

Social Security Experience Panels - Adult Disability Payment: Mobility component eligibility criteria



EQUALITY, POVERTY AND SOCIAL SECURITY

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Executive Summary

Introduction

Adult Disability Payment (ADP) is the twelfth payment now delivered by Social Security Scotland. It replaces the Department for Work and Pensions (DWP) delivered Personal Independence Payment (PIP) in Scotland, and it will provide support to over 600,000 disabled people by 2027. Over the next couple of years, people in Scotland who are in receipt of PIP or working-age Disability Living Allowance (DLA) will be transferred to Adult Disability Payment.

The Scottish Government is committed to an independent review of Adult Disability Payment. This report presents the findings from research conducted as part of the groundwork to prepare for the independent review.

The aim of the research was to understand the views of Experience Panel members regarding the current eligibility criteria for the mobility component of Adult Disability Payment, consisting of the Moving Around criteria, Planning and Following Journeys criteria, and Fluctuating Conditions criteria. This included which areas panel members would like to see changes made within, and to gather suggestions as to how changes could be implemented.

The research was conducted in two phases. The first phase took place during October and November 2022, and consisted of 15 interviews (in-person, by telephone and online), and three in-person focus groups. In total, 34 participants took part in this stage of research. A second phase of research took place from May to June 2023, and consisted of an online survey sent to 1,840 Experience Panels members. In total, 191 respondents took part in this stage.

Moving Around criteria

General views on the Moving Around criteria

Survey respondents were asked to provide some general feedback on the criteria. Almost half of respondents (49 per cent) disagreed that the descriptors were suitable for understanding someone's ability to move around, with a third (36 per cent) agreeing.

Almost half (47 per cent) of survey respondents agreed that the descriptors were clear and easy to understand, and a third (32 per cent) disagreed. Some interview and focus group participants provided positive feedback that the descriptors were clear and easy to understand.

Half of respondents (50 per cent) disagreed that they would find it easy to choose a descriptor or descriptors that reflected their own level of mobility, and two-fifths (39 per cent) agreed.

Use of distances

Many participants and respondents criticised the use of distances within the criteria. Some suggested that continuing to use elements of DWP processes, such as the distances in the descriptors, was inappropriate. Others felt that the distances needed to be revised as they were currently too short, while some suggested removing them altogether. Many stated that they found distances presented in metres quite abstract and difficult to understand in relation to their own mobility.

Accounting for additional factors

Many participants and survey respondents highlighted additional factors that they felt should be considered when looking at a person's ability to move around. These included: pain, consequences of movement, surfaces, time, balance and the effects of medication. The majority of these factors are already included within Social Security Scotland guidance.

A holistic approach to mobility

Some participants commented that asking about the distance a person can move is not a complete picture of mobility. A few participants linked together some of the factors outlined above to describe how intersecting and mutually affecting aspects of their conditions influenced their mobility, for example, where anxiety over moving worsens the consequences of moving.

Others suggested that a better way to understand how these factors impact on an individual's mobility would be to ask about their ability to manage everyday situations or carry out day-to-day tasks. The majority of survey respondents (70 per cent) agreed with a suggestion that the moving around criteria should include categories for everyday tasks and elements beyond distance walked.

Some participants wanted to have additional space within application forms to describe how their condition or conditions affect their mobility. The majority of survey respondents (75 per cent) agreed with a suggestion to have a space available to describe what happens after someone has been walking for a period of time.

Using aids

Some participants and survey respondents highlighted that they were unsure how the use of a mobility aid related to the criteria. They described uncertainty around how they should self-assess based on their use of aids, particularly where this results in very different levels of mobility when compared to moving without an aid. Several participants expressed a preference for mobility to be considered only on the basis of unaided movement, or that movement with an aid is conditional on having access to the required support.

Other suggestions

Some participants and respondents suggested that there should be a greater involvement from health professionals. Suggestions included granting health professionals the authority to trigger a review of a person's mobility needs, and

including in the decision-making process any recommendations or observations made by them.

Participants expressed mixed opinions on face-to-face meetings. A few stated that they would prefer to have the opportunity to discuss their mobility needs with someone face-to-face, as they found it easier and felt there was better understanding in this situation. However, others stated that they found face-to-face interactions intimidating, and described past experiences of these with DWP as demeaning and stressful.

Preferred areas of change

As part of the follow-up survey, respondents were asked to consider three areas for change within the mobility criteria. These were broad suggestions rather than specific changes, which respondents were asked to rank by preference from most to least important.

The most popular suggested area for change was taking a more holistic look at a person's mobility needs, which almost two-thirds (64 per cent) of survey respondents chose as their first preference. The least preferred option was reconsidering the distances used, which was ranked as least important by almost half (47 per cent) of respondents.

Additional mobility costs

Participants were asked about any additional costs that they incurred as a result of limited mobility. Participants described increased transport costs, particularly in rural areas or places with limited accessible means of transport. Others highlighted expenses for help around the home, and household costs associated with immobility, such as bedding, bedclothes and energy costs from additional laundry where someone is bedbound.

Planning and Following Journeys criteria

General views on the Planning and Following Journeys criteria

Almost half of respondents (46 per cent) agreed that the Planning and Following Journeys descriptors were suitable for understanding someone's ability to move around. However, almost two-fifths (38 per cent) disagreed.

More than half of respondents (54 per cent) agreed that the descriptors were clear and easy to understand. Almost a third (29 per cent) disagreed.

Almost two-fifths (39 per cent) of respondents agreed that it would be easy for them to select a descriptor to describe their own ability to plan and follow a journey. However, close to half (46 per cent) disagreed.

Confusion around criteria

Participants and survey respondents expressed confusion around different areas of the Planning and Following Journeys criteria. Some stated that they were initially

unsure of what was being considered in this section, particularly whether the descriptors were relating to only physical, or physical and psychological aspects.

The uncertainty over which areas were being examined through these criteria was reflected in confusion over how to select descriptors. A few suggested renaming the section to improve understanding of what was being considered.

Separating different elements

A number of suggestions made by participants and respondents related to separating out different elements from the Planning and Following Journeys criteria, which they viewed as distinct issues requiring different approaches.

Some participants suggested that the planning stage should be separated from actually undertaking a journey as they relate to different abilities. Survey respondents were asked if they agreed or disagreed with the suggestion to separate planning and following journeys. There was strong support for this, with the vast majority (83 per cent) agreeing.

Some participants and respondents suggested that mental health, cognitive and physical conditions that affect mobility should all be addressed as separate elements.

A few respondents and participants suggested that separate criteria could be used for different types of journey, for example, familiar and unfamiliar. More than three-quarters (77 per cent) of survey respondents agreed with this suggestion.

Mental health and cognitive conditions

A few participants noted that their mental health was unpredictable, and sudden flare-ups could leave them unable to travel. They felt that the current criteria do not offer enough flexibility to account for this. Others commented that they felt the criteria had only limited use for understanding the circumstances of individuals with conditions such as sight loss, cognitive conditions, and those who are neurodiverse.

Journeys

Some participants and respondents stated that there were differences in types of journey that would be important to account for, particularly if the mode of transport resulted in additional difficulties for the person making the journey.

Some survey respondents highlighted that the criteria do not cover a person's ability to navigate any obstacles that are encountered on familiar or unfamiliar journeys, and how these may influence the person through additional stress and anxiety.

Respondents and participants also highlighted that people may experience varying abilities during the journey itself, and that these can be due to diminishing ability over time or unexpected issues which are difficult to account for when selecting criteria. Examples included mental tiredness ('brain fog'), physical fatigue,

unpredictable conditions, needing assistance from another person, stress and anxiety.

Distress

A few participants and respondents noted that while they were able to plan and follow the route of a journey, this could sometimes cause significant distress through stress and anxiety in the lead up to actually undertaking travel, without fully preventing it. Some participants and respondents stated that they felt situations where someone experienced overwhelming psychological distress should score more points.

A few participants and respondents wanted to see a clear definition of what constitutes overwhelming psychological distress. More than three quarters (76 per cent) of survey respondents agreed with the suggestion to include a definition of 'overwhelming psychological distress.'

Use of orientation aids

Some participants and respondents' comments reflected uncertainty around what counts as an orientation aid. These commonly referenced mobile phones and digital map applications that are widely used by people when planning and taking journeys, regardless of whether or not they have a health condition.

One participant suggested that aids be removed from the decision-making process, so that only a person's unaided ability is considered. Survey respondents were asked if they agreed or disagreed with this suggestion, with almost three-quarters (71 per cent) agreeing.

Fluctuating Conditions criteria

General views on the Fluctuating Conditions criteria

Almost half of respondents (45 per cent) agreed that the Fluctuating Conditions descriptors were suitable for understanding how someone's condition can fluctuate. However, more than a third (35 per cent) disagreed.

Responses were mixed regarding how clear and easy to understand the descriptors were, with slightly more respondents disagreeing (41 per cent) than agreeing (39 per cent).

When asked if they found it easy to select a descriptor that reflects their own fluctuating condition (if they have one) more respondents disagreed (51 per cent) than agreed (31 per cent).

Positive feedback

A number of participants provided positive feedback on the fluctuating conditions criteria. Comments included that the 50 per cent format was an improvement, and that changes placing an increased focus on time, safety and fatigue were welcome.

Confusion over criteria

However, a number of participants and survey respondents commented that they found the criteria to be too complicated and confusing. In some instances, this confusion led to a misunderstanding of the circumstances that the descriptors were outlining.

Difficulty using set criteria and measurements

Many participants and respondents commented that they found it difficult to think of how their conditions affect them in terms of percentages or averages, particularly where this was a long-term condition. Survey respondents were asked to comment on a suggestion to provide an example for fluctuating conditions that illustrated what the percentages might look like in terms of number of days, with slightly more than half (59 per cent) agreeing.

Other participants stated that they needed a more flexible and holistic way to describe how their condition affected them. Survey respondents were asked to comment on a suggestion to have greater flexibility through looking at an individual's circumstances holistically, with the vast majority (86 per cent) agreeing.

Unpredictable conditions

Many participants and respondents described the unpredictability of fluctuations as a major challenge to measuring their conditions against the criteria. Some commented that the criteria are unsuitable for when a condition is also seldom triggered, despite being serious, and described issues with categorising such a condition as 'fluctuating'.

Some participants and respondents referred to how their condition can be triggered by a wide range of different factors, making it hard to estimate fluctuations within the percentage criteria. Others highlighted that they could limit how often their condition was triggered by adapting their lifestyle, restricting what they do and lowering their quality of life. These participants suggested that the decision-making process needs to be more aware of how meeting a certain criteria can be related to these life-limiting adaptations.

Automatic qualification

Some participants and respondents felt that there should be automatic qualification for certain conditions or where many different conditions have a cumulative impact. Almost all (93 per cent) survey respondents agreed with this.

Criteria open to abuse or irrelevant

Finally, some participants and respondents commented that they felt the fluctuating conditions section was irrelevant or open to abuse, suggesting that people would self-assess based only on their worst days.

Cross-cutting comments

There were a number of points raised by participants and respondents that applied across all criteria or more generally to the decision-making process.

