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Social Security Experience Panels - gathering supporting information



EQUALITY, POVERTY AND SOCIAL SECURITY



Contents

| | |
|--|-----------|
| Introduction | 3 |
| Summary | 3 |
| Background and research methods | 4 |
| Gathering supporting information for benefit applications | 5 |
| Supporting information | 5 |
| Identifying useful supporting information..... | 10 |
| Asking for more supporting information | 12 |
| What's next? | 14 |

Introduction

In June and July 2019, the Scottish Government carried out a survey with Experience Panel members to understand experiences of gathering supporting information for benefit applications.

This work was part of the Scottish Government's Social Security Experience Panels programme of research. In total, 189 Experience Panel members with experience of the relevant benefits took part in this survey (a response rate of 17 per cent). The findings of this survey reflect the views of the respondents only. This report details the findings and key themes that emerged from this work.

Summary

Respondents were asked what supporting information they could supply to Social Security Scotland that would tell the agency about their health condition. The most common responses were a list of medicines (93 per cent) and a letter from a doctor or consultant (84 per cent). Just under half of respondents said they could provide a statement from their carer (46 per cent) and just under one third said they could provide a letter from their support worker (31 per cent). A report from a social worker, or letter from a school or other educational establishment were the least common options for the types of supporting information respondents could supply. A range of other types of information were also suggested.

Some respondents explained that they would struggle to provide supporting information to Social Security Scotland because they have a lifelong, untreatable, fluctuating or rare condition; are not taking medication; or are not regularly seeing a medical professional.

Respondents were asked if there were any pieces of supporting information they would expect Social Security Scotland to already have access to. The most common reply was that respondents thought that Social Security Scotland should already have access to their medical records or history, including GP records. Some respondents said that they would expect Social Security Scotland to have access to previous benefit applications, supporting information and/or assessments.

Respondents were also asked what supporting information they thought would be most useful for Social Security Scotland in demonstrating that they were eligible for a benefit. The vast majority of respondents said that they thought that a letter from a doctor, consultant or medical professional, or medical records and/or reports would be the most useful supporting information. Some respondents felt that a personal statement or a statement from a carer or family member would be most useful.

Those respondents who said that they would be able to supply a social work report were asked how useful they think the report would be for a Social Security Scotland case manager making a decision on an application. Overall, over seven in ten

respondents (74 per cent) said that they thought that a social work report would be useful.

Respondents were asked what supporting information Social Security Scotland could gather on their behalf. Most responses reflected the wide range of supporting information outlined in the discussion above. A small number of respondents raised concerns about privacy and sharing of personal information, consent and the accuracy of the information gathered on their behalf. A few said they would rather gather information themselves.

Nearly half of respondents (44 per cent) thought it should take about four weeks for Social Security Scotland to gather supporting information on behalf of applicants. One quarter (25 per cent) thought it should take two weeks. 14 per cent thought it should take longer than four weeks and less than one in ten respondents thought it should take about three weeks (nine per cent). Only six per cent of respondents thought it should take about a week and three per cent said less than a week.

Respondents were asked how they would prefer Social Security Scotland to contact them to request more supporting information. The most popular options were by post (37 per cent) and email (31 per cent). Just under two in ten respondents selected phone (18 per cent), and only six per cent selected text.

Over eight in ten respondents (82 per cent) said that they would like advance notice before Social Security Scotland called them to request additional information. Around one quarter of respondents (24 per cent) would like one days notice that Social Security Scotland would call them. Five days (18 per cent) or more than a week's notice (20 per cent) were also popular with around one fifth of respondents each. A few hours' notice (three per cent) and four days' notice (one per cent) were the least popular options. Overall, around half of respondents (52 per cent) said they would like notice of three days or less, and half (49 per cent) said four days or more.

Over eight in ten respondents (84 per cent) said that they would like advance notice of the questions they would be asked by the Social Security Scotland case manager who called them.

Background and research methods

The Scottish Government is becoming responsible for some of the benefits currently delivered by the Department for Work and Pensions.

As part of the work to prepare for this change, the Scottish Government set up the Social Security Experience Panels. Over 2,400 people from across Scotland who have recent experience of at least one of the benefits coming to Scotland have registered as Experience Panel members. The Scottish Government is working with Experience Panel members to design a new social security system that works for the people of Scotland, based on the principles of dignity, fairness and respect.

In this research project, we used a survey to ask Experience Panel members their experiences and views on gathering supporting information for benefit applications. It used open and closed questions to gather views on:

- what supporting information applicants could supply to Social Security Scotland and what information they deem to be most useful in demonstrating their health condition;
- what supporting information Social Security Scotland could gather on behalf of applicants and what information applicants would rather gather themselves; and
- communication preferences if Social Security Scotland needs to contact an applicant to request more supporting information.

