

# Social Security Experience Panels - Personal Independence Payment Health Assessments



# **EQUALITY, POVERTY AND SOCIAL SECURITY**



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## Introduction

In June 2018, the Scottish Government carried out a survey with Experience Panel members to understand their experiences of Personal Independence Payment health assessments. The research explored:

- Views on booking a Personal Independence Payment health assessment, and what factors are important for clients to choose when booking;
- Views on health assessors, their backgrounds and knowledge and whether a health assessment should be recorded;
- How long health assessments should last, and what should happen if the health assessment lasts longer than the client can manage;
- Reasons for needing to miss or cancel a health assessment; and
- Experience of claiming expenses after attending a health assessment.

In total, 128 Experience Panel members took part in this survey (a response rate of 14.84 per cent). The findings of this survey reflect the views of the respondents only, and are not representative of all Personal Independence Payment claimants.

## **Summary**

## Booking a health assessment

Respondents preferred booking options that allowed them the freedom to choose when and where the health assessment would take place. Only one in twenty respondents said they would like to be automatically assigned the first available appointment within one hour's travel time of their home (5 per cent). No statistically significant associations were observed in booking preference between respondents who lived in urban and rural areas, or between respondents who had a disability or were a carer.

Respondents who wanted home visits tended to say this was due to mobility issues, or a specific health condition which would make travelling to a Social Security Scotland venue difficult.

When asked what factors were important to choose when booking a health assessment, respondents said the most important was being able to choose an assessor who had knowledge of their specific medical condition. Many respondents felt that having an assessor who was knowledgeable about their health condition would lead to a higher quality assessment through a more accurate assessment report. The location and time of the assessment also ranked highly.

Respondents told us that the nature of their health condition meant that having the flexibility to book and choose their own appointment was important to them.

#### Re-arranging a health assessment

Just under one in five respondents had missed or cancelled a health assessment in the past (17 per cent). Of those who had missed or cancelled an assessment, just over seven in ten had cancelled (71 per cent) and just under three in ten had missed it (29 per cent).

Respondents told us they missed or cancelled their assessment for a number of reasons, the most common being:

- the respondent lost the appointment letter, or the letter arrived giving insufficient notice to allow arrangements to be made to attend;
- the respondent being unwell, in hospital, or caring for an unwell family member or friend;
- the respondent could not arrange suitable transport to the location where the health assessment was due to take place; and
- the respondent's disability had flared up and they were having a bad day.

#### Travelling to the health assessment

Respondents told us the location of the assessment centres were 'hugely important' for reasons of accessibility, privacy and cost. Respondents told us that they felt the current location of assessment centres did not suit them, with some respondents saying they had been asked to travel far from home. Others said that when they arrived, the assessment venue itself was not fully accessible to them.

Many respondents said that they could only travel at certain times of day. For some, this was the morning as that was when they felt most rested. For others, they wanted an assessment in the afternoon to allow them time to get ready and for their medication to 'kick in'.

Many respondents said they would value being able to book a parking space at the assessment location as they did not want to, or could not use public transport due to their disability.

Overall, respondents said they would like to choose when and where their assessment took place, and that Social Security Scotland should understand and be prepared for the inevitable need for flexibility that is inherent to their client group.

#### At the health assessment

For many respondents, undergoing a health assessment as part of their benefit application was described as one of the most stressful aspects of the process.

Respondents used words such as 'degrading', 'humiliating' and 'stressful' to describe the experience. There was, across most respondents, concern about the competency, reliability and integrity of the health assessors, as well as the value and fairness of the way health assessments are currently implemented.

Many respondents felt that their assessor did not understand their disability, with some saying they were asked inappropriate or insensitive questions as a result. Some respondents felt 'condescended' as their assessor said they 'had never heard of their condition before'. This caused stress amongst clients and reduced their confidence of receiving an accurate, fair and comprehensive health assessment.

Respondents suggested more knowledgeable assessors would lead to more accurate reports, higher quality assessments and fairer outcomes for clients.

Respondents felt that it was especially challenging to communicate the impact of mental health conditions to assessors. Some respondents said they struggled to vocalise the impact of their condition, or found talking to strangers very difficult. Being placed into the stressful and unfamiliar situation of the health assessment made them 'close up'. It was felt that in these cases, it was the job of the health assessor to work with the client to draw out the required information. In many cases, respondents said this did not happen.

Respondents who had multiple conditions felt that assessors could not accurately determine how their conditions interacted with each other and their medication. Some also felt it was inappropriate for the assessor to doubt written evidence supplied by their doctors or health professionals.

Respondents suggested that in the future, they would like to see a move away from standardised questions in favour of a more individualised approach to assessment. This included tailoring health assessments to someone's health condition and reducing the instances of assessors asking inappropriate questions.

Most felt that assessors did not need to have a medical degree – a well-rounded understanding of disabilities and effective training was seen by most to be sufficient.

A recurring theme throughout the research was the accuracy, fairness and quality of the report written by the health assessor. The assessment report is intended to summarise the findings from the health assessment and offer an accurate overview of the applicant's health. Many respondents reported that the report contained inaccuracies or omitted key information they had said at the assessment. Consequently, many respondents said they did not trust the report's content and felt that it was often inaccurate.

## Recording health assessments

Almost three quarters of respondents (72 per cent) said they would like health assessments to be recorded. Respondents said they wanted a verifiable record of what took place in the assessment, which could be used to check what either party said. Many respondents wanted this as they did not trust the assessor to be truthful as a result of their past experiences. Other respondents wanted to record their assessment to assist with any later appeals or to help them remember what was said due to memory issues.