Many participants and respondents suggested that the decision-making process needs to be tailored to the particular conditions that an individual has.

Some participants and respondents suggested that mental health needs to be considered separately from any mobility issues. Survey respondents were asked if they agreed or disagreed with the suggestion to have a separate section covering mental health. The majority (58 per cent) agreed, however almost a fifth (18 per cent) disagreed.

Some participants and respondents said mental health conditions should be formally recorded within the decision-making process. Others highlighted that the application process is too difficult for unsupported individuals with mental health conditions.

Some participants and respondents suggested that the decision-making process should make better use of a person's medical history or the input of health professionals to determine how they are affected by a condition. A few participants noted that it is important to be aware of when someone is self-managing symptoms and rarely or never visits medical professionals, as this will reduce the supporting information that is available to them for applications.

Finally, some participants suggested ways of making the application process more accessible. These included having examples which would help applicants understand what the criteria were asking about or providing applicants with alternative means of communicating about their condition, such as storyboards.

Background and methodology

Background

Adult Disability Payment (ADP) is the twelfth payment now delivered by Social Security Scotland. It replaces the Department for Work and Pensions (DWP) delivered Personal Independence Payment (PIP) in Scotland, and it will provide support to over 600,000 disabled people by 2027. Over the next couple of years, people in Scotland who are in receipt of PIP or working-age Disability Living Allowance (DLA) will be transferred to ADP.

Work to transfer people's payments from the UK Government to Social Security Scotland has started and it will take a few years before everyone has moved onto ADP. The Scottish Government are committed to the safe and secure transfer of people's payments from DWP to Social Security Scotland.

In designing this new payment, the Scottish Government has carefully listened to the views of disabled people, stakeholders, and the public, and have made several improvements that aim to provide disabled people with a more positive experience compared to PIP.

The eligibility rules for ADP have remained largely the same as under PIP as part of the Scottish Government's commitment to a safe and secure transition of the devolution of social security payments. This is to avoid having two sets of eligibility criteria before completing the transfer of people's payments from the UK Government to Social Security Scotland by 2025.

The Scottish Government is committed to an independent review of ADP. As part of this review, it is important to monitor the impact of any changes already made, and to gather the views and experiences of people who will be or already are using ADP. The Scottish Government has already conducted the [Adult Disability Payment: Consultation on the Mobility Component](#) as part of this work.

This report presents the findings from research conducted as part of the groundwork to prepare for the independent review of ADP. The aim of the research was to understand the views of Experience Panel members regarding the current eligibility criteria for mobility component of ADP. This included areas where panel members would like to see changes, and to gather suggestions as to how changes could be implemented.

The findings from this work will be passed to the independent review to consider. Given the need to prioritise the safe and secure transfer of social security payments, the Scottish Government does not intend to make changes to the eligibility criteria before the case transfer process is complete. Allowing the independent review the opportunity to consider all of the evidence holistically will ensure consistency and coherence in any recommendations for future improvements to the payment.

Methodology

The Scottish Government is now responsible for some of the benefits previously delivered by the UK Government DWP. As part of the work to prepare for this change, in 2017 the Scottish Government set up the Social Security Experience Panels. Over 2,400 people who have recent experience of receiving at least one of the benefits devolved to Scotland registered to take part in the Experience Panels when they were launched.

Experience Panels members were invited to take part in a series of focus groups and interviews to give their views on changes to the eligibility criteria for the mobility component of ADP. The research took place concurrently to fieldwork on topics relevant to [Scotland's social security system: enhanced administration and compensation recovery consultation](#).¹

For the research on ADP, panel members were asked for their thoughts on the eligibility criteria used in the decision-making process for mobility, planning and following journeys, and fluctuating conditions. They were also asked about their personal experiences of using the descriptors, their thoughts on any positive or negative aspects of the descriptors, and any ideas they had for how mobility needs could be considered differently.

The research took place in two stages. The first stage ran during October and November 2022, and consisted of interviews (in-person, by telephone and online), and in-person focus groups. These were the first in-person sessions held with panel members since the COVID-19 pandemic. These interviews and focus groups were supplemented by a second stage of research, consisting of an online survey conducted from May to June 2023.

The data have been analysed by Scottish Government researchers. Participation in research with Experience Panels members is optional and it is important to note that the findings contained in this report only represent the views of panel members who took part in the project. Assumptions cannot be drawn on the wider applicability of these findings to panel members as a whole or for those with experience of the social security system in general.

Interviews and focus groups

All active Experience Panels members were invited to take part in focus groups and interviews between October and November of 2022.

Overall, 34 participants took part in this first phase of the research. A total of three focus groups focusing on ADP² took place in Glasgow, consisting of 19 participants

¹ For the report on these topics see [Social Security Experience Panels: Enhanced Administration Powers - re-determinations and appeals, fraud and special measures for COVID-19](#)

² As outlined earlier, fieldwork also covered topics from the Enhanced Administration and Recovery Consultation. Including these additional topics, five focus groups with 30 participants took place in total.

overall. In addition, 15 interviews took place. 10 interviews were conducted remotely by telephone or video call and five interviews took place face-to-face during a research event in Inverness.

Quotations from the focus groups and interviews are used to illustrate the findings discussed in the report. Minor edits to improve readability were made as appropriate. Those who took part in an interview or focus group are referred to as participants throughout the report.

Participant demographics

Where possible, information from interview and focus group participants was matched to demographic information previously supplied by Experience Panels members. Linking was not possible where there was missing or unclear information. The following demographic information is included to give context to the findings of this report. Due to the small numbers involved in the interviews and focus groups, detailed demographic information is not given to preserve anonymity for those who took part.

More women than men took part in the interviews and focus groups. Almost two-thirds of participants identified as woman, girl or female, and around a third identified as man, boy or male. More than three-quarters said that they were heterosexual or straight. Almost a quarter were aged 25-44 years old, two fifths were aged 45-59 years old, and just over a third were aged 60-79 years old. Most participants lived in urban areas. The majority were white, with less than one in ten from a minority ethnic background.

Nearly two-thirds of participants cared for an adult or child with long term health condition, or an adult who needs support due to old age. The majority had a disability or a long-term health condition, and two-thirds had a physical disability.

Follow-up survey

Following the first stage of research an initial analysis was carried out of the data gathered from the interviews and focus groups. On the basis of this analysis, a follow-up survey was created and distributed to 1,840 Experience Panels members. A total of 191 panel members completed the survey from May to June 2023. We refer to those who completed the survey as respondents throughout the report.

The survey asked respondents to provide feedback on the criteria for each element (Moving Around, Planning and Following Journeys, Fluctuating Conditions). Respondents were also asked whether they agreed or disagreed with some suggestions for how to improve the criteria or decision-making process that were made by panel members during interviews and focus groups.

It is important to note that, in discussing the suggestions made by other panel members, this research was not setting out or advocating for a preferred Scottish Government position or policy. These suggestions do not represent a specific commitment from the Scottish Government to implement any of the changes

included, and were asked only as part of exploratory work to understand to what extent Experience Panels members agreed or disagreed with these ideas.

Survey respondent demographics

Where possible, information from survey respondents was matched to demographic information previously supplied by Experience Panels members. Linking was not possible where there was missing or unclear information. The following demographic information is included to give context to the findings of this report. A full breakdown is provided in Annex A.

Just over half of survey respondents identified as woman, girl or female, with around two-fifths identifying as man, boy or male. The majority were heterosexual or straight. Most respondents were white. Around one in ten were aged 25-44 years old, almost half were aged 45-59 years old, and around two-fifths were aged 60-79 years old. Just over three quarters lived in urban areas, with around a quarter living in rural areas.

Just over half of respondents cared for an adult or child with long term health condition, or an adult who needs support due to old age. Almost all had a disability or long-term health condition, and around three-quarters had a physical disability.

Background information on respondents' benefits

Survey respondents were asked to provide some basic background information on which benefits they receive and when their last assessment or consultation for a benefit was. More than nine in ten respondents (93 per cent) were receiving a benefit. Almost three-quarters (74 per cent) were currently in receipt of PIP, with one in ten (11 per cent) receiving ADP.

Table 1. Do you currently receive any of the following benefits? (Tick all that apply) (n=175)

Benefit	% of respondents*
Personal Independence Payment (PIP)	74
Disability Living Allowance (DLA)	14
Adult Disability Payment (ADP)	11
Child Disability Payment (CDP)	#

*Figures do not add to 100 per cent due to rounding and because some respondents received more than one benefit.

- Result suppressed as percentage is lower than 5.

Respondents were asked which benefit or benefits they had undergone assessments or consultations for. The majority (72 per cent) had been assessed or consulted for one benefit, and just over a quarter (28 per cent) for two benefits. Overall, more than four-fifths (82 per cent) of respondents had been assessed for PIP, two-fifths (41 per cent) for DLA. Only 5 per cent had undergone a consultation for ADP.

Table 2. Have you ever had an assessment or consultation conducted for any of these benefits? (Tick all that apply) (n=179)

Benefit	% of respondents*
Personal Independence Payment (PIP)	82
Disability Living Allowance (DLA)	41
Adult Disability Payment (ADP)	5

*Figures do not add to 100 per cent because some respondents had been assessed or consulted for more than one benefit.

Respondents were also asked how recently they had undergone an assessment or consultation for one of their benefits, and which benefit this was for. A fifth (21 per cent) of respondents had their most recent assessment or consultation in the last year. Almost half (49 per cent) had their most recent assessment or consultation between one and five years ago, and nearly a third (30 per cent) more than five years ago. More than three quarters (78 per cent) of respondents had their most recent assessment or consultation for PIP.

Table 3. When was your most recent assessment or consultation? (n=182)

	% of respondents*
Within the last year	21
Between one and five years ago	49
More than five years ago	30

*Figures may not add to 100 per cent due to rounding.

Table 4. Which benefit or payment was your most recent assessment for? (n=180)

	% of respondents*
Personal Independence Payment (PIP)	78
Disability Living Allowance (DLA)	15
Adult Disability Payment (ADP)	7

*Figures may not add to 100 per cent due to rounding.

Moving Around criteria

Panel members were asked for their views on the Moving Around criteria. This included any positives or negatives that they saw, their thoughts on the distances used and their own ideas for how a person's mobility needs could be considered differently. Participants were also asked about any hidden costs to mobility that they feel Social Security Scotland should be aware of.

The eligibility criteria for the Moving Around activity is set out below, along with the number of points for each descriptor:

Descriptor	Points
a. Can stand and then move more than 200 metres, either aided or unaided.	0
b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided.	4
c. Can stand and then move unaided more than 20 metres but no more than 50 metres either aided or unaided.	8
d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres, either aided or unaided.	10
e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided.	12
f. Cannot, either aided or unaided,— (i) stand, or (ii) move more than 1 metre.	12

There have been some changes to the Moving Around element of the decision-making process which were introduced as part of ADP. These include looking at a person's ability to stand and move when outdoors, without symptoms of severe discomfort, pain or fatigue. Breathlessness may be considered as a symptom of severe discomfort. It also considers how quickly someone can walk and the risk of falls, and the types of surfaces that someone might encounter outdoors, such as kerbs and pavements.

