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Social Security Experience Panels: Award Duration and Automatic Entitlement



EQUALITY, POVERTY AND SOCIAL SECURITY



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Introduction

In July and August 2018, Scottish Government researchers held focus groups and carried out a survey with Experience Panel members to hear their views and opinions on award duration and automatic entitlement. This work was part of the Scottish Government's Social Security Experience Panel programme of research.

This report provides a summary of the findings.

Summary

Automatic Entitlement and Award Duration

Automatic entitlement would be where people with particular disabilities are entitled to a benefit award without having to undergo a face-to-face health assessment or provide any further information beyond confirmation of their diagnosis with an eligible condition. Automatic entitlement would reduce the effort required by individuals applying for benefits (for example, by simplifying the application process and reducing the amount of evidence they would need to gather). It could also help reduce the volume of health assessments carried out for disability benefits, whether face-to-face or otherwise.

There was a high level of support among the research participants for introducing a policy of automatic entitlement to disability benefits if an individual had a specific health condition. When asked who should be automatically entitled, participants tended to identify similar groups of health conditions and disabilities that should qualify, such as those who are deaf, blind, amputees, and those with terminal or progressive conditions.

We also asked participants for their views on how long disability benefit awards should be ('award duration'). Longer award durations would remove the need for unnecessary re-assessments, which Experience Panel members have told us are often distressing and frustrating for people whose circumstances are unlikely to improve or change¹.

Participants were less positive about the suggestion of a five year award duration for unchanging conditions. When asked why, participants said they would prefer an indefinite award to be introduced in these cases.

Light Touch Reviews

A light touch review is a potential alternative to a re-assessment. Light touch reviews differ from face-to-face health assessments in a number of ways. The reviews would primarily be paper-based, however sometimes clients may need to

¹ Scottish Government (2018). *Social Security Experience Panels: Personal Independence Payment Discovery – Visual Summary* [online] Available: <https://www.gov.scot/publications/social-security-experience-panels-personal-independence-payment-discovery-visual-summary/>

attend a face-to-face review. Clients' benefits would continue to be paid throughout the review period at the same rate as before.

Participants generally responded positively to the idea of light touch reviews, with many viewing them as a significant improvement over the existing regime of face-to-face health assessments.

Participants were divided on whether Social Security Scotland should use previous evidence from health assessments carried out by the Department for Work and Pensions (for example, as part of their application for Personal Independence Payment). Some participants reported a positive experience at their Department for Work and Pensions (DWP) health assessment, feeling that their assessor had given a chance to demonstrate how their disability impacts on their day to day life. These participants were generally supportive of using evidence, such as the report written by the DWP health assessor.

For some participants, the health assessment had been a highly negative experience. They believed the report did not accurately describe their condition, they felt that they were not listened to and they did not want any evidence from DWP assessments to be used by Social Security Scotland.

When asked where light touch reviews should take place if a face-to-face review was necessary, participants suggested a number of local buildings. When asked about existing DWP buildings, participants talked about having negative experiences of buildings previously used for assessments by DWP. Most participants believed an agency building would be acceptable.

Background and research methods

The Scottish Government are becoming responsible for some of the benefits previously delivered by the DWP. 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 over 2,400 people across Scotland who have recent experience of claiming at least one of the benefits that will be devolved to Scotland.

The Scottish Government is working with Experience Panel members to design a new social security system that works for the people of Scotland. Part of this work includes the creation of Social Security Scotland – Scotland's new social security agency.

As part of the formation of Social Security Scotland, researchers from the Scottish Government have met with Experience Panel members to hear their thoughts and views on automatic entitlement, light touch reviews and award duration.

The research involved a survey and four focus groups. It focused on two areas:

- the ways in which benefits are awarded to people with medical conditions that are unlikely to change or improve over time (award duration and automatic entitlement); and
- what a potential alternative to reassessments, 'light touch reviews' could look like.

All participants were recruited through the Scottish Government's Social Security Experience Panels. The Social Security Experiences Panels are a longitudinal research project. The panels are made up of volunteers from the Scottish population who have lived experience of benefits. As such, the results of the survey should be regarded as being reflective of the experiences and views of the respondents only and are not indicative or representative of the wider Scottish population.

Survey Method

1,425 Experience Panel members with experience of claiming a disability benefit for themselves or someone they care for were invited to take part in this survey. It was called 'Help us understand who should be automatically entitled to disability benefits and how long disability benefit awards should last'.