A small number of respondents referenced the current rules around recording assessments and felt that universal recording would introduce 'fairness'. They felt that conforming to the current rules, such as clients providing an approved recording device, could be expensive and therefore not possible for poorer clients.

Respondents who did not want their health assessment recorded tended to refer to privacy concerns over their personal data. They said it was 'a step too far' and did not trust the government to keep such sensitive data.

Of those who wanted an assessment recorded, just over half of respondents preferred an audio recording (56 per cent). Those who favoured audio recording described it as 'less intrusive' and 'less intimidating' than video recording. For some, video recording was seen as a 'scary prospect'.

Those who favoured video recording said it captured 'the whole picture' and noted that body language was important when conducting health assessments. Respondents also felt that a video recording was most appropriate where physical examinations were to be conducted to show the client's actual response.

#### **Duration of health assessments**

Just under six in ten respondents said health assessments should last 'as long as necessary' (58 per cent). When asked how long would be too long for them personally, almost nine in ten respondents said the assessment could be over 30 minutes (87 per cent), however less than three in ten said they could manage more than an hour (28 per cent). Just over one in ten said they could manage over 1 hour 30 minutes (14 per cent).

Respondents who told us they would prefer a home visit, or who were carers tended to say health assessments should be shorter.

When asked what should happen if they felt they could no longer continue during a health assessment, most respondents said they would like to be able to arrange another assessment at a convenient date and time, including being able to select another assessor if required. Some requested that there be a written record of what had happened up to that point so the future health assessment would be shorter.

Other respondents suggested that it be made clear to clients that they had the right to stop the appointment if they wished, to avoid feelings of stress or worry about consequences should they choose to do so. Some felt that incorporating breaks into the process would reduce the need for clients to cut assessments short.

## Claiming expenses after a health assessment

Just over a fifth of respondents had claimed, or had claimed and received expenses after a health assessment (21 per cent). Respondents tended to be satisfied with the expenses process saying it went 'very quickly' and that it was a 'good solution'.

Respondents differed in the length of time they reported it taking to receive the expenses, however most said it was four weeks or less.

A minority of respondents were unhappy with the process, saying it was 'more hassle than it was worth'. Others felt having to be out of pocket before the assessment was inconvenient, and that some clients couldn't afford to be without the money for such a long time.

# **Background and research methods**

The Scottish Government is becoming responsible for some of the benefits currently delivered by the Department for Work and Pensions. This includes Personal Independence Payment, a benefit designed to help people with the additional costs incurred as a consequence of living with a disability or long term health condition.

As part of the work to prepare for this change, the Scottish Government set up the Social Security Experience Panels. The Experience Panels are made up of around 2,400 people from across Scotland who have recent experience of at least one of the benefits being devolved to Scotland. Through this research, Experience Panel members are working with the Scottish Government to guide what Personal Independence Payment will look like once administered by the Scottish Government.

The development and design of what Personal Independence Payment will look like once transferred to Scotland is well underway, with a number of decisions already made. For example, the Scottish Government has committed to end the current policy of using private healthcare organisations to perform health assessments on applicants and to reduce the overall number of face to face health assessments which take place<sup>1</sup>.

These commitments sit alongside the wider vision of creating a new social security system for Scotland, which is based on treating all clients with dignity, fairness and respect.

This research provides evidence to inform the continued development of Personal Independence Payment in Scotland.

#### This research considered:

- views on booking a Personal Independence Payment health assessment, and what factors are important for clients to choose when booking;
- views on health assessors, their backgrounds and knowledge and whether a health assessment should be recorded;
- how long health assessments should last, and what should happen if the health assessment lasts longer than the client can manage;
- reasons for needing to miss or cancel a health assessment; and

<sup>&</sup>lt;sup>1</sup> Scottish Government (2019). *Social Security – Disability Assistance*. [Online] Available at: <a href="https://www.gov.scot/policies/social-security/benefits-disabled-people-ill-health">https://www.gov.scot/policies/social-security/benefits-disabled-people-ill-health</a> Accessed: 15 April 2019

• experience of claiming expenses after attending a health assessment.

Participants were recruited from the Scottish Government Experience Panels. All Experience Panel members who had Experience of claiming or receiving - or helping someone else to claim or receive - Personal Independence Payment were invited to take part in the survey.

The Social Security Experience Panels are a longitudinal research project. The panels are made up of volunteers from the Scottish population who have experience of at least one of the benefits that are being devolved to Scotland. The results of this work should be regarded as being reflective of the experience and views of the participants only, and are not indicative of the wider Scottish population. Percentages are given only to show a broad sense of the balance of opinion across participants.

The results of the survey have been grouped into broad themes, and the quotes used in each theme may have come from responses to different questions.

#### **Survey Method**

All Experience Panel members who had experience of claiming Personal Independence Payment were invited to take part in the survey. Participation in Experience Panels research is optional, and in this case 128 people chose to complete the survey (a response rate of 14.84 per cent).

Information from the survey was added to information from the 'About Your Benefits and You' and 'Social Security Experience Panels: Who is in the panels and their experiences so far' surveys. The demographic data collected in these surveys was linked to the information supplied by respondents of this survey as part of the longitudinal data set for the wider Experience Panels project. This data was not available for all survey respondents. The following demographic information is given to give context to the findings from the survey.

A third of respondents who we have demographic information for identified as 'man or boy' (33 per cent) and just over two thirds (67 per cent) identified as 'woman or girl'.