Although these changes were active at the time of the first phase of research, the information was not yet available for inclusion in the research guides that participants were provided. Where relevant, this has been noted to provide context to the comments made by participants from the first phase of research.

General views on the Moving Around criteria

Survey respondents were asked to provide some general feedback on the Moving Around criteria based on:

- How suitable they thought the descriptors were for understanding someone's ability to move around.
- How clear and easy to understand they found the descriptors.
- How easy they found it to choose a descriptor which reflects their own level of mobility.

Suitability

Almost half of respondents (49 per cent) disagreed that the descriptors were suitable for understanding someone's ability to move around, with a quarter (25 per cent) strongly disagreeing with this statement. However, just over a third (36 per cent) agreed that the descriptors were suitable and 15 per cent had no strong opinion.

Table 5. The descriptors are suitable for assessing someone's ability to move around (n=191)

	% of respondents*
Strongly agree	6
Agree	30
Neither agree nor disagree	15
Disagree	24
Strongly disagree	25

*Figures may not add to 100 per cent due to rounding.

Understanding

Almost half of respondents (47 per cent) thought that the descriptors were clear and easy to understand. Overall, responses were mixed with around a third (32 per cent) disagreeing with the statement and a fifth (21 per cent) neither agreeing nor disagreeing.

Table 6. The descriptors are clear and easy to understand (n=189)

	% of respondents*
Strongly agree	10
Agree	37
Neither agree nor disagree	21
Disagree	19
Strongly disagree	13

*Figures may not add to 100 per cent due to rounding.

Using the descriptors

Half of respondents (50 per cent) disagreed that they would find it easy to choose a descriptor or descriptors that reflected their own level of mobility, with a quarter (25 per cent) strongly disagreeing. Two-fifths (38 per cent) agreed and just over one in ten (12 per cent) neither agreed nor disagreed.

Table 7. Thinking about my own level of mobility, it is easy for me to choose a descriptor (or descriptors, where a condition fluctuates) that reflects this. (n=187)

	% of respondents*
Strongly agree	9
Agree	29
Neither agree nor disagree	12
Disagree	25
Strongly disagree	25

*Figures may not add to 100 per cent due to rounding.

Positive feedback

Descriptors are clear and easy to understand

A few interview participants provided positive feedback, noting that they found the criteria to be clear and easy to understand. One participant felt that the wording, explanation and layout were clear.

“It is clearer than the PIP form and it does make a clear difference between can you do it unaided, or can you do it aided? [...] So, it is better in that respect and it’s better laid out because it tells you how many points each one gets and it’s spaced out between them. A big problem with PIP is that it’s just one big massive block of writing, at least this is spaced out a bit.” (Interview participant)

Others stated that they found the distances used in the different descriptors helpful as they provided a clear measure to compare their mobility against.

“The positive is that there is a measure that can be used, whereas just going on impressions or thoughts is very difficult, so it’s actually defined [...] I can see the benefit of having a measurable distance.” (Interview participant)

Use of distances

Many participants highlighted areas of the criteria which they thought did not work well or needed improvement. This included the use of distances, which was criticised for a variety of reasons across a range of different topics.

Revising distances

Many participants stated that they thought the distances used were too short, and so felt that some people may be excluded from the support which they need. Some suggested that there should be automatic qualification for mobility support for all people who cannot move more than a lower limit (e.g. 10 or 50 metres).

“But as a person looking just at the broad criteria it seems that you have to be virtually completely immobile in order to qualify for the higher rate of mobility, which seems a little harsh. Personally, I would think that somebody who is unable to get more than 50 metres unaided or with a stick or so on, should really be getting quite a big help with their mobility needs.” (Interview participant)

“To me, surely you just put on a lower limit where if the person can’t walk unaided for more than 10 metres then, surely they qualify for some sort of mobility component.” (Interview participant)

A few participants suggested that distances should be removed altogether in favour of a broader question framed around whether or not someone needs assistance with their mobility.

“I think that’s unhelpful, I think it’s just, do you need any sort of help moving around? I don’t think it should be can you do 50 metres to 100 metres? You can either do it or you can’t. So you’re either on crutches or in a wheelchair, or some other physical disability which means that you can’t do it, so there shouldn’t be a limit: you either can or you can’t.” (Interview participant)

Variable mobility and set distances

A few participants and respondents commented that their mobility can vary from day to day, making set distances an unsuitable way of assessing how far they can move. One respondent commented that they felt these variations in ability were not properly considered during DWP assessments.

“Personally, and mainly based on DWP assessments, variability in my ability was not considered. Aiming to walk a certain distance each day does not mean that this can always be achieved and should not be assessed as such.” (Survey respondent)

Understanding distances

Many participants stated that they found the distances abstract and hard to understand, making it more difficult for them to match the descriptors used to their own level of mobility.

“It is really difficult. I’m not really sure of the distances, like, how far? Like, the window to the door there, how far is it to there?” (Interview participant)

“I just got lost in it. It’s quite complicated and also, like it says 200 metres and things – personally, that means nothing to me. So, 200 metres, I wouldn’t have a blind clue because I don’t really have a picture in my head of how much 200 metres is.” (Interview participant)

A few participants suggested that the distances would be more understandable if different units of measurement were used. One focus group discussed that feet would be more in line with standard UK measurements.

Participant 1: “I still don’t really do metres.”

Participant 2: “Metres is odd here seeing that most of the measurements here in the UK are feet and inches.” (Focus group discussion)

One participant suggested using visual guides to help applicants visualise how far the distances are.

“Like, say if you put drawings on them and then they could sort of mark how far. I think that would be [the clearest way] because a lot of folk might not understand the words [...] you could get diagrams of what folk could do.” (Interview participant)

Use of DWP measurements

Finally, some participants commented that they felt the distances used in the criteria were only present because they had been carried over from DWP

processes. These participants felt that this should be avoided in future, particularly where the rationale for Social Security Scotland using elements of the DWP decision-making process was not clear.

Participant 1: “Why do we have these ambiguous figures of 200 metres, of 50 metres? Why did these figures materialise? Where have they come from? They’ve come from somewhere, haven’t they?”

Participant 2: “I think it comes from the DWP [...] When creating this thing it’s understandable to look at how the DWP did things. It makes sense. But it should be an example of what not to do.” (Focus group discussion)

Accounting for additional factors

Many participants and survey respondents commented that, in addition to distance, other factors need to be considered within the decision-making process when looking at an individual’s ability to move around. A variety of suggestions were made and are outlined below.

The majority of these suggestions (relating to types of surface, pain, fatigue, time and balance) are already reflected within the decision-making process used by Social Security Scotland, as outlined on page 18.

It is important to note that while details of these changes were not available at the time of the first stage of fieldwork in autumn of 2022, the survey that formed the second phase of research did outline the inclusion of these factors within decision-making processes. However, a significant number of survey respondents still mentioned these as areas of concern. The points below are therefore summarised from both stages of research.

Pain, consequences of moving and consistency

Many participants and survey respondents stated that there should be more consideration given to how a person feels while moving, for example if they experience pain. Some participants commented while they would be able to move the set distances, it would cause them considerable pain, which may be felt at the time of movement or over the following days.

“I could do distances. So, the distance is irrelevant for me. It’s the awkwardness and the time consuming and the time around it, and the pain involved.” (Interview participant)

“I’m always in pain but most of the time the pain is manageable, just about. But there are days where it’s completely unbearable and I think that’s a factor that should be taken into consideration as well. Rather than just can you walk 20 metres, what’s the cost of you walking that 20 metres? Are you going to pay for it the next day in pain levels?” (Interview participant)

Although the decision-making process does consider the pain experienced by individuals when moving, participants and respondents still felt that there needed to be a better understanding of this.

“Questions should be clear that it means when you are in pain and/or discomfort when walking instead of asking if you can walk so many metres.” (Survey respondent)

Suggestions included doing this either through some measurement of pain levels or through considering a person’s ability to move consistently and on a regular basis, including the need for rest as a result of movement.

“Include a basic measurement of pain for each condition and activity e.g. 0-10 as practiced by NHS. This would enable the assessor to understand which activities can cause the most pain in relation each of the claimant’s conditions.” (Survey respondent)

“For someone with [multiple sclerosis] or in that kind of line, they might be able to do it today, but they can’t do it tomorrow. Or they can do it today but they’re in their bed three days on the back of it because they’ve pushed through. So, I think it needs to be in the broader sense can you do these things on a regular consistent basis, rather than as a one-off.” (Interview participant)

As part of the follow-up survey, respondents were asked if they agreed with the criteria asking if they can do these things on a regular, consistent basis, rather than as a one-off. The majority of respondents (75 per cent) agreed with this suggestion.

Table 8. The criteria asking: “Can you do these things on a regular, consistent basis, rather than as a one-off?” (n=188)

	% of respondents*
Agree	75
Disagree	13
Neither agree nor disagree	12

*Figures may not add to 100 per cent due to rounding.

Surfaces

Some participants and survey respondents highlighted that it is important to consider the kind of surface a person is walking over, for example rough or uneven surfaces, or walking up an incline or stairs.

“None of these things mention what surface the person stands on. Standing on this wooden floor is quite easy for most people. But get them to stand out on a street corner where they’ve got angles, uneven pavements, maybe deteriorated pavements, some people might not be able to stand on that.” (Interview participant)

Others commented that they felt this was a hidden dimension of how mobility can be limited depending on the type of movement that is being considered.

“I noticed that some people can actually walk on a flat surface, but they can’t actually walk up the stairs. Because if you say to someone, if they can actually walk unaided, yes, they can. But they might not be able to actually walk up the stairs.”
(Focus group participant)

One respondent highlighted that where a person lived affected the kinds of surfaces which they encountered on a day-to-day basis, for example people in rural areas who have to use unpaved surfaces.

“Need to consider that not everybody lives in a place with kerbs and pavements but in rural areas where there are none of these and very uneven surfaces.” (Survey respondent)

Time

Several participants noted that the length of time it takes to travel a set distance is as important as the distance itself.

“There’s also an element of how long will it take to do these things?” (Interview participant)

“Say I’ve got to stop, 15 times, in doing that, is there a timescale on the distance that you walk - the 200 metres - as well? Or is it just a case of, well, you can walk 200 metres in an hour so you’re fine.” (Interview participant)

Others highlighted that they think in terms of time rather than distance when considering journeys e.g. a five or ten minute walk, rather than 200 metres. One participant suggested that travel time should be used in the decision-making process in addition to distances.

“Put an assessed time on it, for walking the distances.” (Interview participant)

Respondents were asked to comment on this suggestion as part of the follow-up survey. Responses were mixed, with just over a third of respondents (39 per cent) disagreeing, compared to similar numbers agreeing (34 per cent) and just over a quarter (27 per cent) neither agreeing nor disagreeing.

Table 9. “Put an assessed time on it, for walking the distances.” (n=186)

	% of respondents*
Agree	34
Disagree	39
Neither agree nor disagree	27

*Figures may not add to 100 per cent due to rounding.

Balance and confidence

Several participants and survey respondents suggested that the decision-making process should look at how an individual’s balance can affect their mobility. Both in terms of trips or falls, and how poor balance can create the need for additional support when moving around or reduce confidence in moving.

