even try and do well." – Individual

Appendix D: The planning and following journeys activity

Recurring themes

Criteria language

“The planning and following journeys criteria are overly simplistic. This is again the main reason for them being difficult for applicants to interpret and understand. They lack clarity and detail and use a lot of vague subjective terms to describe the criteria. One person’s interpretation of what constitutes a journey may be different from the next person’s. What is classed as familiar will vary from person to person adding a great deal of subjectivity in to the application process. This subjectivity will then be replicated in the decision-making process as this will add in further level of individual interpretation.” - MS Society Scotland

6. Do you agree or disagree that the planning and following journeys activity eligibility criteria are easy to understand?

6(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

Other themes

Both overarching and less commonly mentioned themes in relation to the criteria are noted in Appendix D.

Some highlighted a difficulty in understanding how criteria related to individual situations and called for a more person-centred approach. This included concern about the lack of variation allowed by the closed questions structure, and specific considerations about mental health experiences not being well-represented by the criteria.

The overarching themes of considering the additional impacts of planning and following journeys and considering real life situations and environments were also mentioned by some. These included mid-journey brain fog, changed plans, route diversions, and weather conditions.

The following themes were each mentioned by a few respondents:

- A request to expand the definition of orientation aids as mentioned in the overarching themes section of this chapter.
- General critiques of the criteria and application without further specification.

**9. What impact do you think the changes to how we make decisions on the planning and following journeys activity have on understanding a person’s ability to plan and follow journeys?
Please give reasons for your answer**

Other positive feedback

“We welcome the inclusion of support from other people such as carers, family and professionals in the guidance on this criteria as they have a key role in a person’s life. This is in line with the social model approach to disability and could create confidence that there is an effort to understand the applicant’s condition and needs beyond medical needs.” - Scottish Association of Social Work (SASW)

Not enough data on the process yet

Some organisations noted that they had to withhold judgement of the changes until they were able to collect more data from first-hand experiences of the new process.

“We do not have any experience of these changes as they mostly relate to the way consultations are carried out, and we have not, to date, advised anyone who has had a consultation. However, we broadly welcome these changes and think that they should result in more accurate reports. In particular, we think that ensuring that practitioners have relevant experience may make a big difference for people with learning disabilities and mental health conditions. We would still like to see that all evidence is weighed appropriately by case managers where a consultation report is available, including information on the application form.” - The Action Group & VOCAL & Grapevine at Lothian Centre for Inclusive Living

10. If there was an opportunity to change any specific aspects of the planning and following journeys activity, what changes would you make (if any)?

The following themes were each mentioned by a few respondents:

- Inclusion of variable or fluctuating conditions, such as providing space in the application to allow those with fluctuating conditions to explain their experiences.
- Comments that no further changes were needed to the planning and following journeys activity, with no further detail being given.
- Suggestions about points-based system changes, such as providing more points to those clients who need assistance from another person to get around.
- Suggesting that practitioners have specific training, including an understanding of visual impairments and how to speak with clients who have specific conditions. Two individual respondents requested that practitioners listen and believe the information provided to them.
- Consideration of environmental factors, public transport routes and difficulties during the journey.

Appendix E: Support for people with fluctuating conditions

11(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

11(b). How could we make the fluctuating conditions criteria easier to understand?

Singular comments or those made by a small number at Q11a and Q11b included:

- Those with solely mental health symptoms should engage in treatment.
- The criteria were a “massive addition” to the form.
- Examples of how fluctuating conditions affected respondents.
- Calls for the application form to be amended so clients have more open text space to describe their situation.
- Blesma felt the prompts were improved compared to the PIP form but additional questions on the length of use of an aid and the safety impact would be helpful.

12(a). If you said “yes”, what other issues with the fluctuating conditions criteria do you think need to be considered?

Less commonly mentioned themes

Some requested changes to the form, with two suggesting general improvements, such as clarifying that this section is about fluctuating conditions or providing more examples and explanations. Specific suggestions included:

- Including an image of a prosthesis alongside other aids and appliances, probably a prosthetic leg.
- Adding narrative around ‘good days’ and ‘bad days’ in the descriptor.
- Using Crohn’s and Colitis as an example in this section due to their unique nature.

A few mentioned the role of professionals in providing supporting information. One felt consideration should be given to determining the best person to provide information, with another commenting that their GP would need to know them better to provide helpful supporting information. One organisation highlighted other issues in obtaining supporting information from professionals.