Table 1: Gender of survey respondents (n=119)

Gender	%
Man or boy	33
Woman or girl	67
Total	100

<sup>&</sup>lt;sup>2</sup> Scottish Government (2017). Social Security Experience Panels: About Your Benefits and You – Quantitative Research Findings. [Online] Available at: www.gov.scot/Publications/2017/11/7769/

<sup>&</sup>lt;sup>3</sup> Scottish Government (2018). *Social Security Experience Panels: Who is in the panels and their experiences so far.* [Online] Available at: www.gov.scot/Publications/2018/10/3083/

Almost nine in ten survey respondents were aged 45 or over (88 per cent) and just under a third were aged 60 or over (31 per cent). Just over one in ten respondents were aged between 25 and 44 (12 per cent) with none under the age of 25.

Table 2: Age of survey respondents (n=118)

Age	%
Under 25	0
25 – 44	12
45 – 59	57
60 – 79	30
80 or over	1
Prefer not to say	1
Total	101

Over eight in ten respondents (84 per cent) had a disability or long term health condition.

Table 3: Disability status of respondents (n=120)

Disability Status	%
Disabled	84
Not disabled	16
Total	100

Over two thirds of respondents had a physical disability (69 per cent) and two thirds exactly had chronic pain (66 per cent). Four in ten had a mental health issue (40 per cent) and around one in ten had a severe hearing impairment (12 per cent) or severe visual impairment (7 per cent). Almost two thirds told us they had some other kind of disability or long term health condition (61 per cent).

Table 4: Disability types of respondents (n=119-120)<sup>4</sup>

Disability Types	%
Has a physical disability	69
Has chronic pain	66

<sup>&</sup>lt;sup>4</sup> The percentage is of total respondents, not disabled respondents. Respondents were able to select multiple disability types.

Has a mental health condition	40
Has a severe hearing impairment	12
Has a severe visual impairment	12
Has a learning disability	4
Has another kind of disability or long term health condition	61

Almost half of survey respondents cared for a family member or friend (52 per cent).

**Table 5: Caring status of respondents (n=117)** 

Caring status	%
Carer	52
Not a carer	47
Prefer not to say	1
Total	100

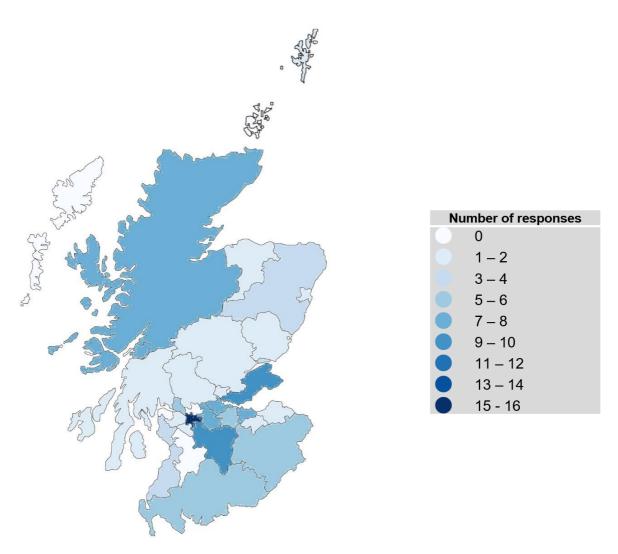
Survey respondents most commonly cared for an adult friend or relative (41 per cent), but over one in five was a carer due to old age (22 per cent). Just over one in ten cared for a child (13 per cent).

Table 6: Who do respondents care for? (n=120)

Care status	%
Cares for an adult	41
Cares for a child	13
Carer due to old age	22

Survey respondents took part from twenty-seven of the thirty-two local authority areas in Scotland.

Figure 1: Heat map of respondent locations



The majority lived in an urban area (77 per cent).5

Table 7: Location of respondents (n=132)

Location	%
Urban	77
Rural	23
Total	100

<sup>&</sup>lt;sup>5</sup> 17 per cent of the Scottish population lives in a rural area. Scottish Government (2018). *Rural Scotland Key Facts 2018.* [Online] Available at: <a href="https://www2.gov.scot/Resource/0054/00541327.pdf">www2.gov.scot/Resource/0054/00541327.pdf</a>

Survey respondents who took part had experience of claiming or helping someone else to claim a wide range of benefits.

The most common benefits claimed by survey respondents were Disabiltiy Living Allowance (100 per cent) and Personal Independence Payment (99 per cent). The least common benefits claimed were for Funeral Expenses (17 per cent), Industrial Injuries Disabiltiy Benefit (10 per cent) and Sure Start Maternity Grant (10 per cent).

Table 8: Respondents benefit experience (n=120)<sup>6</sup>

Benefit	%
Disability Living Allowance	100
Personal Independence Payment	99
Carer's Allowance	50
Cold Weather Payment	42
Winter Fuel Payment	37
Discretionary Housing Payment	28
Attendance Allowance	23
Scottish Welfare Fund	23
Severe Disablement Allowance	23
Universal Credit	17
Funeral Expenses	17
Industrial Injuries Disability Benefit	10
Sure Start Maternity Grant	10

More detailed demographic information on the Experience Panels as a whole can be found in 'Social Security Experience Panels: Who is in the panels and their experiences so far' 7.

<sup>6</sup> Respondents had experience of applying for (themselves or someone else) or receiving these benefits within the last three years, but were not necessarily in receipt of the benefit at the time of the survey.