241 Experience Panel members out of the 1,425 completed the survey (seventeen per cent).

Panel members were given the option to complete the survey online, returning a paper form or by calling the Experience Panels helpline and completing the survey over the phone.

The information was added to the previous information from 'About Your Benefits and You' (Scottish Government, 2017²) and 'Social Security Experience Panels: Who is in the panels and their experiences so far' (Scottish Government, 2018³). The data collected in these surveys was linked to the information supplied by participants as part of the longitudinal dataset for this project. Demographic information was not held for all participants. The figures in tables one to five include demographic data of only those participants whose records could be matched.

Eight out of ten participants (80 per cent) were aged 45 or over, and just under three in ten (27 per cent) were aged between 60 -79.

² 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

³ 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

Table 1: Age of survey participants (n=241)

Age	%
16 – 24	--
25 – 44	15
45 – 59	53
60 – 79	27
Prefer not to say	--
Total	95

Just over six in ten participants identified as ‘woman or girl’ (63 per cent) and three in ten identified as ‘man or boy’ (32 per cent).

Table 2: Gender of survey participants (n=241)

Gender	%
Man or boy	32
Woman or girl	63
Total	95

Almost nine in ten survey participants had a disability at the time of the survey (87 per cent):

Table 3: Disability status of survey participants (n=226)

Disability Status	%
Disabled	87
Not Disabled	13
Total	100

Just over half of survey participants cared for a friend, relative or partner at the time of the survey (51 per cent):

Table 4: Care status of participants (n=226)

Care Status	%
Carer	51
Not Carer	47
Prefer not to say	1
Total	99

Just over nine in ten survey participants (94 per cent) were in receipt of a benefit at the time of the survey:

Table 5: Participants who are in receipt of a benefit award (n=241)

Response	%
In receipt of benefit award	94
Not in receipt of benefit award	6
Total	100

Over a third of survey participants had an indefinite benefit award (37 per cent) and just under two in ten had an award of more than four years (18 per cent). One in a hundred participants (1 per cent) had an award duration of less than twelve months.

Table 6: Participants who are in receipt of a benefit award (n=235)

Award Duration	%
Less than 12 months	1
Between 1 and 2 years	11
Between 2 and 3 years	21
Between 3 and 4 years	12
More than 4 years	18
Indefinitely	37
Total	100

All participants had experience of claiming or helping someone to claim Disability Living Allowance (100 per cent) and over seven in ten (71 per cent) had experience with Personal Independence Payment (PIP).

Just over one in five participants had experience with Attendance Allowance (22 per cent), Severe Disablement Allowance (22 per cent) while less than one in ten (8 per cent) had experience of Industrial Injuries Disability Benefit (IIDB).

Table 7: Participants who have experience of each disability benefit (n=229)

Benefit	%
Disability Living Allowance	100
Personal Independence Payment	71
Attendance Allowance	22
Severe Disablement Allowance	22
Industrial Injuries Disability Benefit	8

More detailed demographic information on the Experience Panels as a whole can be found in the 'Who is in the panels and their experiences so far' report (Scottish Government, 2018⁴).

Focus Groups

Focus groups on automatic entitlement and award duration were carried out in Glasgow and Edinburgh. Most focus group attendees who took part in the focus groups had experience of claiming a disability benefit.

Thirteen participants took part across four 90 minute focus groups. Post-its and flipcharts were used to facilitate discussion with participants. A Scottish Government staff member acted as a note-taker in each session. In the interest of maintaining privacy, the focus groups were not recorded. The analysis is based on the notes taken at each group.

This report presents analysis from the survey outlined above and the focus groups.

Automatic Entitlement

Automatic entitlement is where people with particular disabilities are entitled to a benefit award without having to undergo a face-to-face health assessment or provide any further information beyond confirmation of their diagnosis with an eligible condition. Automatic entitlement could reduce the stress experienced by

⁴ 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

individuals applying for benefits and help the agency reduce the volume of health assessments carried out for disability benefits, whether face-to-face or otherwise.

This is a change from the current system where for some disability benefits (for example, Personal Independence Payment) the decision is based on the extent to which the disability affects the client's day to day life. This is determined through a health assessment which the applicant is required to attend as part of the application process.

It is expected that automatic entitlement to disability benefits for some conditions would benefit those who have lifelong conditions.

Should certain conditions qualify people for automatic entitlement?