This report details the findings and key themes that emerged from this survey with Experience Panel members.

Respondents were recruited from the Scottish Government Experience Panels. All Experience Panel members who have told us they have experience of relevant disability benefits were invited to take part in the survey.¹

The Social Security Experience Panels are a longitudinal research project. The panels are made up of volunteers from the Scottish population who have relevant experience. 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 views of a wider Scottish population. Percentages are given only to show a broad sense of the balance of opinion across participants.

Demographic information for the Experience Panel members who took part is not available for this project. 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*'².

Gathering supporting information for benefit applications

Supporting information

When people apply for a disability benefit, Social Security Scotland will need to have a full understanding of how their condition or disability affects them. For most people, Social Security Scotland will need to see supporting information that

¹ Disability Living Allowance, Personal Independence Payment, Attendance Allowance, Severe Disablement Allowance, Industrial Injuries Disablement Benefit

² 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

explains the impact a particular condition or disability has on the applicant. This will be done by either applicants telling Social Security Scotland where they can find supporting information, or by them sending it to Social Security Scotland themselves.

Respondents were asked what supporting information they could supply to Social Security Scotland that would tell them about their health condition. This was asked using both open and closed survey questions. In the closed question which provided respondents with a pre-defined list, the most common selections were a list of medicines (93 per cent) and a letter from a doctor or consultant (84 per cent). Just under half of respondents said they could provide a statement from their carer (46 per cent) and just under one third said they could provide a letter from their support worker (31 per cent). Report from a social worker, or letter from a school or other educational establishment were the least popular options for the types of supporting information respondents could supply.

Table 1: Which of the supporting information below could you supply to Social Security Scotland? (n=189)

| | % |
|---|----|
| List of medicines I am taking | 93 |
| Letter from my doctor or consultant | 84 |
| Statement from my carer | 46 |
| Letter from my support worker | 31 |
| Something else (please tell us what) | 29 |
| Report from my social worker | 23 |
| Letter from a school or other educational establishment | 18 |

Just under three in ten respondents (29 per cent) said they could supply some other kinds of supporting information to Social Security Scotland. These respondents were provided with an open text box to specify. The most common ‘something else’ suggestions provided by respondents were:

- a statement from a family member or friend;
- other forms of medical information, for example, registration certificates, hospital letters, tests and results; and
- Letters from other individuals and groups, such as specialist medical professionals, employers, physiotherapists, occupational health therapists, counsellors, charities and support groups.

A few respondents suggested they could supply general information about their condition. Other suggestions included a personal statement, a log of daily living activities, previous DWP paperwork and information regarding housing adaptations.

The responses to the open text question asking what supporting information about their health condition they could supply to Social Security Scotland returned similar themes:

- Letters and reports from hospitals and medical professionals;
- A statement from a carer;
- Prescription or medication list;
- Diary or overview of how a disability or condition affects daily life;
- Appointment letters, date or times; and
- A letter from work, school or charity.

Some respondents explained that they would struggle to provide supporting information to Social Security Scotland. Some of the reasons included having a lifelong, untreatable, fluctuating or rare condition; not taking medication; and not regularly seeing a medical professional.

"It's very hard to get supporting evidence because I don't always see the doctor very often as there is no treatment that works. Also medications don't really help so I'm not often on a lot of meds."

"This is difficult - I have a progressive long term illness for which there is no treatment, so there is very little point in my taking up the time of health professionals. I have a phone call with the nurse once a year and that is all. I am getting progressively more disabled, but because of the above would have little supporting evidence to this effect."

For a few respondents, there were no medical consultants or professionals who specialised in their condition who could provide supporting information.

"My condition does not currently have clinics or experts in the field. This means that I would not be able to provide a consultant report, or any sort of test results. I'm not even sure what my GP might say about me. This is not the only illness that is difficult to evidence. It's a fluctuating condition, it's chronic."

“I would have a bit of a tough time with this. I have a genetic condition however, there are no specialists/consultants in Scotland. None. I have all my care coordinated by my GP and see whatever consultant I need to see for whatever issue is most pressing at that time, but no consultant is overseeing my care for my specific condition. There are some I am currently under the care of but there have been a lot of sporadic appointments with consultants over the years where this specific part of my condition is now monitored and managed by my GP. This means that curating evidence for someone in my position could be a challenge and perhaps wouldn't fairly reflect on my actual current condition.”

Respondents were asked if there were any pieces of supporting information they would expect Social Security Scotland to already have access to. The most common reply was that respondents thought that Social Security Scotland should already have access to their medical records or history, including GP records. Some respondents said that they would expect Social Security Scotland to have access to previous benefit applications, supporting information and/or assessments.