<sup>7</sup> Scottish Government (2018). Social Security Experience Panels: Who is in the panels and their experiences so far. [Online] Available at: www.gov.scot/Publications/2018/10/3083

# **Booking an assessment**

In the past, we have heard from Experience Panel members that booking a health assessment for Personal Independence Payment can be a stressful experience<sup>8</sup>. The stress can be a result of the booking procedure, a lack of information about the assessment itself or apprehension about the upcoming health assessment.

Health assessments for Personal Independence Payment are currently carried out by third party organisations contracted by the Department for Work and Pensions<sup>9</sup>. A number of respondents told us they had negative experiences when interacting with these organisations when booking, or attempting to seek information about their health assessment:

"I had to get an office appointment. I tried to get information about who to see in order to prepare my son, but the Atos staff were most unhelpful and in one case very rude. I tried to explain that because of my sons autism I might not be able to get him to attend. They told me he wouldn't get PIP."

#### **Booking a health assessment**

In the future when Social Security Scotland takes responsibility for administering Personal Independence Payment, they may offer clients different ways to book a health assessment. This will allow clients to book an assessment in the way that is most convenient for them.

There are three methods of booking a health assessment under consideration: the client books the assessment themselves, choosing the date, time and location; the client is automatically assigned the first available appointment within an hour's travel of their home; or the client is given the opportunity to arrange a home visit.

When asked which option they would prefer, respondents overwhelmingly opted for choices that allowed them to choose when the assessment took place. Almost half of the respondents wanted to choose the date, time and location of the health assessment themselves (47 per cent). A further 48 per cent wanted to be able to choose a home visit instead of visiting a Social Security Scotland venue. Just one in twenty wanted to be automatically assigned the first available appointment within an hours travel of their home (5 per cent).

<sup>&</sup>lt;sup>8</sup> Scottish Government (2018). Social Security Experience Panels: Personal Independence Payment Discovery - Visual Summary. [Online] Available at: www.gov.scot/publications/socialsecurity-experience-panels-personal-independence-payment-discovery-visual-summary/

<sup>&</sup>lt;sup>9</sup> GOV.UK (2019). Personal Independence Payment (PIP). [Online] Available at: www.gov.uk/PIP [Accessed 10 April 2019].

Table 9: Respondent preference for booking assessments (n=128)

Booking method	%
Client chooses the date, time and location	47
Client chooses the date and time of a home visit	48
Client is given the first available appointment within one hours travel of their home by public transport	5
Total	100

No statistically significant associations were observed for booking preferences between respondents in urban and rural areas, or between respondents who had a disability or were a carer. This is similar to previous work which suggests that clients in urban and rural areas have broadly similar preferences for how they access and interact with the agency<sup>10</sup>.

In the future, Social Security Scotland will offer home visits to clients who require them. Respondents who told us they would prefer a home visit tended to refer to mobility issues or specific health conditions as a reason for this:

"My son has a learning disability [...] He can't attend a centre so location i.e. a home visit is imperative."

## Important factors when self-booking a health assessment

To further understand what is important to clients when booking their own health assessment, they were supplied a list of six factors and asked to select all of the factors that they would like to be able to choose as part of a future online booking system.

#### These factors were:

- The assessor's knowledge of specific medical conditions;
- The location of the health assessment:
- The time of the health assessment;
- The date of the health assessment;
- The assessor's experience (i.e. their qualifications); and
- Specific access requirements at assessment locations (e.g. a venue with a car park or no stairs).

<sup>10</sup> Scottish Government (2019). *Social Security Experience Panels – Agency Buildings*. [Online] Available at: https://www.gov.scot/publications/social-security-experience-panels-agency-buildings/

The most popular request was to choose an assessor who had knowledge of the client's particular medical condition (95 per cent). Choosing the location (90 per cent) and time (76 per cent) were also popular.

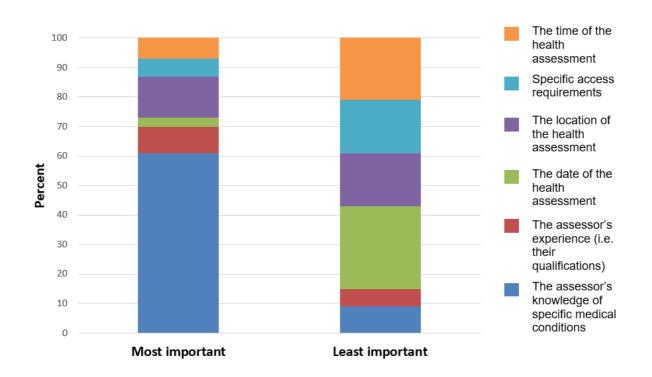
Table 10: What is important when booking a health assessment? (n=128)

Factor	%
The assessor's knowledge of specific medical conditions	95
The location of the health assessment	90
The time of the health assessment	76
Specific access requirements	65
The assessor's experience (i.e. their qualifications)	63
The date of the health assessment	55

In order to inform the design of the future online booking system, respondents were asked to choose the single most and least important factor from the list above.

The most popular choice was to be able to choose an assessor based on their knowledge of particular conditions, followed by the location of the health assessment venue. The least important choice when booking an assessment was the date of the assessment itself, closely followed by the time and being able to choose an assessment venue by specific access requirements.

Figure 2: Most and least important factors when booking an appointment



#### Client choice in booking assessments

Many respondents told us it was important that they had the option to book their own health assessments. For many respondents, the changeable nature of their health condition meant that they placed a high value on flexibility.