Participants were asked whether people with certain conditions should be automatically entitled to disability benefits. Four in five participants (80 per cent) believed this should be the case, with ten per cent of participants disagreeing with the idea and ten per cent uncertain.

Table 8: Should people with certain conditions be automatically entitled to disability benefits (n=241)

Response	(%)
Yes	80
No	10
Don't know / not sure	10
Total	100

Some participants believed that those whose medical condition would not change or improve over a long period of time should not have to undergo repeated assessments.

“Because there are certain lifetime conditions that are never going to improve or be cured, so why put people through unnecessary assessments when they will never get better. All this does is add even more stress and this in turn exacerbates the illnesses that people are already coping with.”

- Survey participant

The level of stress and anxiety caused by assessments contributed to participants wanting to only be assessed when absolutely necessary:

“...life is hard enough without having to sit in front of strangers answering questions...”

- Survey participant

Other participants said that for long term conditions it could often be difficult to provide up to date evidence from a GP or consultant. This is because many participants were now at the stage of managing their condition rather than actively seeking treatment for it. These participants saw their health professionals on a very infrequent basis and were reluctant to 'waste' their doctors time by making an appointment solely to ask the doctor to provide an updated report on their condition.

What conditions should qualify someone for automatic entitlement?

When asked what conditions should qualify, participants tended to talk in broad terms rather than about specific conditions. The most common conditions mentioned were:

- Terminal conditions
- Learning disabilities
- Autism
- Cognitive disorders
- Chronic conditions
- Progressive conditions

Participants believed that assessing people with these conditions was hard to justify:

“Certain conditions are progressive so are only going to get worse not better. If a medical diagnosis of such conditions has been confirmed benefits should be automatic.”

“People who are coming to terms with life limiting conditions should not have to jump through hoops to get financial assistance.”

“There is no cure, so why can she not get a lifetime award”

- Survey participants

There was less consensus on whether mental illnesses should qualify for automatic entitlement.

Some participants believed that variations in the severity of mental illness between different individuals made them unsuitable for automatic entitlement or would be difficult to assess. Some believed it was important to recognise the difference between those who had a repeated history of severe mental illness and those who were undergoing a severe, but short-term episode.

To address the issues with automatic entitlement and mental illness, some participants suggested Social Security Scotland base the decision on a discussion with psychiatrists as to whether an individual's condition was severe enough to qualify (although this is not automatic entitlement in the strictest sense as there is still some level of assessment involved). Others believed the length of time the

individual had been diagnosed with the condition should be taken into account. This would aid in distinguishing between those who had a long history of mental illness and those who did not.

Who should decide who is automatically entitled

Participants were asked who they thought should decide which conditions should qualify for automatic entitlement. Both survey and focus group participants were given the same list of options, and both groups were allowed to suggest other ideas.

Survey participants were asked to choose all options they felt comfortable with. More than eight in ten survey participants (84 per cent) said they would be comfortable with doctors or other health professionals deciding which conditions qualify for automatic entitlement, and just under two fifths (39 per cent) of participants were comfortable with an independent group of advisors. Thirty-seven per cent were comfortable with Social Security Scotland deciding.

Table 9: Who should decide what conditions qualify for automatic entitlement (n=241)

Response	(%)
Doctors or other health professionals	84
An independent group of advisors	39
Social Security Scotland	37

Sixteen per cent of survey participants selected 'Someone else' and were given the option of telling us who. Suggestions included:

- A panel of disabled people
- Disability organisations
- A panel of healthcare professionals

There was little consensus amongst focus group participants on who should make the decision. Most participants believed that many of the suggested options were viable, emphasising that the most important requirement was the person or people deciding had a medical background and a good understanding of disabilities.

Participants were asked how they would feel if Social Security Scotland made the decision. Most participants did not believe this would be an issue, however some disagreed. Those who disagreed said they would prefer the decision maker to be independent from the agency.

Identifying those who are automatically entitled

Participants were asked if they could think of any ways that Social Security Scotland could identify those who may be automatically entitled before they apply.

Responses tended to fall into three groups: enhanced data sharing between the NHS and government, an improved application form and referrals from third parties.

A number of participants suggested that a health professional could signpost a patient to the Agency once they had been diagnosed with a qualifying condition. Others believed a letter or report from a GP to Social Security Scotland should suffice or that the client's health records could be sent to the Agency.

In terms of the application form itself, many suggested a tick-box with a list of qualifying conditions at the start of the form.