“What about using the word balance? Because that’s part of my daughter’s problem, and I’m sure a lot of disabled people struggle with their balance. If you can’t balance at all without holding on to something, you need help moving around and just because your balance is poor and you need help doesn’t mean you can’t walk at all, you can’t make the effort. So, balance for me is part of the issue with this.” (Interview participant)

“And there’s also the mental thing that goes along with [balance], because if you’ve had some bad falls then that affects you mentally.” (Focus group participant)

Stamina and limits of mobility

A few participants and respondents suggested that stamina needs to be considered during the decision-making process, and that it would also be important to understand the limits of a person’s mobility, particularly when fatigue becomes an issue.

“The ability to repeat the task over a day should be assessed. Conditions can fluctuate but also deteriorate rapidly when repeated.” (Survey respondent)

“One of the things that it doesn’t take into account is stamina and capacity for anything more than 200 meters [...] I think it might be worthwhile saying ‘How far could you walk, unaided, without being tired or needing help?’” (Interview participant)

As part of the follow-up survey, respondents were asked whether they agreed or disagreed with the suggestion to ask how far a person could walk without being tired or needing help. The majority (66 per cent) agreed, as summarised in Table 10 below. However, almost a fifth (19 per cent) disagreed.

Table 10. The criteria asking: “How far could you walk, unaided, without being tired or needing help?” (n=189)

	% of respondents*
Agree	66
Disagree	19
Neither agree nor disagree	15

*Figures may not add to 100 per cent due to rounding.

Effects of medication

A few participants and respondents suggested that decisions should take account of any significant side effects from medication which may affect mobility, particularly where these result in issues not directly caused by an individual’s condition.

“By looking at actual effects of medication that the person has described – they don’t have to look at the side effects on every single label. But, if the person is describing a significant side effect, don’t ignore it.” (Interview participant)

A holistic approach to mobility

Some participants stated that asking about the distance that someone can move is a one-dimensional approach to mobility which cannot fully capture their own experiences, and that a more holistic approach is required. A few participants linked together some of the factors outlined above, describing how the intersecting and mutually affecting aspects of their conditions influenced their mobility. For example, where anxiety over moving worsens the consequences of moving.

“It’s not, for me, the distances, it’s the time and the pain and I get anxious, you know, because you’re always going to be somewhere, so you want to be there quickly. But, in my case, as soon as I try to speed up, because I’m very slow anyway, [with my condition], speed makes it worse.” (Interview participant)

Everyday situations

Others suggested that a better way to understand an individual’s mobility would be to ask about their ability to manage within everyday, real-life situations.

“Not just saying, let’s just look purely at what you’re physically able to do. Let’s look at this in what real world situations you would come up against. If we dumped you in the middle of a supermarket with lots of things around you – which is an everyday situation that a lot of people find themselves in – which one of these descriptors would apply? None of them would apply.” (Interview participant)

“I think there should be categories for like, everyday sort of things. Like, can you carry a shopping bag? Obviously if it’s a day with my two sticks it’s just not possible. Even if it’s a one stick day, carrying heavy shopping just isn’t a thing for me. [...] So I think there should be, everyday tasks, and not just, how far can you walk. ‘Cos a person could be able to walk like 10, 20 metres, but what’s the point of walking 10, 20 metres if you can’t do anything except walk those metres or whatever. What’s the point of walking if you can’t do anything else? You can’t do your shopping, can’t you know, take a dog for a walk or you can’t complete an everyday task, doing the gardening, whatever. There should be more scope and variance, not just, can you walk this far.” (Interview participant)

As part of the follow-up survey, respondents were asked if they agreed or disagreed with the suggestion to include categories for everyday actions within the criteria. The majority of respondents (70 per cent) agreed with this suggestion.

Table 11. The criteria including: “Categories for like, everyday sort of things. Like, can you carry a shopping bag? [...] more scope and variance [to what mobility means], not just can you walk this far.” (n=188)

	% of respondents*
Agree	70
Disagree	14
Neither agree nor disagree	16

*Figures may not add to 100 per cent due to rounding.

Describing mobility

Some participants suggested that the complexity and variety of factors that influence mobility meant an open-text format - where people could describe how their condition or conditions affect their mobility - would be more suitable than choosing from different criteria.

“Would it not be better just to get a description from somebody on how they get about and the difficulties that they have, and then make a kind of judgement? [...] I think there are so many variations on disability that I don’t think you can put it down to a points system where you’re only deciding to judge on a person’s ability to walk.” (Interview participant)

“Describing what happens when you’ve been walking for a period of time. Can you walk on a level? Can you walk on a slope? Can you walk on an uneven ground? [...] Being able to describe it. It’s not a yes or no question, it’s a situation that has a context.” (Interview participant)

Survey respondents were asked if they agreed or disagreed with the suggestion to have a space available for describing what happens after they have been walking for a period of time. The majority of respondents agreed (75 per cent), with less than one in ten (9 per cent) disagreeing.

Table 12. “[Have a space to describe] what happens when you’ve been walking for a period of time. [...] Being able to describe [the context around walking].” (n=187)

	% of respondents*
Agree	75
Disagree	9
Neither agree nor disagree	16

*Figures may not add to 100 per cent due to rounding.

One respondent noted that even if additional space was provided for someone to describe how their conditions affect them, this may not be an accessible method for everyone. They also noted that the length of time someone has been living with a condition can affect how well they are able to self-assess and describe its effects on them.

“Questions fail on 2 things: 1) a person's ability to self-describe in clear prose is subjective. Few have that self-awareness or writing skill. 2) if someone spent 20 years getting incrementally worse, describing their reality to a fit person is impossible.” (Survey respondent)

Individual symptoms or effects

For some survey respondents, it was particularly important that an individuals’ mobility needs be considered on the basis of their specific conditions and individual symptoms. Comments highlighted that respondents felt no two people experienced conditions in the same way, and that for those whose conditions have been deteriorating over a long period of time, it may be especially difficult to self-evaluate in the way required by the current criteria.

“It depends on each person, everyone is different.” (Survey respondent)

“With some life-long diagnosis where there is no cure only therapy, it is virtually impossible to give an accurate gauge, it really is time to stop persecuting these people with lengths, times, and assumptions.” (Survey respondent)

A few participants and respondents commented that a more holistic approach is required for people with visual impairments. They highlighted that these individuals

may have good mobility and be able to walk the distances used in the descriptors, but face other challenges which limit moving around, for example, blurred vision.

“I would prefer that mobility be considered as a whole person activity, with personal risk versus benefit being taken into consideration, for example walking with blurred or double vision.” (Survey respondent)

Using aids

Some participants and survey respondents highlighted that they were unsure how the use of a mobility aid related to the criteria and how they should self-assess based on their use of aids, particularly where this results in very different levels of mobility when compared to moving without an aid.

“Aided vs Unaided is an issue. Not everyone has an aid, and just because you do, it doesn't mean you can walk. What is an aid? A crutch/person/other? Each has a different impact on ability and independence. What about the why? Pain, muscle control?” (Survey respondent)

“If youse could break it down, dumb it down, so's that somebody like myself would be able to understand the difference between walking aided with a crutch down the stairs to your living room, to a total of maybe a couple of feet, to having to use a wheelchair when you're outside and not walking at all. If the wheelchair is down as one of the aids in your descriptors I think you need to explain, dumb it down, so that we understand it more.” (Interview participant)

A few participants commented that if an individual is capable of moving when using an aid, but not without, this should not result in a lower score.³ These participants expressed a preference for mobility to be considered only on the basis of unaided movement.

“It is very easy for someone to use a Zimmer frame, for example, or a walker which means they can move more than 1 metre. But, take the walker away so they're unaided and immediately they can't do that, they're into [descriptor] F. So, you when you say aided or unaided, a lot of people who use aids can do better with aids than without, so should it be the case that the person with an aid should be penalised in that respect? [...] It's the aspect of, an aid can enable you to do something, but it should be a case of you should be assessed on the ability without the use of supports.” (Interview participant)

³ In situations such as this, where an individual was unable to move or walk unaided, but could walk 200 metres while aided then descriptor A would, based on this information alone, be correct. However, it is important to note that their case would also be considered in the context of the reliability criteria i.e. how are they affected by walking? Can they do it safely? How long does it take them? Depending on these circumstances the Case Manager may then decide that a different descriptor is more appropriate, seeking additional input from a Practitioner or the Decision Support Team if they need further guidance.

Relatedly, one focus group participant pointed out that movement with an aid is conditional and depends on having access to that aid, meaning that aided and unaided movement cannot be considered equally.

“If they are aided or unaided, they’re not necessarily the same. Some people might be able to do it aided, but they might not have aid.” (Focus group participant)

Other suggestions

There were various other suggestions made by participants and survey respondents, which are covered in brief below.

Increased involvement of health professionals

Some participants and respondents suggested that there should be a greater involvement from health professionals in the decision-making process. Suggestions included granting health professionals the authority to trigger a review of a person’s mobility needs, and including in the decision-making process any recommendations or observations made by them.

“A review should be triggered if your health professional thinks it’s required. [...] That’s probably something where your health professional can say, ‘Right, I think you need to trigger this with the social security because your mobility has changed.’ I think it’s something that you should be able to ask for, rather than be assessed by.” (Interview participant)

“Assessments should include reports from medical personnel regarding clients’ capabilities.” (Survey respondent)

Face-to-face meetings and consultations

An important difference between ADP decision-making processes and those used by the DWP for PIP, are that there are no UK Government-style assessments. For ADP, people are only invited to a consultation on occasions when Social Security Scotland require more information so that they can make a decision. In addition, there aren’t any degrading functional examinations, such as asking a person to “touch their toes”. However, previous experiences of DWP assessments led to participants and respondents holding mixed views on whether consultations should take place in person or through another means.

A few participants stated that they would prefer to have face-to-face meetings when a consultation was required as part of the decision-making process with Social Security Scotland. One participant commented that they felt a previous phone assessment by DWP had resulted in a negative outcome as they were not able to communicate well with the person conducting the assessment, combined with a lack of knowledge about their conditions.

“I think [the reason that the outcome was negative for me] partly is the assessment was done over the phone, by somebody who didn’t know anything about the health conditions that I have.” (Interview participant)

However, others described previous face-to-face assessments with DWP as stressful and demeaning, leading to a preference for having face-to-face consultations removed from Social Security Scotland where possible.

“It’s just face-to-face, you know, it’s nerve-wracking. Getting watched, and also, face-to-face you’re getting, ‘Oh, can you do exercises?’ you know, lift your leg – that’s demeaning.” (Interview participant)

Accounting for temporary conditions or mobility issues

One focus group participant described a situation where a neighbour had been refused support for a serious mobility issue by DWP because the condition had been viewed as temporary. They suggested that there should be some support available for short to mid-term conditions which seriously affect a person’s mobility.