"I am not able to travel far on my own. I often struggle to even get to the local supermarket and there are times when I am unable to do even that. Travelling to Glasgow for my assessments is traumatic."

Other respondents had to arrange for a carer, friend or family member to accompany them on the trip, therefore they had to be able to arrange the assessment time to fit in with their schedules.

"It would be better for me if I could pick the day of the assessment as I would need someone to come with me and would be easier to arrange if there was a degree of flexibility about the day."

# Rearranging a health assessment

As stated above, the current and previous research with Experience Panel members has suggested that they place a high value on flexibility. In order to consider how Social Security Scotland might provide such flexibility in the future, we explored the topic of rearranging health assessments.

Respondents were asked if they had ever missed or cancelled a health assessment at short notice. For the purposes of this survey, we defined 'short notice' as cancelling up to 48 hours before the appointment was due to take place, and that 'missing' a health assessment referred to not turning up to a previously booked appointment without giving advanced notice of intent to not be there.

Just under one in five respondents (17 per cent) had missed or cancelled a health assessment at short notice.

Table 11: Have you ever missed or cancelled a health assessment at short notice? (n=128)

Response	%
Yes	17
No	80
Don't know / can't remember	3
Total	100

Of those who had missed or cancelled their appointment, just over seven in ten (71

per cent) had cancelled their appointment and just under three in ten (29 per cent) had missed it.

Table 12: Respondents who missed or cancelled an appointment (n=21)

Response	%
Missed	29
Cancelled	71
Total	100

We asked respondents why they had missed or cancelled their appointment. Responses across both groups were broadly similar, with common reasons being:

- the respondent was unwell, in hospital or caring for an unwell family member or friend:
- the respondent could not arrange suitable transport to their health assessment:
- the respondent's disability had flared up and they were having a bad day; or
- they lost the appointment letter, or the letter arrived giving insufficient notice to allow arrangements to be made to attend.

## Travelling to the health assessment

Many of the themes covered by respondents in this topic mirrored those stated by respondents as part of the Social Security Experience Panels – Agency Buildings research and therefore have not been repeated here. A detailed consideration of Experience Panel member expectations on agency buildings – including health assessment locations – can be found in that paper<sup>11</sup>. Where themes have been expressed in different terms, or have not previously been expressed, they have been included below.

We heard that the location of assessment centres was 'hugely important' for reasons of accessibility, privacy and cost. Respondents told us that they felt the location of assessment centres did not meet their needs, with some respondents saying they had been asked to travel far from home.

"The location is also important, why should we have to travel 40 miles as is the current arrangement for an assessment..."

<sup>&</sup>lt;sup>11</sup> Scottish Government (2019). Social Security Experience Panels – Agency Buildings. [Online] Available at: https://www.gov.scot/publications/social-security-experience-panels-agency-buildings/

For some, being asked to travel far from home made an already stressful experience worse. It was felt that assessment centres should be located in areas that were easily accessible to all.

"If an assessment is required, then a location that does not impact on getting there should not cause stress or strain before what is obviously a stressful process."

Many respondents told us that travelling to an in-person health assessment was difficult as a result of their health condition. Some respondents told us they only have a small window each day where they are able to travel. Respondents who required a carer to travel with them felt that flexibility was vital in order to allow sufficient time to arrange a travel companion.

"With wheelchair and dementia, flexibility [...] is vital as carers have to be organised..."

"I am a wheelchair user and need someone to accompany me anywhere I go. To allow for such, I need to arrange for my partner to take time off work or employ a carer to be with me. Such arrangements take time to get in place and it cannot always fit the date and time assigned by the DWP."

Other respondents told us that they would value the ability to book a parking space, as they could not use public transport.

"The ability to book a parking space is important to a wheelchair user..."

"I need to be able to drive to an assesment and park very close to wherever it is as I can't use public transport. Not being able to do this makes the difference between being able to attend and not being able to attend."

It should then be easy to get from the car to the front door.

"My local assessment centre has almost no parking and is impossible to get car doors open enough to get a disabled person out safely. [...] ...further to this, It has a cobblestone surface that is like an ice rink at the first sight of rain leading to both myself and my wife falling in the past."

Respondents told us they would value having an assessment in a familiar location, closer to home. This would, for some, reduce the stress of having to travel a long way for an assessment:

"If I did not know how to get to the location I would panic about being late or getting lost."

Many respondents told us that the time of travel was also important to them. For some, early morning appointments were unsuitable as it could take them a long

time to get ready to start the day, or their health condition was worse in the mornings. Having an appointment later in the day allowed time for their medication to 'kick-in', their 'brain to get in gear' and ensured their sometimes lengthy morning routine would not be curtailed or rushed.

"Time of day is important as he is less able to function in the morning."

"Early mornings are very difficult for me, so if I was called for an early appointment it would entail painful inconvenience."

For others, early morning appointments were preferable as it meant they were less likely to be tired.

Overall, respondents suggested that they should be able to choose the location and time of the health assessment, and that Social Security Scotland should understand and be prepared for the inevitable need for flexibility that is inherent to their client group.

## At the health assessment

Many Experience Panel members have reported that undergoing a health assessment as part of their disability benefit application is one of the most stressful aspects of the process. The stressful nature of the health assessment is due to:

- having little to no control over the time and location of the assessment;
- poor transport links to the assessment centre;
- assessment centres not being fully accessible;
- a lack of confidence in assessors, their qualifications, background, inclusiveness and accuracy; and
- negative media portrayal about assessments.

Respondents to this survey were broadly in line with past research, reporting health assessments as highly negative experiences. Respondents used words such as 'exhausting', 'degrading', 'humiliating' and 'stressful' to describe the experience.