The most common suggestions usually referred to data sharing between the Agency and the NHS, allowing for quick identification and verification of those who had been given a diagnosis of a qualifying condition.

Award Duration

Award duration refers to how long a client is awarded a benefit before their eligibility for that benefit has to be reassessed. The Scottish Government has committed to introducing longer-term disability benefit awards for conditions that are unlikely to get better. Longer term awards will remove the need for unnecessary reassessments, which are often distressing and frustrating for people whose circumstances are unlikely to ever get better.

Participants were asked whether they thought an award duration of five years was more appropriate for people who had a condition that was unlikely to change or improve.

Just over four in ten survey participants (43 per cent) believed an award duration of five years was very appropriate or appropriate for people whose condition was unlikely to change or improve. Almost six in ten felt that it was not that appropriate or not appropriate at all (57 per cent).

Table 10: How appropriate is an award duration of five years for people whose medical condition is unlikely to change or improve? (n=241)

Response	%
Very appropriate	28
Appropriate	15
Not that appropriate	22
Not appropriate at all	35
Don't know / no opinion	< 1
Total	100

Some participants said they would prefer to be given an indefinite award for unchanging conditions. Focus group participants were more supportive of an award length of five years, believing it would give clients more time to prepare. Some participants noted the length of the appeals process made short awards more stressful, as they felt that by the time the process had been completed, they had to start preparing for their next application.

For a large number of participants, their views on award duration appeared to related to a desire to minimise the number of times they would need to be assessed.

Light Touch Reviews

A light touch review is a potential alternative to a reassessment. Light touch reviews differ from face-to-face health assessments in a number of ways. The reviews would primarily be paper-based, however sometimes clients may need to attend a face-to-face review. Client's benefits would continue to be paid throughout the review period at the same rate as before. The review would be designed to be as easy and stress-free as possible for the client.

What evidence should be used

In order to minimise the amount of evidence that participants have to gather for assessments or reviews, one potential future option is for Social Security Scotland to use evidence from past DWP health assessments as part of the light touch review. This could include the report produced by the health assessor.

These health assessments were carried out by a health professional appointed by the Department for Work and Pensions, typically as part of a PIP application. We

know from previous research⁵ that many Experience Panel members feel strongly about the accuracy of these reports therefore we wanted to understand their thoughts on this suggestion.

Thirty-nine percent of survey participants wanted previous evidence from DWP assessments to be used by Social Security Scotland. Just over one in five participants did not (22 per cent) and just under a third wanted the choice (30 per cent). Ten per cent of participants were unsure.

Table 11: Should evidence from DWP health assessments be used by Social Security Scotland when making a benefit decision? (n=241)

Response	%
Yes, evidence from previous DWP assessments should be used by Social Security Scotland	39
No, evidence from previous DWP assessments should not be used by Social Security Scotland	22
I would like to choose	30
Don't know / not sure	10
Total	101

Excluding participants who chose 'I would like to choose' and 'Don't know', just over two thirds (64 per cent) wanted previous DWP evidence to be used by Social Security Scotland (35 per cent did not).

In focus groups, participants talked about not trusting the reports produced as part of their previous health assessment, believing them to be inaccurate or incomplete.

Many participants commented that their previous health assessment had been a highly negative experience and that using previous evidence from DWP did not align with the concept of a fresh start for the new agency:

“The reason for this survey is to improve the system. Looking at previous claims won't always work at this stage as at my last assessment the nurse put lies on the decision. Things that were not true and had a devastating affect [sic] on my claim and mental wellbeing.”

- Survey participant

⁵ Scottish Government (2018). *Social Security Experience Panels: Personal Independence Payment Discovery - Visual Summary*. [online] Available at: www.gov.scot/publications/social-security-experience-panels-personal-independence-payment-discovery-visual-summary

Other participants raised concerns about the information in the health assessments being out of date or incomplete.

Some were happy for the previous health assessment evidence to be used – these were usually participants who had a positive experience with their assessor or had seen their reports and felt them to be accurate.

Participants were also asked what other sources of evidence Social Security Scotland should use in deciding whether to make an award. A range of sources were offered including health professionals, schools and social workers or carers. Participants across all focus groups and in the survey consistently stated evidence provided by GPs or consultants who directly knew the claimant should be trusted.

What should light touch reviews be like

Participants were mostly positive about having a light touch review instead of a reassessment, however there were some differences in their views on what the review should be like.