It was not clear whether this referred to previous DWP applications or Social Security Scotland applications. Previous Experience Panels research on the case transfer process from the DWP to Social Security Scotland found nearly all participants asked said they would be happy for Social Security Scotland to take over application information. The vast majority would also be happy for Social Security Scotland to take over information submitted for applications. Participants' views were mixed on Social Security Scotland taking over information from previous assessments and case management information.³

Respondents were also asked what supporting information they thought would be most useful for Social Security Scotland in demonstrating that they were eligible for a benefit. The vast majority of respondents said they thought that a letter from a doctor, consultant or medical professional, or medical records and/or reports would be the most useful supporting information.

“For me it would need to be a full report from my GP, physio, and any consultants I have been treated by.”

Some respondents felt that a personal statement or a statement from a carer or family member would be most useful for Social Security Scotland in demonstrating that they were eligible for a benefit.

“As well as the ‘professionals’, talk to people who actually know me and know my abilities first hand. Sometimes the diagnosis is very different from the day to day realities of the condition.”

³ Scottish Government (2019). Social Security Experience Panels: designing the benefits case transfer process. [Online] Available at: <https://www.gov.scot/publications/social-security-experience-panels-designing-case-transfer-process-main-report/>

“The main information which should be acceptable is my own information as to how my health impacts on my life, my GP updates should also be acceptable.”

Those respondents who said that they would be able to supply a social work report were asked how useful they think the report would be for a Social Security Scotland case manager making a decision on an application. Just under six in ten respondents (58 per cent) said that they thought that a social work report would be very useful, whilst a further 16 per cent thought it would be useful. 17 per cent thought that it would not be that useful or not useful at all. Just under one in ten respondents said they were not sure.

Table 2: How useful do you think a social work report would be for a Social Security Scotland case manager? (n=43)

| | % |
|-------------------|-----|
| Very useful | 58 |
| Useful | 16 |
| Not that useful | 12 |
| Not useful at all | 5 |
| I'm not sure | 9 |
| Total | 100 |

Respondents were asked to explain their answers. Some respondents thought that a social work report would be useful because social workers themselves may have information about the applicant’s disability or condition, and the impact of this on their daily life. A few respondents highlighted that social workers are bound by professional standards and so they felt they would therefore provide unbiased, accurate information to Social Security Scotland.

“Social workers have intimate and in-depth knowledge of both an individual and their medical condition/disability relevant to their claim. They are also a recognised professional body who must adhere to professional standards so the information they supply can be trusted as valid and insightful.”

“Some people have access to Social Workers who deal with them on a regular basis so know them pretty well. They would be able to provide an unbiased assessment of the person they deal with and should also have up to date information about that persons current circumstances.”

Respondents who thought that a social work report would not be useful for a Social Security Scotland case manager felt that social work reports may not be contain

relevant medical information. Another respondent said that contact with a social worker is too limited for a report by them to be useful.

"Social Work reports can sometimes be subjective and has no basis in medicine. For example, a person may be diagnosed with depression by their GP, a Social Worker may state that the person does not 'appear to be depressed.'"

"Social work reports tend to have a family focus rather than a focus on the child's actual disability. So the whole report might not be useful, but could contain some information about levels of care etc."

"These days not many people have regular contact with a social worker. Initially they may have but once the various support systems have been put in place the social worker is only contacted in a crisis. Current austerity pressures have drastically reduced access to support workers."

Identifying useful supporting information

Respondents were told that Social Security Scotland will be able to gather certain supporting information on their behalf, if that was their preference. Using an open text question, respondents were asked what supporting information Social Security Scotland could gather on their behalf. The vast majority of respondents said that Social Security Scotland could gather medical information on their behalf, such as records, reports and letters from GPs and medical professionals.

"Everything and anything medical pertaining to my health."

"Letters/reports from consultants and a full report from my GP."

Some respondents raised concerns about privacy and sharing of personal information, consent and the accuracy of the information gathered on their behalf. A few said they would rather gather information themselves.

"People are able to gather their own supporting information from their GP regarding their own health and if they wish to share it then it should be their choice."

"Anything I choose to give them permission to do. But copies must be made available to applicants before being assessed so that applicants can ensure these pieces of information are fully accurate and correct and get them revised if necessary."

Nearly half of respondents (44 per cent) thought it should take about four weeks for Social Security Scotland to gather supporting information on behalf of applicants. One quarter (25 per cent) thought it should take two weeks. 14 per cent thought it should take longer than four weeks and less than one in ten respondents thought it

should take about three weeks (nine per cent). Only six per cent of respondents thought it should take about a week and three per cent said less than a week.

Table 3: How long do you think it should take Social Security Scotland to gather supporting information on behalf of applicants? (n=185)

| | % |
|------------------------|------|
| Less than a week | 3 |
| About a week | 6 |
| About two weeks | 25 |
| About three weeks | 9 |
| About four weeks | 44 |
| Longer than four weeks | 14 |
| Total | 1014 |

Respondents were asked if there is any supporting information they would rather gather themselves, rather than have Social Security Scotland gather on their behalf.