“That was a really bad situation for her for at least six months, because she couldn’t move – she was laid on her front for three months. Then she had to learn how to walk, how to move and everything but they still wouldn’t agree that she was actually disabled. [...] [The DWP] were thinking that within three or five months she will be fine to do her activities, but actually she was restrained from doing so many things because of her spinal cord [...] she couldn’t actually leave home sometimes.” (Focus group participant)

Preferred areas of change

As part of the follow-up survey, respondents were asked to consider some areas for change within the mobility criteria. These were broad suggestions rather than specific changes, which respondents were asked to rank by preference from most to least important. The three suggestions were:

- 1) An increased focus on everyday tasks and activities which involve moving around.
- 2) Reconsidering the distances used.
- 3) Taking a more holistic look at a person’s mobility needs, taking into account personal, environmental and health circumstances.

The most popular suggested area for change was number 3 – taking a more holistic look at a person’s mobility needs – which almost two-thirds (64 per cent) of respondents chose as their first preference. The least preferred option was number 2 – reconsidering the distances used – which was ranked as least important by almost half (47 per cent) of respondents. Table 13 below shows the number and percentage of respondents for each option who ranked it as the most important area for change.

Table 13. Most preferred area for change within moving around criteria (n=186)

Option (from most to least popular)	% of respondents*
3) A more holistic look at a person's mobility needs, taking into account personal, environmental and health circumstances	64
1) Increased focus on everyday tasks and activities which involve moving around	23
2) Reconsider the distances used.	13

*Figures may not add to 100 per cent due to rounding.

Additional mobility costs

Participants were asked if there were any additional costs which they incurred as a result of having limited mobility.

Increased transport costs

Some participants highlighted the increased transport costs that they have, particularly where public transport is limited, such as in rural areas, or where there are limited options for accessible transport.

"I personally live in a small village, you can't get a bus. So, if you're not physically able, you have to have a car, you have to have your own transport." (Interview participant)

"The nearest station to the venue I go to is totally inaccessible. It's only got stairs. So, I've got to get a ticket to the next station, which is accessible." (Focus group participant)

Additional support at home

A few participants commented that there might be additional costs where extra help is needed with tasks around the home such as cleaning.

"There might have to be a home carer, or somebody to do your housework." (Interview participant)

Increased outlay on other items

One participant provided a detailed description of the additional costs that their conditions caused through immobility, which left them largely bed-bound. This meant that there was a need for additional bedding and bed clothes, and also increased energy costs through the need to do more washing and drying.

“I’ve got multiple [skin conditions], cause I’m in bed all the time my wife constantly has to buy sheets and pillows for me ‘cause of the blood, basically me scratching during the day, during the night. Obviously lying in the bedsheets they get dirty as well [...] so, there’s a lot of costs that you don’t think about when you’ve got a disability, that you don’t realise until you’re actually disabled, the extra things you need [...] definitely for me, with my condition, new t-shirts, new [pyjamas], new bedsheets, and that’s on a regular basis and then on the other end of it you’ve got the washing [and if you can’t dry it outside] you’ve maybe got to put the heating on to dry your clothes and your bedsheets and all that to try and get them dry for the night. So, it kicks in, things like the electricity and the gas and that people may not think about but that’s an added bill you’ve got that many people maybe don’t think about when you’ve got a disability.” (Interview participant)

Planning and Following Journeys criteria

As with the Moving Around criteria, panel members were asked for their views on the Planning and Following Journeys criteria. This included any positives or negatives to the descriptors, their personal experiences of assessments and consultations, anything that they felt was missing from the criteria, and if they felt that the criteria reflected the kinds of activities that someone may need or want to carry out in day-to-day life. Participants were also asked for any suggestions they may have for how to consider a person's ability to plan and follow journeys better or differently, or how to improve the criteria.

The eligibility criteria for the Planning and Following Journeys activity are set out below:

Descriptor	Points
a. Can plan and follow the route of a journey unaided.	0
b. Needs the prompting of another person to be able to undertake any journey to avoid overwhelming psychological distress to the individual.	4
c. Cannot plan the route of a journey.	8
d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid.	10
e. Cannot undertake any journey because it would cause overwhelming psychological distress to the individual.	10
f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid.	12

This activity looks at a person's ability to plan and follow a journey outdoors, either on a familiar or an unfamiliar journey.

Consideration is given to a person's ability to:

- plan the route in advance.
- leave home and go on the journey.
- follow the route once they leave home.
- deal with unexpected changes during the journey (such as diversions or roadworks).

Safety risks are also considered, such as:

- a tendency to wander into the road.
- being unable to cross the road safely.
- the risk of self-harm.

- symptoms of overwhelming psychological distress.

General views on the Planning and Following Journeys criteria

Survey respondents were asked to provide some general feedback on the planning and following journeys criteria based on:

- How suitable they thought the descriptors were for considering someone's ability to plan and follow a journey.
- How clear and easy to understand they found the descriptors.
- How easy they found it to choose a descriptor which reflects their own level of ability when planning and following a journey.

Suitability

Almost half of respondents (46 per cent) agreed that the descriptors were suitable for considering someone's ability to plan and follow a journey. However, more than a third (38 per cent) disagreed, with 16 per cent strongly disagreeing. The same proportion of respondents (16 per cent) neither agreed nor disagreed.

Table 14. The descriptors are suitable for assessing someone's ability to plan and follow a journey (n=185)

	% of respondents*
Strongly agree	9
Agree	37
Neither agree nor disagree	16
Disagree	22
Strongly disagree	16

*Figures may not add to 100 per cent due to rounding.

Understanding

More than half of respondents (54 per cent) agreed that the descriptors were clear and easy to understand. Almost a third (29 per cent) disagreed, with 9 per cent strongly disagreeing. Close to a fifth (18 per cent) neither agreed nor disagreed.

Table 15. The descriptors are clear and easy to understand (n=187)

	% of respondents*
Strongly agree	13
Agree	41
Neither agree nor disagree	18
Disagree	20
Strongly disagree	9

*Figures may not add to 100 per cent due to rounding.

Using the descriptors

Almost four in ten (39 per cent) respondents agreed that it would be easy for them to select a descriptor to describe their own ability to plan and follow a journey. However, close to half (46 per cent) disagreed that they would find it easy to use the descriptors, with 16 per cent strongly disagreeing. The same proportion (16 per cent) neither agreed nor disagreed.

Table 16. Thinking about my own ability to plan and follow journeys, it is easy for me to choose a descriptor (or descriptors, where a condition fluctuates) that reflects this. (n=187)

	% of respondents*
Strongly agree	11
Agree	28
Neither agree nor disagree	16
Disagree	30
Strongly disagree	16

*Figures may not add to 100 per cent due to rounding.

Confusion around criteria

Participants and survey respondents expressed some confusion around different areas of the Planning and Following Journeys criteria. Some stated that they were initially unsure of what was being considered in this section, and wanted it to be made clearer if this was related only to mental health and psychological conditions, or if it also included physical conditions.

“When we read that, we didn’t think that meant what it actually means, which we know now. Can you plan and follow the route of a journey unaided? Well, I can’t because I can’t follow any route or journey unaided because I use a wheelchair. But I don’t think that’s what it actually means. It means can you, sort of, mentally follow the route of a journey [...] but it’s quite an ambiguous statement, planning and following a journey.” (Interview participant)

Relatedly, several participants and survey respondents expressed uncertainty over how to select the criteria because they were unsure if they were also being asked about physical barriers to planning and following a journey. This was reflected in some confusion over how to answer the criteria when someone was able to plan a journey but not physically follow it.

“This doesn’t say anything about not being able to drive, not being able to take a bus, because you cannot be sure that there will be a place for you to sit because you can’t stand for any length of time. Will there be wheelchair access? If it’s public transportation and you’re in a wheelchair you can’t follow the route of a journey because there’s no space for a wheelchair access. So, I’m not sure where these are coming from, if they’re supposed to be purely psychological or not?” (Interview participant)

“To me it sounds like a psychological thing, it’s to do with your mind. You know, the first question is can you plan a trip? Well, yes, but I cannae [follow it], because my legs are knackered, I cannae walk. So, how do I answer that?” (Interview participant)

A few participants stated that these criteria needed to be titled differently to make it clearer what is being considered.

“If these are all regarding only the psychological component it needs to say that, maybe at the top.” (Focus group participant)

Separating different elements

A number of suggestions made by participants and respondents related to separating out different elements from the Planning and Following Journeys criteria, which they viewed as distinct issues requiring different approaches.

Separating planning from undertaking a journey

Some participants suggested that the planning stage should be separated from actually undertaking a journey as they relate to different abilities.

“I would like to see planning and following of a journey uncoupled. You might have the confidence to follow a route, but not have the ability to plan a route. So, in order to avoid the possibility of people slipping through the cracks, or again having that situation of oh, I can only answer half a question, we need to unbundle the two.” (Interview participant)

Survey respondents were asked if they agreed or disagreed with the suggestion to separate planning and following journeys. There was strong support for this, with the vast majority (83 per cent) agreeing and only 4 per cent disagreeing.

Table 17. “I would like to see planning and following of a journey uncoupled. You might have the confidence to follow a route, but not have the ability to plan a route.” (n=189)

	% of respondents*
Agree	83
Disagree	4
Neither agree nor disagree	13

*Figures may not add to 100 per cent due to rounding.

Separating mental health, cognitive and physical issues

Some participants and respondents suggested that mental health, cognitive, and physical issues that affect mobility should be addressed as separate elements.

“Mental health difficulties shouldn't be considered in this category alongside those with cognitive issues.” (Survey respondent)

“Mental ability needs to be assessed separately, or have special assessment if mobility also requires to be assessed. Everything can't always be lumped in together.” (Survey respondent)

Separating familiar and unfamiliar journeys

A few respondents and participants suggested that separate criteria could be used for different types of journey, for example, familiar or unfamiliar.

“Familiar and unfamiliar journeys: at [criteria] C, may be able to plan familiar but not unfamiliar [journeys]. Separate planning and undertaking journeys; separate familiar and unfamiliar journeys.” (Survey respondent)

“I think it needs to separate where you've got a familiar journey that you do every week, or something that's out of the ordinary.” (Interview participant)

As part of the follow-up survey, respondents were asked to comment on the suggestion to separate familiar from unfamiliar journeys. More than three-quarters (77 per cent) agreed. A small number (6 per cent) disagreed.

Table 18. “Separate where you’ve got a familiar journey that you do every week, or something that’s out of the ordinary.” (n=186)

	% of respondents*
Agree	77
Disagree	6
Neither agree nor disagree	17

*Figures may not add to 100 per cent due to rounding.

Mental health and cognitive conditions

Unpredictability

A few participants noted that their mental health was unpredictable, and sudden flare-ups could leave them unable to travel. They felt that the current criteria do not offer enough flexibility to account for this as an unpredictable event that can affect their ability to travel, rather than a fluctuating condition.

“I can plan and follow but it takes a huge amount of effort and anxiety [...] Because there are lots of times that I am able to go somewhere that I’m very familiar with. But, sometimes it crops up and I’m really just extremely anxious about even going out of the house.” (Interview participant)

Criteria not suitable for certain conditions

Others commented that they felt the criteria had only limited use for understanding the circumstances of individuals with conditions such as sight loss, cognitive conditions, and those who are neurodiverse.