There was, across most respondents, concern over the competence, reliability and integrity of the health assessors, as well as of the value and fairness of the way health assessments are currently implemented.

#### Conduct of health assessors

A great deal of the negative comments from respondents related to the conduct of health assessors during the assessment itself. Respondents reported feeling 'on trial' and 'under suspicion' whilst attending their health assessment.

"...we have been through this process with my son and it felt like we were on trial at court, not a good experience what so ever."

"I have attended PIP interviews with my children and been apalled at how little the person knew about their conditions. They wrote ridiculous comments on the report."

The conduct of assessors was seen by many as 'self confident' and 'arrogant'. Many respondents felt they made 'inaccurate and ill-informed assumptions' about clients and their conditions. Some reported cases of health assessors ignoring their requests or failing to report what they said accurately.

Many respondents also had concerns about the health assesor's knowledge of disabilities and their particular medical condition.

"Having been through two health assessments for PIP, it is obvious that health professionals have no real understanding of the effects of my condition and only very limited and out of date medical knowledge."

"Previous experience with assessments showed a distinct lack of knowledge regarding my symptoms."

Respondents with specific conditions felt particuarly misunderstood:

"My condition (epilepsy) is very misunderstood and I have had numerous problems with assessors in the past."

Some respondents said that they had felt 'condescended' as their assessor had said they had 'never heard of their condition before'. This caused the respondents to feel stressed and reduced their confidence of receiving an accurate, fair and comprehensive health assessment.

In other cases, health assessors who had little knowledge of conditions were seen to ask 'inappropriate requests' of clients, such as asking them to complete tasks which would either be impossible, or painful if they complied.

Many respondents could recall their assessor asking inappropriate questions or making insensitive remarks.

"[The assessor] didn't agree my daughter had problems using the toilet as she didn't wet/soil herself in the interview."

"[The assesor] told me they didn't agree my daughter had problems eating as she wasn't overweight..."

## **Knowledge of health assessors**

It was generally felt that more knowledgeable assessors would lead to more accurate reports, higher quality assessments and fairer outcomes for clients:

"Having someone who has knowledge of the condition will ensure the assessment is fair and time isn't wasted trying to explain your symptoms."

"A decision cannot be made without empathy and a thorough understanding of how any condition impacts a persons life."

For mental health conditions, respondents told us that the manner of interaction would influence how open the client would be with the assessor. Respondents with particular conditions said they felt reluctant or unable to fully express how their condition affects them. In this case, it was felt to be the job of the assessor to work with the client to draw this out. In many cases, respondents said this did not happen.

Many respondents felt that it was 'unlikely' that an assessor could carry out an accurate, thorough and detailed health assessment without having at least a rudimentary understanding of their health condition, or the way in which being disabled can affect someones day to day life.

"You can't assess complex conditions without at least a working knowledge of the claimant's issues."

"I fear clients are not being fairly assessed if the Health Care Professionals do not fully understand their condition."

This was particuarly the case where people have multiple conditions with complex interactions between them and any medication being taken.

The lack of medical and disability related knowledge in assessors led to many respondents perceiving assessors to be lacking in competence. This was further demonstrated by health assessors asking generalised questions, making clients feel the assessment was a 'tick box' exercise, with an assessor 'disinterested' in presenting an accurate picture of their health and it's impact on their life.

"I have in the past been assessed by nurses who don't even know what my conditions are [...] They always ask everyone the same questions. Not one question suits all."

"I am fed up of being assessed by nurses who have zero knowledge or experience of the conditions and illnesses that I have, and then the fact they disregard anything you say relating to your conditions as well as evidence provided to support the condition."

In future, many respondents said they would like to see a move away from standardised questions, in favour of a more individualised approach to assessing clients.

Most respondents felt that improving assessor knowledge of disabilities and a move away from generalised questions did not necesserily require assessors to have a medical degree – a well rounded understanding of disabilities and effective training was seen by most to be sufficient.

#### Assessment reports

At the end of a health assessment, the assessor will write a report detailing their views on the client's health. This report is then used by the decision maker (employed by the Department for Work and Pensions) in deciding whether to award the benefit, and the duration of the benefit award. The quality, accuracy and perceived fairness of the reports were a recurring theme amongst respondents. Respondents tended to not trust what was written by assessors, potentially as a result of the issues of perceived conduct and knowledge discussed above. Some felt it was 'inappropriate' for assessors to dispute evidence presented by the client's doctor or specialist, who was seen to be a 'medical 'expert' in comparison to the assessor.

# Recording health assessments

Within the current system as operated by the Department for Work and Pensions, clients have the option to audio record their health assessments. To do so, clients are required to adhere to rules set by DWP, including using an approved recording device, providing an identical copy of the recording to the health assessor on the day and giving permission for the health assessment organisation to keep a copy of the recording<sup>12</sup>. Video recording is not allowed<sup>11</sup>.

In order to understand whether there was appetite for health assessments to be recorded in the future when the benefit was administered by Social Security Scotland, respondents were asked their preference.

Almost three quarters of respondents said they would like their assessment recorded (72 per cent) with almost a quarter saying 'Maybe' (23 per cent). One in twenty responded negatively (2 per cent), or that they had no opinion (3 per cent).

Table 13: Would you like your health assessment to be recorded? (n=128)

Response	%
Yes	72
Maybe, it depends	23
No	2
No opinion / don't know	3
Total	100

12 GOV.UK (2019). *PIP Assessment Guide part 1: the assessment process*. [Online] Available at: <a href="https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-1-the-assessment-process">https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-process</a> [Accessed: 10

April 2019].