Table 4: Is there any supporting information you would rather gather yourself, rather than have the Social Security Scotland gather for you? (n=150)

| | % |
|---|-----|
| A list of medicines I am taking | 40 |
| Something else | 34 |
| A letter from my doctor or consultant | 21 |
| A report from my social worker | 1 |
| A letter from a school or other educational establishment | 4 |
| Total | 100 |

Four in ten respondents (40 per cent) said would rather gather a list of medicines themselves. One fifth (21 per cent) said they would rather gather a letter from their doctor or consultant. Very few respondents said they would rather gather a social work report (1 per cent) or letter from a school or other educational establishment themselves (4 per cent.)

⁴ Results are presented as whole numbers for ease of reading. Due to rounding, percentages may not add up to exactly 100%.

One third of respondents selected 'something else.' Most of these respondents said they would rather gather a letter from a family member, friend or carer themselves. Some noted a combination of the information sources above.

Asking for more supporting information

Respondents were told that sometimes Social Security Scotland might need to request additional supporting information after someone has submitted an application. This could happen if the supporting information initially provided by the applicant is not enough to make a decision on an application.

Respondents were asked how they would prefer Social Security Scotland to contact them to request more supporting information. The most popular options were by post (37 per cent) and email (31 per cent). Just under two in ten respondents selected phone (18 per cent), and only 6 per cent selected text.

Table 5: If Social Security Scotland needs to contact you to request more supporting information, how would you prefer they do this? (n=188)

| | % |
|-------------|-----|
| Post | 37 |
| Email | 31 |
| Phone | 18 |
| Another way | 7 |
| Text | 6 |
| Total | 100 |

Over eight in ten respondents (82 per cent) said that they would like advance notice before Social Security Scotland called them to request additional information.

Table 6: If Social Security Scotland called you to request additional information, would you like advance notice that this would happen? (n=189)

| | % |
|-------|-----|
| Yes | 82 |
| No | 19 |
| Total | 101 |

Around one quarter of respondents (24 per cent) would like one day's notice that Social Security Scotland would call them. A few hours' notice (three per cent) and four days' notice (one per cent) were the least popular options. Overall, around half

of respondents (52 per cent) said they would like notice of three days or less, and half (49 per cent) said four days or more.

Table 7: How much advance notice would you like before Social Security Scotland called you? (n=148)

| | % |
|---------------------|-----|
| A few hours | 3 |
| One day | 24 |
| Two days | 13 |
| Three days | 12 |
| Four days | 1 |
| Five days | 18 |
| More than a week | 20 |
| More than two weeks | 10 |
| Total | 101 |

Over eight in ten respondents (84 per cent) said that they would like advance notice of the questions they would be asked by the Social Security Scotland case manager who called them.

Table 8: If you were called by a case manager, would you like advance notice of the questions they would ask you? (n=183)

| | % |
|-------|-----|
| Yes | 84 |
| No | 16 |
| Total | 100 |

What's next?

The Scottish Government will continue to work with the Experience Panels in the development of Scotland's new social security system.

You told us that a personal statement or a statement from a carer or family member would be useful for Social Security Scotland in demonstrating that applicants were eligible for a benefit.

We are addressing this in the following ways:

- All information will be considered on its own merits, ensuring that information and statements from family members and carers is given due weight. Social Security Scotland will ensure that they are taking into account information from who the client has told us has the best understanding of the impact of their condition or disability.
- Case Managers will seek one source of supporting information from a formal source, such as confirmation of a diagnosis or letter from a support worker. Together with information from family members and carers (where applicable), this will be used to determine, on the balance of probabilities, that the individual's condition is consistent with the general care and mobility needs detailed on their application.

You told us that Social Security Scotland gathering supporting information on the client's behalf would be beneficial.

- Social Security Scotland Case Managers will help applicants identify what types of supporting information are most useful and give guidance on how best to gather them. In addition, where best for the client, Social Security Scotland will gather information from other parties or support the client in gathering this information themselves.

You told us that not every applicant will have supporting information.

- We will ensure that no-one will be disadvantaged by a lack of supporting information. Social Security Scotland's position is that consultations with Social Security Scotland Practitioners will only be used when there is no other reasonable way to gather sufficient information about functional ability. Case Managers will have the discretion to make an award in the absence of supporting information.

You told us potential timelines which members of the Experience Panels deemed appropriate for gathering supporting information alongside preferences about communication with Social Security Scotland.

- These preferences will be taken into consideration in the design of these aspects of the service of Social Security Scotland, as we consider how best to meet the needs of our service users.

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 further information.
- Cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.



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The views expressed in this report are those of the researcher and do not necessarily represent those of the Scottish Government or Scottish Ministers.

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