“These are not designed for people with learning disabilities, in all honesty [...] Outside of his local environment, [my brother] wouldn’t be able to book and plan [a journey].” (Interview participant)

“You’re also looking at the fact that for that planning and following a journey, people who have got visual impairment, people who have got hearing impairment, there’s another reason for why the title is wrong. They’re not cognitively impaired: they can’t see or hear.” (Interview participant)

“This activity really lets down people who are neurodiverse (ADHD, Aspergers, autism), it treats people in this category as if they must have a cognitive deficit to qualify, rather than recognising these are conditions with complex neuro processing.” (Survey respondent)

Journeys

Many participants and survey respondents commented on the journey aspect of these criteria, across a range of different topics.

Journey type or reason for travel

Some participants and respondents stated that there were differences in types of journey that would be important to account for, particularly if the mode of transport resulted in additional difficulties for the person making the journey.

Participant 1: “What kind of journey? Is it a walking one, or...”

Participant 2: “Walking journey, or it’s actually to take a transport or...”

Participant 1: “Work out the buses, are you taking the underground?”

[...]

Participant 2: “Some people might be confident in doing one, but not doing others.”

(Focus group discussion)

“There could be a definition of a short walking journey where crowds may be overwhelming, or a longer car or bus journey. Most cars have sat navs, but having to change buses or trains again can cause anxiety and distress!” (Survey respondent)

One survey respondent also commented that the reason for making a journey, rather than its familiarity, can affect an individual’s ability to plan and follow the route.

“A person's ability can vary a lot depending on why the journey has to be made, i.e. shopping or a funeral.” (Survey respondent)

Obstacles or unexpected issues during a journey

Some survey respondents highlighted that the criteria do not cover a person’s ability to navigate any obstacles that are encountered on familiar or unfamiliar journeys, and how these may influence the person through additional stress and anxiety. Examples given of obstacles included roadworks, diversions and a lack of accessible transport such as no disabled spaces on public transport, or no toilet access.

“None of the above planning criteria has anything to do with a person’s mobility, but more their mental acuity, confidence, or the simplicity of the journey. In all cases, anything unexpected can influence the time, physical, mental/stress levels involved.” (Survey respondent)

“A familiar journey may be planned but when encountering road works and diversions can cause disorientation and extreme distress.” (Survey respondent)

Changing ability during a journey

Respondents and participants highlighted that people may also experience varying levels of ability during the journey itself, and that this can be due to diminishing energy over time or unexpected issues which are difficult to account for when selecting criteria. Respondents and participants included mental tiredness (‘brain fog’), physical fatigue, unpredictable conditions, needing assistance from another person, stress and anxiety as factors which can unexpectedly affect their ability to successfully follow a planned journey.

“It’s the unpredictable events that exacerbate variable things like fatigue, exhaustion, pain levels, brain fog, etc. that make these criteria seem way too ‘clean’. Living with disabilities is a fluctuating challenge. Fixed criteria oversimplify journeys.” (Survey respondent)

“I’ve done it myself, planned journey, got half way, realised I couldn’t make it back without help.” (Survey respondent)

“My son is epileptic and he could do all these things like plan a journey, but if he has an absence, it will throw him off and he couldn’t do it, he’d be lost, he’d be in the middle of a journey and he’d be lost.” (Interview participant)

Distress

Participants and respondents made a variety of comments around the topic of distress, both in terms of how best to account for distress that is caused when planning or following journeys, and around the use of the term ‘overwhelming psychological distress’ within the criteria.

Distress when planning or following a journey

A few participants and respondents noted that while they were able to plan and follow the route of a journey, this could sometimes cause significant distress through stress and anxiety in the lead up to undertaking travel, without reaching levels that fully prevented it. This could also result in disproportionately long preparation times for only short journeys.

“The only thing I’ve mentioned is just the sheer effort of how much planning it takes. You know, can plan and follow, is, yeah it might be true but it might have taken three days out of your life. So, I guess something around there is the only thing I would say because it can actually be quite severe, even if at the end of the day you do actually manage to get out of the door with somebody and do the journey.” (Interview participant)

“Needs to emphasise more how stressful it is. Also how mentally and physically draining planning and following a route is, both during and how long to recover. How much time you need to prepare for a journey. The preparation could take days for something short.” (Survey respondent)

Overwhelming psychological distress

Other participants and survey respondents stated that they felt situations where someone experienced overwhelming psychological distress needed to be considered differently within the criteria (descriptors B and E).

“Under (e) should be an automatic 12. (e) is a higher standard than (f). If you’re housebound, then surely that should score higher. They should be on a par.” (Interview participant)

“B should score six points as it is quite overwhelming.” (Interview participant)

A few participants and respondents wanted to see a clear definition of what constitutes overwhelming psychological distress.

“I think one of the things that’s missing is some kind of definition of what constitutes overwhelming psychological distress. And whether or not there is an objective or a subjective measure that can be used there.” (Interview participant)

Survey respondents were asked to comment on this as part of the follow-up survey. More than three quarters (76 per cent) agreed with the suggestion to include a definition of ‘overwhelming psychological distress.’ Less than one in ten (9 per cent) disagreed, and 15 per cent neither agreed nor disagreed.

Table 19. The criteria including: “Some kind of definition of what constitutes overwhelming psychological distress.” (n=188)

	% of respondents*
Agree	76
Disagree	9
Neither agree nor disagree	15

*Figures may not add to 100 per cent due to rounding.

However, a few participants and respondents suggested that the term should be removed as it was too narrowly focused on psychological distress, or implied that an unnecessary level of suffering was needed to qualify for the points.

“Is there really a need for “psychological” distress? It’s medically based, offensive and irrelevant as long as severe distress, can be highlighted and witnessed.” (Survey respondent)

“[Overwhelming psychological distress] is a horrible phrase. Because, what you’re actually describing there, from a mental health perspective, is watching someone quite literally tear themselves apart. That is what you’re actually describing. So, we have got to, as human beings, be reduced to that level before they’ll be considered for assistance. Rather than looking at the assistance preventing that overwhelming distress.” (Interview participant)

Use of orientation aids

Some participants and respondents’ comments reflected uncertainty around what counts as an orientation aid for planning or following a journey. These comments commonly referenced mobile phones and digital map applications that are widely used by people when planning and taking journeys, regardless of whether or not they have a health condition.

“Surely everyone can’t follow a plan, because we all use the maps function on our phone [...] no-one follows a journey unaided if you’re going somewhere new.” (Interview participant)

One survey respondent stated that they were aware of someone losing support because their use of a phone was deemed to have changed their ability to plan and follow a journey.

“I’ve assisted someone who uses a phone to plan a journey but can’t actually use the information because of her condition and has lost the benefit because she could use her phone to plan it, so the phone use was deemed as achieving the goal, not good!” (Survey respondent)

Remove aids from decision-making process

One participant suggested that aids be removed from the decision-making process, so that only a person’s unaided ability is considered. As part of the follow up survey, respondents were asked if they agreed or disagreed with this suggestion.

“I would take out the [orientation] aid, because again an aid makes it better or easier to do something and it should be assessed on how bad the person is, not how good the person can be with a support.” (Interview participant)

Almost three quarters (71 per cent) of survey respondents agreed with this suggestion, with less than one in ten (8 per cent) disagreeing. However, almost a fifth (21 per cent) neither agreed nor disagreed.

Table 20. “I would take out the [orientation] aid, because again an aid makes it better or easier to do something and it should be assessed on how bad the person is, not how good the person can be with a support.” (n=187)

	% of respondents*
Agree	71
Disagree	8
Neither agree nor disagree	21

*Figures may not add to 100 per cent due to rounding.

Impact of literacy on planning and following a journey

One focus group also highlighted that issues such as literacy affect someone’s ability to plan and follow journeys, and their ability to use common aids such as mobile phones.

Participant 1: “Literacy. Because there’s nowhere where it takes into consideration if you’re not able to read.”

Participant 2: “Or write.”

Participant 1: “That’s right.”

Participant 2: “Or even do some research. Even though everybody has a mobile phone these days, if you can’t read...”

(Focus group discussion)

Fluctuating Conditions criteria

Panel members were also asked about the criteria for fluctuating conditions. Participants were asked if they had any personal experience of trying to explain a fluctuating condition and if they think that these criteria can ensure that a person with fluctuating conditions has their needs fully met. Participants were also asked in what ways fluctuating conditions might impact on people differently and how Social Security Scotland can best communicate how a person with a fluctuating condition should use the criteria.

For people with a fluctuating condition, the descriptor that applies for a particular activity will be established as follows:

If one descriptor is satisfied on over 50 per cent ⁴ of days	That descriptor
If two or more descriptors are each satisfied on over 50 per cent of days	The descriptor that scores the higher or highest number of points
If no descriptor is satisfied on over 50 per cent of days, but two or more descriptors when added together amount to more than 50 per cent of days	The descriptor which is satisfied for the greater or greatest proportion of days, or Where both or all descriptors are satisfied for the same proportion, the descriptor which scores the highest number of points

When someone applies for ADP for the first time, the period of time considered when looking at whether a person's condition fluctuates is the:

- 13 weeks (about 3 months) prior to the date of application is made, and
- 39 weeks (about 9 months) from the date the application is made.

Case managers within Social Security Scotland will also consider whether someone can complete an activity reliably. To complete the activity "reliably" means that they can do so:

- safely – in a manner unlikely to cause harm to themselves or to another person, either during or after completion of the activity.

⁴ Descriptors have been amended in this report from '50%' to '50 per cent' for accessibility reasons.

- to an acceptable standard – to a reasonable standard for the activity, taking account of the impact on the individual of carrying out the activity to that standard.
- repeatedly – as often as the activity being considered is reasonably required to be completed.
- within a reasonable time period – no more than twice as long as the maximum period that an individual without a physical or mental health condition would usually take to complete that activity.

Participants were also informed of the following key changes made by the Scottish Government:

- Providing a legal definition of what it means to carry out an activity to an acceptable standard, so that it considers factors such as pain and fatigue. This is not defined in the equivalent PIP regulations.
- Amending the definition of what it means to complete an activity safely, to make clear that the person's ability to move must be undertaken in a way that is unlikely to cause harm.
- Developing a prompt tool to ensure practitioners cover the reliability criteria and help them to ask questions relevant to a particular disability or health condition.

General views on the Fluctuating Conditions criteria

Survey respondents were asked to provide feedback on the Fluctuating Conditions criteria based on:

- How suitable they thought the criteria were for understanding how someone's condition can fluctuate.
- How clear and easy to understand they found the descriptors.
- How easy they found it to choose a descriptor which reflects how their own condition fluctuates over time.

Suitability

Almost half of respondents (45 per cent) agreed that the descriptors were suitable for understanding how someone's condition can fluctuate. However, more than a third (35 per cent) disagreed. A fifth of respondents (20 per cent) neither agreed nor disagreed.

Table 21. The descriptors are suitable for assessing how someone's condition can fluctuate (n=188)

	% of respondents*
Strongly agree	11
Agree	34
Neither agree nor disagree	20
Disagree	21
Strongly disagree	14

*Figures may not add to 100 per cent due to rounding.