#### Why do respondents want health assessments recorded?

Respondents gave varying reasons for why they would like their assessment recorded.

The most common reason was the desire to create a verifiable record of the health assessment itself that could, if required, be used to verify what the client or the health assessor said.

Many respondents wanted this as they did not trust the health assessor as a result of their past experiences.

"The reports completed in my assessments were inaccurate and if the assessment had been recorded it would have been clear that was the case..."

"[I] have experienced an assessment where the nurse lied about me carrying out certain movements that did not actually happen, i.e. she made most of it up. Recording would protect the claimant and the medical professional."

""When I appealed my mobility decision, I was made to feel like a liar as I accused the assessor of lying on my form. A recorded interview or assessment would validate what both parties are saying..."

Others did not trust the health assessment companies, and felt they did not honestly report the results of their health assessment.

Some respondents felt that recording the assessment would 'improve' the quality of the reports, 'give them redress' should they choose to appeal and ensure the assessor treated them fairly.

A small number of respondents said their particular health condition impacted on their memory, and that having a record would help them personally remember what happened:

"I can't remember details due to ptsd. If asked questions later, I could refer back to the recording..."

Finally, respondents who had wanted – but been unable to – record their assessments in the past felt that a policy of recording all assessments should be fair, especially for people who could not provide the equipment required under the current policy.

"I had to spend £150 on equipment so I could record the assessments afer the health care profesional lied on the form at my first assessment."

"The hurdles put in place regarding recording assessments is outrageous. People should be entitled to have their assessment recorded if they wish."

#### Why do respondents not want their health assessment recorded

Respondents who said they did not want their health assessment recorded were in the minority, however they gave several reasons as to why they felt this way.

Some respondents had concerns around the privacy, or the protection of sensitive personal data:

"Not sure about recording as this seems a step too far in "big brother" type of attitude..."

"I mistrust the current assessment process and would not like intimate details of how my condition affects me to be at potential risk of inappropriate viewings."

Others were worried about what the data would be used for, or would find being recorded stressful:

"...part of me worries that in the hands of an unscrupulous government it might be viewed by body language specialists to decide the outcome of the claim."

One respondent said that if health assessments were recorded by default, they would feel like they could not attend as it would cause them 'great distress'. Ensuring clients are aware in advance that recording is optional may reassure such clients.

#### How should health assessments be recorded

Respondents who said they would, or would maybe like their assessment recorded were asked whether it should be an audio or video recording. Most respondents preferred an audio recording (56 per cent) however just under half would also be happy with video (44 per cent).

Table 14: Respondent recording preference (n=112)

Response	%
Audio	56
Video	44
Total	100

Respondents who favoured audio recording felt that it was 'less intrusive' and 'less intimidating' than video recording. Some respondents said video recording was a 'scary prospect' and did not like the idea of being watched on film. Some felt that an audio recording would capture all of the needed information:

"An audio recording would capture the relevant information without being as uncomfortable as being filmed during an already traumatic experience."

Respondents who favoured video recording gave a range of reasons for this.

Many said that a video recording would present 'the whole picture' and result in 'absolutely no ambiguity in what was said or done during the assessment'. Some respondents felt that audio recording would miss out body language, which for them was important in showing how their condition impacted their lives.

"If I have a partial seizure during a conversation, sometimes it can be seen in a video but is not noticable if you don't know what to look for."

"Body language is also important. If a claimant is in pain or discomfort, or extremely anxious, it may be evident in the video recording."

Some respondents suggested a video recording would be most useful where a physical examination was conducted, to accurately show the client's response to requests made by the assessor. It was also felt to be more suitable in protecting the client should a physical examination take place.

Some respondents also hoped video recording would improve the quality of the assessment.

"...can be used to assess the assessor's interpersonal skills [...] – so often they barely lift their head from the computer to address the claimant..."

## **Duration of health assessments**

Past research with Experience Panel members has revealed that due to certain health conditions, there are limits on how long panel members feel they can talk to staff in person<sup>13</sup> and on the phone<sup>14</sup>.

To ensure that the duration of health assessments were appropriate and suitable for client's needs, respondents were asked how long a face to face health assessment should last.

Just under six in ten respondents felt said that health assessments should last 'as long as necessary' (58 per cent). Around two in ten respondents thought assessments should last around thirty minutes (17 per cent). Around one in ten thought they should last around 45 minutes (10 per cent) or an hour (13 per cent). Just one in a hundred said they should last two hours (1 per cent).

<sup>&</sup>lt;sup>13</sup> Scottish Government (2019). *Social Security Experience Panels – Agency Buildings*. [Online] Available at: <a href="https://www.gov.scot/publications/social-security-experience-panels-agency-buildings/">https://www.gov.scot/publications/social-security-experience-panels-agency-buildings/</a>

<sup>&</sup>lt;sup>14</sup> Scottish Government (2019). *Social Security Experience Panels – Communicating with Social Security Scotland by phone*. [Online] Available at: <a href="https://www.gov.scot/publications/social-security-experience-panels-communicating-social-security-scotland-phone/">https://www.gov.scot/publications/social-security-scotland-phone/</a>

Table 15: How long should face to face health assessments last? (n=127)

Duration	%
About 30 minutes	17
About 45 minutes	10
About an hour	13
About 2 hours	1
As long as necessary	58
Don't know / no opinion	1
Total	100

A chi-square test of association was carried out to identify any differences in respondent preference on length of home visit compared to length of appointment in an agency venue. No significant associations were identified<sup>15</sup>. Similiarly, no associations were identified between duration of appointment and age or disability status. A significant association was identifed between duration of appointment and care status, with respondents who had caring responsibilities tending to want shorter appointments<sup>16</sup>.