Some participants wanted as little communication as possible through the review process, only being contacted when necessary as needless letters caused more stress. Many participants spoke of the “dreaded brown envelope” from the Department for Work and Pensions arriving, with some being too stressed or anxious to open the letter. They believed streamlining the process, with Social Security Scotland doing as much work as possible without having to contact the client, would minimise this stress and the client’s workload. Other participants disagreed, and would prefer more regular updates (through email or post) on the status of the review.

If the client had to be brought in to a Social Security Scotland office as part of the review, participants emphasised the importance of not asking a generic set of questions to everyone and instead tailoring the assessment to people’s individual circumstances. Most participants who had undergone a health assessment could recall being asked generalised questions that were inappropriate or insensitive to their condition. These types of questions made participants feel that their assessor had a poor understanding of their condition.

Participants across focus groups and the survey made a large number of specific suggestions as to what should happen during a review. Almost all of these suggestions related to the review being face to face rather than paper based.

These suggestions can be summarised as:

- If a face-to-face review is necessary, clients should be made aware before the review that they are able to bring a representative, advocate or carer;
- Reviews should be scheduled at a convenient time for clients, with the option to reschedule as needed;
- The review should be carried out in a private space, in an easily accessible location;

- The review should take as long as necessary to allow the client to communicate how their condition affects them, without being overly arduous or excessively detailed; and
- Generalised sets of questions should be avoided where possible.

Who should carry out the light touch review?

Participants differed in their views in who should carry out the review. They suggested nurse practitioners and agency staff as potential options. Most participants felt that having a medical background was not strictly necessary – having a good understanding of disabilities and how they affect someones life was seen to be much more important.

Other important factors identified by participants included:

- Staff should speak plain English and not use jargon when communicating with clients during the review;
- Clients should be treated with dignity and respect by staff;
- Staff should be mindful that disabilities can affect clients in different ways;
- Staff should be patient, understanding and friendly to clients; and
- Staff should listen to clients.

Where should assessments and face-to-face light touch reviews take place?

Participants offered a range of suggestions (GP offices, health centres, town halls, etc.) however the main split was between those who would prefer them to be in a Social Security Scotland building and those who would prefer to have a choice of locations.

Participants who preferred a choice of locations typically viewed certain locations as being so stressful as to make them unable to attend. This was usually through past associations with DWP. As such, having a choice was a potential means of reducing or avoiding that stress. Others voiced concerns that having reviews in locations such as GP offices and health centres would remind them of the social security presence when they visited these buildings in the future.

Most focus group participants did seem to accept that the most likely outcome was for face-to-face light touch reviews to be carried out within an agency building and that so long as the building was accessible and easy to travel to, this could be acceptable.

Participants highlighted the need to offer home visits as an option, especially for clients who live in isolated areas or who have medical conditions that make travelling difficult.

Communicating light touch reviews

Communicating the difference between light touch reviews and reassessments was seen to be important in reducing client stress and giving them confidence that the light touch review process would be different to reassessments.

Participants had a number of suggestions as to how to do this: some suggested a leaflet could be included within the application pack and then again with future correspondence to make sure clients were aware and prepared for the review. Other participants wanted more extensive advertising of the process to ensure that everyone was aware that it was an alternative to a reassessment.

Participants emphasised the importance of giving enough notice of an impending light touch review. Many wanted to be informed of the month and year of their next light touch review upon being awarded the benefit, followed up by a reminder letter sent out six and then one month beforehand. Not everyone agreed with this, with some preferring a single reminder two months beforehand.

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 other work to assist in the development of Social Security Scotland.

The Scottish Government will consider the findings from this report in conjunction with the advice given to the Cabinet Secretary for Social Security and Older People from the Disability and Carers Benefits Expert Advisory Group (DACBEAG) on both award duration and automatic entitlement to benefits.

This advice and feedback from Experience Panel members in this project alongside ongoing work on individual benefits will inform our policy approach to disability benefits in Scotland, which we will also consult on publicly.

Following consultation, both the Scottish Commission on Social Security and the Scottish Parliament will scrutinise regulations on each individual disability benefit – Disability Living Allowance, Personal Independence Payment and Attendance Allowance.

How to access background or source data

The data collected for this <statistical bulletin / social research publication>:

- are available in more detail through Scottish Neighbourhood Statistics
- are available via an alternative route <specify or delete this text>
- 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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