“Another factor that was flagged was issues with getting ‘fresh’ evidence which can adversely impact decision-making. This could be for numerous reasons, including waiting on the formal diagnosis, a person self-managing, thus not seeing a medical professional regularly or due to waiting lists and waiting times for appointments.” - EEPPIIC

A small number of respondents felt more attention should be paid to the state of illness during the application, gave examples of fluctuating conditions, commented on practitioners, and two respondents called for a discretionary exceptional circumstances award.

12(b). In your view, what are the positive aspects of the fluctuating conditions criteria that we have not captured above?

The proposals, or aspects of them, were welcomed by some. For instance, two thought providing an average could measure fluctuating conditions, whilst Scotland Versus Arthritis welcomed the recognition of multiple conditions within the fluctuating conditions section.

Some felt there would be no positive impacts - all were individuals except for the organisation MACS. Some mentioned the role of practitioners, and a small number mentioned the descriptors, with two organisations calling for condition-specific descriptors not to be used as these were felt to be based on the medical model and did not well reflect complexities in people's lives, leading one to suggest:

“General categories and indicative examples within existing descriptors would be more flexible.” Health and Social Care Alliance Scotland

Glasgow City Council also suggested a way to ease the transition:

If it was possible to have the points system as a means to assess straightforward conditions and then to have what were the former tests under DLA (and now CDP) as an alternative test, then you would be able to have the best of both systems. Furthermore, it would offer a smooth transition from CDP to ADP without the risk of loss of entitlement where only age has changed and not the disabling condition. Glasgow City Council

13. How effective do you think the fluctuating conditions section of the application form is at helping us understand the needs of people with fluctuating conditions?

“More examples of how a condition fluctuates would be helpful to the applicant. This would include explaining changes to cognition (including confusion, anxiety, and memory) as well as how someone might be physically affected (fatigue, balance, appetite, falls).” - Neurological Alliance of Scotland

The Health and Social Care Alliance Scotland felt insufficient information about what it means to carry out an activity to an acceptable standard was provided, despite the legal definition appearing to give greater clarity. The MS Society Scotland felt it was insufficient to provide a detailed account of how people's functional abilities changed due to living with complex conditions. Alzheimer Scotland suggested using 'worst' or 'bad day' terminology may help a client better understand and describe the variable nature of fluctuations.

A few respondents suggested specific amendments to the form, including gathering information about reliability criteria and revising wording to include 'wheeled' when

referencing walking. Two organisations suggested additional prompts. Blesma felt a prompt asking if an individual has days where they cannot use their aid or appliance reliably. It would be helpful noting that some people who have experienced loss of a limb seemed to focus on how they managed on days they wore prosthetics rather than days they couldn't. CAS suggested providing a prompt to explain post-exertion symptoms.

Factors that may impact client supporting information

"Fluctuating conditions may be seasonal in that they become worse in cold and/or wet weather (e.g. rheumatoid arthritis). This means that if a disabled person claims in winter or spring, they may truthfully state that their condition has impacted them to the extent required in the descriptors on over 50% of the days in a month. Yet a similar disabled person with exactly the same condition might not be entitled if they instead applied in the summer." - Inclusion Scotland

14. Thinking about the changes we have made to how we make decisions about fluctuating conditions, what impact do you think this is having on understanding the impact of a person's fluctuating conditions? Please give reasons for your answer.

Staff training and knowledge

"The systemic issues raised, such as legacy issues of trust in the system and limited opportunity to express the realities of your conditions beyond arbitrary figures such as the 50%, means that there is a lot more work to be done still to give people the confidence that fluctuating conditions will be considered effectively." - EEPIC

15. If there was an opportunity to change any specific aspects of the fluctuating conditions criteria, what changes would you make (if any)?

15(a/b). If you proposed changes, what positive impacts/negative impacts could these have, and for who?

Two organisations also called for introducing discretionary safety net criteria modelled on paragraph 4 of Schedule 9 of the Universal Credit Regulations 2013. As an alternative, ENABLE Scotland suggested a return to the principles outlined in "Moyna (Respondent) v. Secretary of State for Work and Pensions (formerly against the Social Security Commissioner) (Appellant)." Another safety net could be provided by using:

"the rules relating to DLA/CDP as an alternative route to entitlement. This would also provide a seamless transition from CDP to ADP and could avoid situations where entitlement is reduced where there has been no improvement in a person's condition."
Glasgow City Council

Appendix F: Other considerations

16. If there was an opportunity to consider alternative approaches to a points-based system to understand disabled people's needs, what alternatives would you propose (if any)?