Understanding

Responses were mixed regarding how clear and easy to understand the descriptors were, with slightly more respondents disagreeing (41 per cent) than agreeing (39 per cent). However, around a fifth (19 per cent) strongly disagreed. The same proportion (19 per cent) neither agreed nor disagreed.

Table 22. The descriptors are clear and easy to understand (n=188)

	% of respondents*
Strongly agree	10
Agree	29
Neither agree nor disagree	19
Disagree	23
Strongly disagree	19

*Figures may not add to 100 per cent due to rounding.

Using the descriptors

When asked if they found it easy to select a descriptor that reflects their own fluctuating condition (if they have one) more respondents disagreed than agreed. Half of respondents (51 per cent) disagreed, compared to just under a third (31 per cent) who agreed. More than a quarter (26 per cent) of respondents strongly disagreed.

Table 23. Thinking about my own fluctuating condition or conditions, it is easy for me to choose an option which reflects how this fluctuates over time (n=170)

	% of respondents*
Strongly agree	12
Agree	19
Neither agree nor disagree	18
Disagree	24
Strongly disagree	26

*Figures may not add to 100 per cent due to rounding.

Positive feedback

A number of interview and focus group participants provided positive feedback on the fluctuating conditions criteria. Comments included that although the criteria were still felt to be complicated, using the 50 per cent format was an improvement as this does not rely on how someone had felt over the last week but could be generalised to better account for fluctuations over a longer period of time.

“It’s really difficult to explain to someone who has never experienced it. But, it’s really important, it’s a positive change. Because, some days I don’t feel too bad and other days I can’t move because of pain. And then when you get these forms in you don’t know what to put in what box. Because it says something like ‘in the last week’ and I think well, I had quite a good week last week, but the four weeks before that I was awful. So, at the moment that’s the sort of thing they use which isn’t good. That’s a positive, you know “50 per cent of the time” is a good way to do it. And I think that’s a good, positive change which should help.” (Interview participant)

Other participants welcome the increased focus on factors such as time, safety and fatigue.

“Looking at what the Scottish Government are proposing [the additional changes to take into account safety, time and acceptable standards for completing an activity], that’s the kind of thing that should already be there but isn’t. It’s factors like these that should be taken into consideration but aren’t.” (Interview participant)

Confusion over criteria

However, a number of participants and survey respondents commented that they found the criteria to be too complicated and confusing, particularly if their conditions were affecting their concentration.

Participant 1: “I just couldn’t work it out at all.”

Participant 2: “It’s just not clear.”

Participant 3: “Well...it’s complicated.” (Focus group discussion)

“I found the current descriptors really confusing to read with foggy fibromyalgia brain - simplify please.” (Survey respondent)

In some instances, this confusion led to a misunderstanding of the circumstances that the descriptors were outlining, indicating how this may affect a person’s responses during application or review.

“How can two descriptors apply on "over 50 per cent of the time" - that's more than 100 per cent! Needs explained better.” (Survey respondent)

“That is really confusing. It seems to be assuming that a condition that fluctuates is 50/50, and it isn’t. I don’t know anybody’s that is.” (Interview participant)

Difficulty using set criteria and measurements

Many participants and respondents commented that they found it difficult to think of how their conditions affect them in terms of percentages or averages. For some, this was because they found it hard to estimate how their condition fluctuates due to variations in their symptoms over time.

“I found it difficult putting a percentage figure on, because I didn’t use percentages, but I used sort of ‘This happens all the time’ – that’s easy. But once you get into the fluctuating bit, saying this might happen four days out of seven, or whatever – it’s very difficult actually to come up with that. Because in an average week, one week you might want to try and go out every day and find that you can do it five out of seven days to a familiar place, but some weeks not. It’s a snapshot.” (Interview participant)

Provide examples

Some survey respondents commented that it was very difficult for somebody with a long-term condition to judge how different their own mobility is to that of someone with no mobility issues, and where there has been a gradual deterioration over time.

“Again, you demand self-knowledge from someone who has been getting incrementally worse for perhaps decades. The measurement against a 'norm' is impossible to quantify for such a person. This seems like an exercise in further cruelty.” (Survey respondent)

A few participants and respondents suggested that there would need to be examples included in order to help applicants understand this.

“Examples need to be given on what is considered a reasonable time to take to do a task. A person may not realise they take a lot longer to do something than others.” (Survey respondent)

One participant suggested that providing examples which illustrate what fluctuations might look like in terms of number of days could help people to understand what is meant by the percentages used in the fluctuating conditions criteria.

“Perhaps in the examples you can say, perhaps you can do this five days out of seven, or four times out of seven or whatever – and just get people into the thought of ‘how often does this happen to me?’” (Interview participant)

Survey respondents were asked to comment on the suggestion to provide an example using number of days, with slightly more than half (59 per cent) agreeing. A quarter (25 per cent) neither agreed nor disagreed, and 16 per cent disagreed.

Table 24. “Perhaps in the examples you can say, perhaps you can do this five days out of seven, or four times out of seven or whatever – and just get people into the thought of ‘how often does this happen to me?’” (n=188)

	% of respondents*
Agree	59
Disagree	16
Neither agree nor disagree	25

*Figures may not add to 100 per cent due to rounding.

More flexibility to describe the effects of conditions

However, others stated that they needed a more flexible, holistic way to describe how their condition affected them, and that it could be difficult to think about the complex ways their conditions affected them in the terms used by the descriptors.

“It’s important that they know just how tricky some people find relating their experience that they’re living to something which is out on a piece of paper and says ‘Is it this or that?’ Sometimes you need a lot of help just to elucidate what actually is your experience.” (Interview participant)

One participant argued that it would not be possible to consider how conditions fluctuate using set criteria as conditions and how they affect different people can vary widely. They suggested a more flexible approach could be used.

“To be honest with you, you’ll never be able to put it into rules. For the simple reason that what you’re trying to do is pigeonhole human beings. What you have to do is allow flexibility and how that flexibility comes out with assessing is that you need to look at that person as an individual, be holistic with them.” (Interview participant)

Survey respondents were asked to comment on the suggestion to have greater flexibility through looking at an individual’s circumstances holistically, with the vast majority (86 per cent) agreeing. Just over one-in-ten (12 per cent) neither agreed nor disagreed, and only 2 per cent disagreed.

Table 25. “What you have to do is allow flexibility and how that flexibility comes out with assessing is that you need to look at that person as an individual – be holistic with them.” (n=188)

	% of respondents*
Agree	86
Disagree	2
Neither agree nor disagree	12

*Figures may not add to 100 per cent due to rounding.

Unpredictable conditions

As mentioned above, many participants and respondents described difficulties in trying to think of their condition in terms of averages or percentages, related to how fluctuations in their condition vary across time. Similarly, many described the unpredictability of fluctuations as a major challenge to measuring their conditions against the criteria.

“There are NO patterns to many fluctuating conditions. It can change by day or by week or by month. Nobody can plan for that reason, not know[ing] when a change will occur.” (Survey respondent)

A few participants disagreed with the criteria as their condition – or that of the person that they were caring for – was not only unpredictable but also seldom triggered. This meant they may not fulfil the criteria for a fluctuating condition over a period of time, despite very serious consequences when their condition was triggered.

“I do not agree with 50 per cent rule, mainly because of epilepsy. My son is epileptic, it is a stupid rule, to be honest. He would have to have, in the present conditions, he would have to have a seizure every other day to be qualifying for payments. And it is a life-threatening condition, so it should be a lot higher up the scale.” (Interview participant)

Others stated that the unpredictability of their condition meant it could not be accurately described as constant or fluctuant.

“[My condition] is described as fluctuant because it’s not constant, but that’s still not an accurate term. These things can happen at any stage, at any time during the day. If I’m out and about there’s more risk of it, but I can’t state categorically that 50 per cent of the time [it will happen].” (Interview participant)

Triggers

Unpredictability was often linked to triggers or intersecting factors which may cause a sudden change. This included events or circumstances that were hard to predict or avoid, such as weather, pollen, and time of day. For some participants and respondents, this meant that attempting to generalise how much their condition affected them over a period of time was difficult.

“I mean you’ve got epilepsy, even things like severe asthma, COPD [chronic obstructive pulmonary disease], where some days you’re fine and some days you’re really bad, particularly in the summer with pollen or in the winter when cold weather affects lungs.” (Interview participant)

“It’s not practical, it’s not logical. Fluctuating conditions don’t always have averages. It just doesn’t work that way [...] The other thing is one thing can trigger another, so you can do one thing but then something else happens. So, fluctuating conditions quite often have a massive amount of triggers. I might be perfectly fine, but then if I leave the house I will not be fine. [...] It’s not about can you do it or can’t you do it, but it’s about everything affects each other and you won’t ever have averages, it won’t ever be 50 per cent of the time, or four days a week. It just doesn’t work that way.” (Focus group participant)

“I have a mobility issue that varies each hour of the day. There seems to be no defined way to express this on any of the multiple forms that need to be completed.” (Survey respondent)

Lifestyle adaptations

A few participants and respondents related the triggers for their conditions to activities that they chose to undertake. They stated that limiting what they do, and lowering their quality of life, would reduce how often their condition was triggered and could result in them meeting different criteria. As a result, they suggested that the decision-making process needs to be more aware of when someone meeting a certain criteria is related to these life-limiting adaptations.

“It almost feels with these kinds of descriptors that if I chose not to be here today, I probably wouldn’t tick all these boxes [I would feel better]. But because I want to have a life, which is my right and I should be able to participate in life fully, it might tick some of these boxes.” (Focus group participant)

“Criteria for reassessment should take into account how someone has adapted their life to cope. It may be possible to reduce other things and thus quality of life to allow one to do more of something else.” (Survey respondent)

Automatic qualification

Some participants and respondents felt that there should be automatic qualification for certain conditions – such as those which are long-term or cause constant or chronic pain and fatigue – or circumstances where many different conditions have a cumulative impact.

“In my case, I have several things that fluctuate. Obviously, that has a very pronounced knock on cumulative effect, so I think in instances like this, there comes a point where it’s automatic to supercede the points.” (Survey respondent)

“My condition gives me constant and various levels of pain all over my body, I agree that some conditions should have automatic qualification, such as fibromyalgia or similar conditions which result in chronic pain and fatigue.” (Survey respondent)

Survey respondents were asked to comment on the suggestion to have automatic qualification for certain conditions. Almost all (93 per cent) respondents agreed with this, with only 2 per cent disagreeing.

Table 26. “Certain conditions could have automatic qualification” (n=189)

	% of respondents*
Agree	93
Disagree	2
Neither agree nor disagree	5

*Figures may not add to 100 per cent due to rounding.

Degenerative or deteriorating conditions

Others suggested that conditions which have progressively worsened over time or are degenerative need to be considered differently to ‘static’ conditions.

“In my own case it is a day-to-day basis. Also, over the years my condition has deteriorated causing more discomfort and pain so I feel it’s important to have that taken into consideration.” (Survey respondent)

Criteria open to abuse or irrelevant

Finally, some participants and respondents commented that they felt the fluctuating conditions section was irrelevant or open to abuse, as people would self-assess based on their worst days.