Respondents were also asked how long an assessment would be too long for them. Almost nine in ten respondents said the assessment could be over 30 minutes long (87 per cent), however less than three in ten said it could be over an hour (28 per cent). Just over one in ten said it could be over 1 hour 30 minutes (14 per cent).

Table 16: How long an assessment would be too long? (n=124)

Duration	%
Over 30 minutes	14
Over 40 minutes	14
Over 50 minutes	9
Over 1 hour	35
Over 1 hour 15 minutes	7
Over 1 hour 30 minutes	8
Over 1 hour 45 minutes	3
Over 2 hours	11
Total	101

 $<sup>\</sup>frac{15}{15} \chi^2$  (1, n=124) = 0.711, exact p=0.399

 $<sup>^{16}</sup>$   $\chi^2$  (1, n=112) = 4.708, exact p=0.030

Responses were grouped into maximum acceptable assessment times for respondents:

Table 17: Acceptable assessment time for respondents

Duration	%
30 minutes	100
40 minutes	86
50 minutes	72
1 hour	63
1 hour 15 minutes	28
1 hour 30 minutes	22
1 hour 45 minutes	14
2 hours	11

A number of statistically significant associations were observed for certain demographic groups. Of those respondents who were carers, over two fifths said they would need an assessment of less than an hour (82 per cent), where as just over six in ten non-carers would want this (64 per cent). A chi-square test of association revealed this to be a significant association 17.

Respondents who selected up to an hour felt that this should be 'plenty of time to gather all that is needed'. It was suggested that if both parties were adequately prepared for the meeting, then it should take no longer to cover all areas.

Respondents who preferred shorter health assessments often refered to the stressful nature of the experience. They said that they 'struggle with people' and 'feel anxious' so the 'shorter the better'. Other respondents said they were easily tired, and that sitting in a meeting for a long time could be painful.

"I get so tired easily and the pain I also feel when I have to sit up for longer than 10 minutes is excruciating even with pain killers..."

Some respondents referred to the negative environment within the test centre, saying that it limited how long they could be there.

"[The] environment, often lighting, seating, adds to anxiety and pain levels."

Respondents said that assessments lasting over an hour were 'physically and mentally exhausting'.

 $<sup>^{17}</sup>$   $\chi^2$  (1, n=112) = 4.708, exact p=0.030

"My assessment lasted 1 hour and 20 minutes and when I came out I felt mentally drained and exhuasted. It felt like I had been interrogated rather than interviewed."

Many respondents suggested the health assessment should be long enough to gather the information, with a view of keeping it no longer than necessary so as not to harm the client.

#### What should happen if a client can no longer continue

We asked respondents what they would like to happen if they felt they could no longer continue with a health assessment. This may be a result of the client being in pain, unhappy with the assessor or simply feeling like they cannot continue at that current time.

Many respondents said they would like to be able to arrange a further health assessment at a convenient date and time, including the option to select another assessor if required. Some requested that there be a written record of what had happened up to that point, so the future assessment would be shorter.

Other respondents suggested that it was made clear to clients that they had the right to stop an appointment, to avoid them feeling stressed or worrying about consequences if they did so.

It was suggested that by incorporating breaks into the process, it would reduce the need for clients to cut an assessment short.

# **Expenses**

After attending a health assessment, clients are – in some circumstances – able to make a claim for expenses incurred as a result of travelling to the assessment centre. To identify if there were any possible improvements that could be made to the current expenses system, we asked respondents to tell us their views.

Just over a fifth of respondents had claimed or claimed and received expenses after a health assessment (21 per cent), with over four fifths having not claimed (72 per cent).

Table 18: Respondents who have claimed, or claimed and received expenses after a health assessment (n=118)

Response	%
Yes	21
No	72
Don't know / can't remember	6
Total	100

Respondents who had claimed expenses tended to be happy with the process.

"[It went]...very quickly and very well. I was paid fuel expenses and it arrived within 10 days in my bank account."

"I received payment for car travel direct into my bank account. This was a good solution as I live in a rural area and use internet banking so a cheque would have been difficult to process."

Respondents differed in the length of time they thought it had taken to receive their expenses after claiming, however most respondents mentioned a time of four weeks or less.

"I completed a form and posted it off. It was dealt with within four weeks."

A minority of respondents were unhappy with the process. Some felt the process was 'more hassle than it was worth'. Others felt that having to be out of pocket before the assessment was not right, and that some clients couldn't afford to be without the money for such a long time. Some respondents suggested that instead of claiming back the mileage, the Department for Work and Pensions should pay a flat rate mileage to the client before the appointment, based on the distance from their home address to the assessment centre.

## What's Next?

The Scottish Government will continue to work with the Experience Panels in the development of Scotland's new social security system. This will include further research on individual benefits in addition to work to assist in the development of Social Security Scotland.

The content of this report will be used by the Scottish Government and Social Security Scotland to inform the ongoing design, development and implementation of Personal Independence Payment within Scotland.

How to access background or source data
The data collected for this <statistical bulletin="" publication="" research="" social="">:  □ are available in more detail through Scottish Neighbourhood Statistics</statistical>
$\square$ are available via an alternative route <specify delete="" or="" text="" this=""></specify>
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