Less commonly mentioned themes

The importance of taking a system-wide perspective when considering criteria was noted by some respondents. Comments included views that changes to one part of the system could impact elsewhere, e.g., improving mental health funding could positively impact independent living and the need for better inter-agency working between Social Security Scotland and other departments. As explained in the overarching theme section, some respondents reiterated the need to broaden the criteria to include other conditions.

There was a call by some to examine more closely what works well, either in Scotland, Europe or further afield.

A few respondents commented that indefinite awards should be made in relevant cases, i.e. where no future improvement was envisaged. One noted occupational therapists were well placed to make such recommendations.

16(b). If you proposed changes, what negative impacts could these have, and for who?

“We recognised that a more individualised assessment model is likely to lead to more detailed questions, responding to which may feel more onerous for the applicant and that the assessment of responses may lead to outcomes which are potentially subjective and may be inconsistent.” - Law Society of Scotland

16(c). If you proposed changes, which of these would you prioritise?

Addressing barriers to participation

Ensuring fairness in decision-making was mentioned explicitly by some, with one noting a wider range of conditions should be included in the criteria to facilitate this, e.g. Crohns and colitis. Another individual felt the exclusion of fluctuating conditions was illegal.

Some respondents noted that the priority should be to change the mobility component criteria. Two called for a removal of a points system. One organisation recognised the complexities associated with this and argued a scaling approach could be prioritised more easily:

“There is a concern, however, that budgetary and passporting implications may mean scrapping a points based system would not be feasible. As such, our next priority would be to implement a scaling approach and other measures to ensure points are not the final decider in whether a person is entitled to social security.” - Sight Scotland and Sight Scotland Veterans

The Neurological Alliance of Scotland and MS Society of Scotland recommended the 50% eligibility criteria be modified and made more flexible to accommodate fluctuations in conditions over time. Some organisations including National Carer Organisation, Scottish Post Polio Network and the Cross Party Group on MS called for the removal of the ‘20-metre rule’, with the MS Society Scotland suggesting replacing it with the ‘50-metre rule’.

Other priorities

A small number mentioned other priorities. These included: the need to be flexible and avoid ‘tick box’ approaches, involving carer views, not having reviews and recognising that aids do not remove mobility issues. EEPIC highlighted the need to co-design and implement the new system with people with lived experience.

17. Other than changes to the eligibility criteria, are there any changes you think we could make to Adult Disability Payment to support people’s mobility needs (if any)?

Improve decision-making approach

“I scored far higher in the everyday component than the mobility component. This meant that the payment was balanced in the wrong direction. I need to hold on getting up from the toilet and I can't kneel down or do anything below knee level. However, I'd say that the lack of mobility on bad days has a far greater impact on me as there isn't solutions. I've had to pay extra for an automatic car but that's not considered.” - Individual

“A more flexible approach needs to be considered, such as allowing people on 8+ points to pay a supplement to get access to a motability car... People who score 10 points, for example, can only walk 50 meters. It's more than 50 meters to the bus stop. But they can't get a car or even a scooter. The Motability scheme really needs investigating. People who are disabled but don't get 12 points could still benefit from the scheme yet are prevented from getting access to it.” - Individual

Independent support and advocacy

Citizens Advice Scotland cited findings from the [Grey report](#) that access to independent advice contributed to inconsistency in PIP decision-making and that those who reported the most satisfaction with the process tended to have additional support with their application.

Cerebral Palsy Scotland noted that those with neurological conditions had no legislative right to independent advocacy and urged the Scottish Government to remedy this. Issues with existing referral pathways were also highlighted:

In terms of advocacy support for disabled people, we have serious concerns that (i) many disabled people with advocacy needs are not being referred for advocacy support and (ii) that the advocacy service that the Scottish Government has commissioned does not itself refer disabled people to welfare rights support. Advocacy staff are not welfare rights workers...Advocacy support that limits itself to assisting disabled people with completing application forms to ADP is neither holistic nor genuine independent advocacy - which should be motivated with providing support that meets the disabled person's needs rather than its contractual obligations with a third party.” - Inclusion Scotland

One individual felt family members could support clients, such as carers, parents and guardians, whilst Age Scotland highlighted delays in processing ADP applications could impact carer finances. Two respondents felt disabled people should be able to nominate a representative to act on their behalf.