“This criteria just invites dishonesty. People know what answer is the *right* one.” (Survey respondent)

Participant 1: “Surely you would put down your worst day? [...] I think it’s a waste of time.”

Participant 2: “I’m not 50 per cent of this or 50 per cent of this, every second of the day I get up I am masking, I am this, I am that. How do you tell them that every minute of every day is affected? Every minute is calculated.”

(Focus group discussion)

Others suggested that they felt themselves to be constantly living with disability even if they were not currently experiencing a flare-up in their symptoms, making the idea of a ‘fluctuating condition’ irrelevant.

“How can I say this? They might not be telling the truth [...] If you ask somebody who’s disabled do you have a good day and a bad day? Well, when you’re disabled, you’re disabled 7 days a week, 24 hours a day. So, are you really gonnae have a good day? What equates to a good day and what equates to a bad day? You’re disabled, it’s as simple as that. I wake up every morning and I’m in a mess. I go to my bed at night and I’m in a mess. I’m in severe pain. I take morphine for the pain and everything. So, for me personally, I’ve either got a bad day or a worse day. I don’t have good days at aw. I think there can be too many questions at times, that people can twist to get the points they need.” (Interview participant)

Cross-cutting comments

There were a number of points raised by participants and respondents that applied across all criteria or more generally to the decision-making process.

Consultations tailored to conditions

Many participants and respondents suggested that consultations need to be tailored to the particular conditions that an individual has. While changes by the Scottish Government committing to consultations being conducted by suitable health and social care practitioners were welcomed, a few participants noted that there still needs to be an awareness of how conditions and their effects vary between individuals.

“The fact that you’re saying the assessments are going to be different, they’re going to be by people who understand your medical condition, is a big plus for me. Because [if people don’t understand my condition] then the questions that they ask just make you feel like – it makes you feel like you’re trying to cheat the system. When, actually, you’re trying to survive.” (Interview participant)

“Assess each case on an individual basis - you cannot be too prescriptive.” (Survey respondent)

Mental health

Many comments and suggestions related to mental health and how to best account for this within the consultation process.

Consider mental health conditions separately

Similar to comments made for the planning and following journeys criteria, some participants and respondents suggested that mental health needs to be considered separately from any mobility issues.

“What would be nice is if there was [a section] specifically covering mental health [...] Take mental health out of the whole assessment process, and make it separate but in the same manner as what has been done [for the existing criteria].” (Interview participant)

As part of the follow-up survey respondents were asked if they agreed or disagreed with this suggestion to have a separate section covering mental health. The majority (58 per cent) agreed, however almost a fifth (18 per cent) disagreed and a quarter (25 per cent) neither agreed nor disagreed.

Table 27. “[Have an assessment] specifically covering mental health [...] Take mental health out of the whole assessment process, and make it separate but in the same manner as what has been done [for the existing criteria].” (n=187)

	% of respondents*
Agree	58
Disagree	13
Neither agree nor disagree	12

*Figures may not add to 100 per cent due to rounding.

Accurate recording of psychological or mental health conditions

Some participants and respondents commented that they felt there needed to be a full accounting of the psychological conditions that someone may face, citing past examples where they had not been properly recorded. This was seen as important for ensuring that an accurate report of any mental health conditions was formally recorded and acknowledged within the decision-making process.

“Mental ill health is a disability in its own right and psychological distress is simply not covered fully for the condition.” (Survey respondent)

“The way it’s set up just now, when I had my last PIP assessment they didnae give me any points for my psychological and emotional - the person just didn’t hear me at all, they didn’t take in what I was saying. I clearly explained that there can be weeks where I can’t even go over front door or get out of bed and they still scored me zero for psychological side. So, it’s like they thought ‘Oh well he’s got enough points on his physical so he doesn’t need points for his psychological.’” (Interview participant)

Process inaccessible for those with poor mental health

Others commented that the application and decision-making processes are too difficult for people with mental health conditions, especially where they are unsupported.

“Anybody who has got an advocate with them, or somebody to help them, no problem. But you’ve got to remember that we’ve got a lot of people in the population who shut down. And they shut down on their bills, their forms – [the ADP application form is] too long for someone with a mental health condition.” (Interview participant)

Medical history or supporting information

Gathering supporting information

Some participants and respondents suggested that the decision-making process should make better use of a person's medical history or the input of health professionals to determine how they are affected by a condition.

“See if somebody is unwell, they go to their doctors on a regular occurrence [...] If someone's unwell, there will be a trace or a track of going to the doctor, taking medication, going to the hospitals.” (Interview participant)

“The disability in above cases has been assessed/determined by a health professional, who takes all aspects of the persons condition(s) into account, including fluctuations, duration and prognosis. A care official is not qualified to make such assessments.” (Survey respondent)

A few participants and respondents suggested that there may be cases where someone else is the best person to seek additional information from, such as close family or friends.

“Some consideration needs to be given as to who is the best person or people to get additional information from. Because my brother would not have the competence to answer any of those questions himself [...] The reason that [my sister and I] went for guardianship just a few years ago is because decisions were being made by people who really did not know him well enough.” (Interview participant)

Self-management of conditions

A few participants noted that it is important to be aware of when someone is self-managing their condition and rarely or never visits medical professionals, as this will reduce the supporting information that is available to them for applications.

Participant 1: “One of the biggest issues that we've raised over the years is that some people have a lack of proof [of a condition] or a lack of support in their lives [...] You don't have proof, you don't have anything. You don't have consultants, you don't have GPs, because they do prescriptions for you but they don't get to see you ever. So you can't prove how it affects you, you can't prove anything [...]”

Participant 2: “[That is] personal management of your condition.”

Participant 1: “But again, how do you prove that? How do you justify that in an assessment or anything? Because I think that a lot of times the DWP ask when did you last see your GP? And I say, well I haven't seen my GP in two or three years now because I don't need to, but that doesn't mean I'm not unwell, that doesn't mean I don't have pain.”

(Focus group discussion)

A few participants and respondents also suggested that there needs to be consideration given to any medication that a person has been prescribed and how this affects them, for example using pain medication to lessen the impact of a condition.

“[The people involved in making decisions need to look] at actual effects of medication that the person has described, they don’t have to look at the side effects on every single label. But, if the person is describing a significant side effect, don’t ignore it.” (Interview participant)

Accessibility

As discussed in the mobility and fluctuating conditions sections above, some participants suggested that having examples would help applicants understand what the criteria were asking about. One participant suggested providing accessible versions of the form and supplementing text with images, supporting information and examples.

“Put it in big print for folk that are partially sighted, or in Braille for people who understand Braille [...] put in pictures maybe, pictures of things, like a timetable, a train.” (Interview participant)

Another participant suggested that for people who struggle with text-based responses, images or storyboards could be used to provide an alternative means of communicating about their condition.

“I just feel like, maybe it’s just me, I don’t like forms, but, you know, asking somebody to write a storyboard. Describe their average week or whatever just in a bullet-pointed storyboard, you know, would make far more sense than asking all these individual questions.” (Interview participant)

Respondents were asked to comment on this suggestion as part of the follow-up survey. More respondents disagreed (42 per cent) than agreed (29 per cent), with almost a third (29 per cent) neither agreeing nor disagreeing.

Table 28. “[Ask] somebody to write a storyboard. Describe their average week or whatever. Just in a bullet-pointed storyboard.” (n=186)

	% of respondents*
Agree	29
Disagree	42
Neither agree nor disagree	29

*Figures may not add to 100 per cent due to rounding.

What's next?

The Scottish Government is committed to an independent review of ADP. As part of this review, it is important to gather the views and experiences of people who will be or already are receiving ADP. The findings from this work will be available for the independent review to consider.

Between January and April 2023, the Scottish Government consulted on the eligibility criteria for the mobility component of ADP. As in this research, the consultation did not set out or advocate a preferred Scottish Government position or policy but sought to provide an opportunity for the people of Scotland and stakeholders to provide views on the evidence presented on the mobility component.

The review will be independent of Government and will secure the input of disabled people and stakeholders. The Scottish Government wants to get any decisions right for the people of Scotland. That includes reflecting carefully on the evidence. A range of evidence will be considered by the independent review, to ensure consistency and coherence in any recommendations for future improvements to the payment.

How quickly recommendations could be implemented would depend on what those recommendations were and whether further legislation is required to support them. Given the need to prioritise safe and secure transfer, it is our intention that changes to the eligibility criteria should not be made before the case transfer process is complete. However, whilst the eligibility criteria have not been significantly changed, the Scottish Government has made several improvements to provide disabled people with a more positive experience compared to PIP.

The Scottish Government will provide further details on the independent review soon.

Annex A: About survey respondents

Where possible, information from survey respondents was matched to demographic information previously supplied by Experience Panels members. The following demographic tables are included to provide context to the findings presented in this report. The tables show proportions based on available information and the total number of respondents is given as (n) in the table title.

Where the result for a category was lower than 5 per cent, this number has been suppressed to preserve anonymity. This is shown as # in the tables. So that the suppressed figure cannot be calculated from other values shown, the next smallest category has also been suppressed in the table.

Table 29. Gender of respondents (n=160)

	% of respondents*
Female/woman/girl	53
Male/man/boy	#
Other	#

*Figures may not add to 100 per cent due to rounding.

Table 30. Sexual orientation of respondents (n=141)

	% of respondents*
Heterosexual/straight	84
Gay/lesbian	8
Prefer not to say/other	8

*Figures may not add to 100 per cent due to rounding.

Table 31. Age of respondents (n=161)

	% of respondents*
16-24 years old	0
25-44 years old	14
45-59 years old	47
60-79 years old	39
80 years old or over	#
Prefer not to say	#

*Figures may not add to 100 per cent due to rounding.

Table 32. Ethnicity of respondents (n=145)

	% of respondents*
White	97
Ethnic minority	#
Other ethnic group	#

*Figures may not add to 100 per cent due to rounding.

Table 33. Location (n=164)

	% of respondents*
Urban	78
Rural	22

*Figures may not add to 100 per cent due to rounding.

Table 34. Caring responsibilities (n=161)

	% of respondents*
Yes	55
No	45

*Figures may not add to 100 per cent due to rounding.

Table 35. Has a disability or long-term health condition (n=161)

	% of respondents*
Yes	95
No	5

*Figures may not add to 100 per cent due to rounding.

Table 36. Physical disability (n=161)

	% of respondents*
Yes	73
No	27

*Figures may not add to 100 per cent due to rounding.

Annex B: List of abbreviations

List of abbreviations used in this report:

ADHD – Attention deficit hyperactivity disorder

ADP – Adult Disability Payment

CDP – Child Disability Payment

COPD – Chronic obstructive pulmonary disease

COVID-19 – Coronavirus

DLA – Disability Living Allowance

DWP – Department for Work and Pensions

GP – General practitioner (doctor)

NHS – National Health Service

PIP – Personal Independence Payment

How to access background or source data

The data collected for this social research publication:

- are available in more detail through Scottish Neighbourhood Statistics
- may be made available on request, subject to consideration of legal and ethical factors. Please contact socialsecurityexperience@gov.scot for further information.
- cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.



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