Less commonly mentioned themes

Another theme mentioned by some related to the quality of the system, with the most prevailing issue being the need to spot check or audit decisions to ensure system principles are met, decision-making is correct the first time, and to identify fraudulent applications.

Some mentioned the need to address delays in the system, which could impact negatively on client and carer wellbeing and finances:

“Delays cause considerable distress and can entrench financial hardship. Social Security Scotland data shows ...Of the 3,130 new applications processed in January 2023...1,105 ...were processed in 81-100 days. Citizen’s Alert: An East of Scotland CAB reports on the 2nd of March 2023 reports on the impact of delays to a decision on an application for ADP completed on the 24th of October 2022 on a client with progressive degeneration of the spine and his carer. The adviser reports that the carer, who is dyslexic, “stated that her cheerful positive attitude has been replaced by a sense of foreboding when the phone rings.... She feels overwhelmed, she lives in dread of receiving no money, she fears waiting for payments and receiving the wrong amount”. - CAS

Delays could also impact carers, who cannot apply for Carer’s Allowance until a decision about the client’s ADP application has been made.

Some described changes to the form they felt should be made, such as simplifying questions or using images and having access to a paper version.

A few respondents argued for co-design with clients, offering a range of methods and focusing on engagement with those who face the most significant barriers.

18. How can the independent review ensure that any recommendations it makes are both deliverable and affordable?

An equitable, human rights approach

A fairer system will pay more out in benefits but should be less expensive to administer. Reducing poverty should be important, but also, the money received will boost the economy, improve claimants' health, lessen spending on the health service, social work, policing etc., and have generational benefits. Providing security and an adequate income helps those who can work to do so and means stability and mitigation against worsening health for those who can't." - Individual

Financial considerations

"In terms of ensuring any recommendation is affordable, this requires more accessible information and transparency on Scottish Budgets and future projections and scrutiny by the independent review. Priorities are for the Scottish Government." - EEPIC

Improved practice and decision-making

"There is an opportunity to minimise additional costs through practice and effective decision-making. The getting it right first time approach may reduce extra staff costs through challenges of decisions." - Blesma

Falkirk Council suggested that health practitioners review supporting information to ensure the requested information is relevant to the client and their condition. The Scottish Government could disseminate guidance on what constitutes relevant supporting information to GP practices. They argued print and postage cost savings could occur through a reduced size form or digitised information transfer, e.g. a shared portal to share data between agencies, which could speed up processing speed.

Crohn's and Colitis UK noted that making a range of changes, including improved access to advocacy and welfare rights advice and a reduction in challenges due to implementing a human rights approach, would reduce overall costs arising from administering ADP.

"The DWP's approach to PIP which focussed on costs rather than disabled people's rights ended up being wholly counter-productive. In 2019, the Office for Budget Responsibility revised the estimated cost of the move to PIP from DLA to account for modifications to the PIP eligibility criteria following several successful legal challenges and the high number of appeals pursued by claimants and predicted an overspend of at least £1.5 billion (DLA-to-PIP-CHAD-Project-Report-26-March-final-report.pdf (chadresearch.co.uk)). Those legal challenges continue to be made and continue to succeed and the costs of PIP continue to rise." - Crohn's & Colitis UK

A small number recommended making use of data or improving the data collected.

Comments included:

- Assess waiting list data to ascertain what experience case managers will require to speed up the process.
- Testing impact across client groups with anonymised case data from current workloads to allow direct comparison between current rules and proposed changes.
- Enhancing data collection about case outcomes, decision-making and appeals
- Capturing sufficient equality data to analyse the impact on those with protected characteristics.
- Analysis of wider impact on public expenditure of effective disability assistance.

Broader social security system issues

Some argued the review should consider the whole system when determining affordability, highlighting the inter-related nature of funding. Affordability should be considered alongside other Government spending on health and social care, transport and housing.

"We acknowledge that at present, depth of analysis involving, for example, modelling of the tax revenue impacts of extended and/or increased financial support for mobility, is currently unavailable; this picture strongly suggests that improvements to the design and delivery of extra costs disability support are likely to have inextricably linked and profound positive social and economic effects." - Scottish Campaign on Rights to Social Security

A few respondents noted the inter-related nature of benefits, for instance, the impact on passported benefits or different qualifying criteria, and felt clients should not be disadvantaged. ENABLE Scotland suggested a further review could occur once the Scottish Government identified options that did not adversely impact reserved benefits.

"Other benefits mentioned in consultation e.g. Scottish carers assistance, pension age winter heating assistance, pension age disability payment, target those of pension age; as such, younger people won't qualify due to their age. Access to ADP is therefore vital, and other social security payments should not be relied upon to fill gaps." - Sight Scotland and Sight Scotland Veterans

Less commonly mentioned themes

Some respondents felt it necessary to co-design any new system by engaging with and listening to stakeholders, mainly clients and carers. Parkinson's UK Scotland argued reform must be transparent, subject to stakeholder and Scottish Parliament scrutiny before any Bill is passed and that Ministers must be accountable for the new system. Another theme identified by some was that they felt the review team and Scottish Government should take decisions about which changes to make, rather than asking respondents for suggestions. However, Inclusion Scotland also noted the Scottish Government is bound to uphold international treaties to which it is a signatory, including the Convention of the Rights of Persons with Disabilities.

The Scottish Association for Mental Health argued the review team should make recommendations through the lens of a social model of disability, equality and human rights law, principles and standards, including “how reform of ADP can further realise people's rights under the UN Convention on the Rights of Persons with Disabilities.”

19. How can the independent review consider the impact of any recommendations on existing “passporting” arrangements?

Joint working between the Scottish and UK Governments

“With appropriate partnership working between the governments, this mechanism could be used to allow the Scottish Government to pursue further changes to Scottish social security whilst maintaining passporting by assuming liability for any additional costs arising for the UK Government. In line with our responses to other questions, this should form part of a human rights-based approach to social security and be paired with measures to maximise revenues available for public services.” - Health and Social Care Alliance Scotland

Impact on specific benefits

Respondents noted that an enhanced rate mobility award under ADP provides access to the Accessible Vehicles and Equipment (AVE) Scheme and a passport to the Scottish Government's Blue Badge parking scheme, a disabled person's bus pass and local transport schemes.

"Increasingly, a blue badge is being used as a way to identify disabled people in relation to, for example, Low Emission Zones exemptions as well as parking spaces. People with Parkinson's tell us that this form of passporting is invaluable, and we know that the lack of passporting from Attendance Allowance to the Blue Badge scheme can be a major barrier to some older people applying for, or being granted, a Blue Badge." - Parkinson's UK Scotland

Respondents felt it essential to retain entitlement to these passporting benefits, with one noting this could ensure an individual does not need further assessments. Inclusion Scotland highlighted that the power to grant passporting to these benefits is already devolved and noted that CAS does not anticipate a significant impact on benefit arrangements resulting from changes to ADP entitlement but acknowledges potential increased costs for the Scottish Government.

A few specifically mentioned that vehicle tax exemptions are currently not devolved. ScoRRS also highlighted that VAT applies to the leasing of a Motability vehicle, again not a devolved matter, and wished the independent review to consider "...the existence of a road tax exemption for those in receipt of high rate of Mobility, and a 50% discount for those awarded standard rate mobility; this is not devolved."

Concerns were noted about a passporting issue if entitlement to ADP determines eligibility for the health element of Employment Support Allowance and Universal Credit in the UK's *Transforming Support, The Health and Disability White Paper*:

"Scottish Government needs to begin negotiating now with the UK Government about the almost certain additional costs (i.e. in both processing and administering thousands of additional claims, a large proportion of which may prove unsuccessful as the qualifying criteria for ADP and ESA are entirely different) and additional benefits claimants (i.e. some current ESA/UC claimants who do not claim PIP/ADP will nevertheless be entitled to these benefits). If such UK-wide changes do result in additional costs for Scottish Government we hope that these will be refundable via the renegotiated Fiscal Framework." - Inclusion Scotland

A small number mentioned that Carer's Allowance could be impacted by changes, as ADP may allow a carer to apply for Carer's Allowance. One participant noted that Carer's Allowance in Scotland will shortly be replaced by Carer Support Payment, and therefore the Scottish Government will hold powers to continue passporting.



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